

**Submission to Parliament of Australia  
Senate Inquiry into the funding and  
operation of the Commonwealth  
State/Territory Disability Agreement**

---

**Submitted by**  
**Autism Aspergers Advocacy Australia**  
*4 August 2006*

Senate Inquiry Terms of Reference  
[http://www.aph.gov.au/SENATE/committee/clac\\_ctte/cstda/tor.htm](http://www.aph.gov.au/SENATE/committee/clac_ctte/cstda/tor.htm)

Document Version  
1.0 – Aug 4, 2006 - Final

## Table of Contents

<b>Submission to Parliament of Australia Senate Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement .....</b>	<b>1</b>
<b>About Autism Aspergers Advocacy Australia, A4.....</b>	<b>4</b>
<b>Autism Spectrum Disorder .....</b>	<b>4</b>
<b>Summary and Recommendations.....</b>	<b>5</b>
<b>Disability Advisory Bodies .....</b>	<b>5</b>
<b>Dual government roles.....</b>	<b>5</b>
<b>Inclusion.....</b>	<b>5</b>
<b>Generic versus Specialist Support.....</b>	<b>5</b>
<b>Legislation.....</b>	<b>5</b>
<b>National Quality Standards .....</b>	<b>5</b>
<b>Unmet needs .....</b>	<b>6</b>
<b>Health care.....</b>	<b>6</b>
<b>Conclusions.....</b>	<b>6</b>
<b>Section 1 - Examination of the Effect and Intent of the Current Multilateral CSTDA .....</b>	<b>7</b>
<b>1.1 Disability Advisory Bodies .....</b>	<b>8</b>
1.1.1 Case Study – The Disability Advisory Council of Victoria.....	10
<b>1.2 Dual Roles and Cooperation between Governments .....</b>	<b>12</b>
<b>1.3 Inclusion.....</b>	<b>14</b>
1.3.1 Positive Assumptions and Challenging Behaviour .....	15
1.3.2 Definition and Standards of Inclusion .....	16
1.3.3 Opting out of inclusion .....	16
1.3.4 Inclusion and Education.....	17
1.3.5 Children with ASD and Inclusion.....	17
1.3.6 Replacing a Clinical Diagnosis with a Moral Diagnosis.....	19
<b>1.4 Generic Services versus Specialist Services .....</b>	<b>19</b>
1.4.1 Children with ASD and Specialist Services.....	19
1.4.2 Specialist early intervention for autism is different from kindergarten – Victorian Service Models.....	21
Parent involvement .....	21
Curriculum .....	21
<b>1.5 The CSTDA, Legislation and Affirmation of Human Rights .....</b>	<b>22</b>
1.5.1 Inconsistent definitions of disability in State and Federal legislation.....	23
<b>1.6 Contradictions between Rights and Australian legislation .....</b>	<b>23</b>
1.6.1 The Right to Disability Services in Australia .....	24
1.6.2 Rights, Responsibilities and Restrictive interventions – The Victorian Disability Act 2006 .....	27
1.6.3 Strengthened Responsibilities .....	27
1.6.4 Mandate of Restrictive Intervention .....	27
1.6.5 Mandate of inclusion as the primary “right” for a person with a disability .....	28
<b>1.7 National Quality Standards .....</b>	<b>28</b>
<b>Section 2 - The appropriateness of joint funding arrangements, .....</b>	<b>30</b>
<b>2.1 Unmet needs .....</b>	<b>31</b>
<b>2.2 People with ASDs have high support needs.....</b>	<b>31</b>
<b>2.3 High level of unmet need for people with ASD .....</b>	<b>32</b>

<b>2.4 Unmet need and children with ASD.....</b>	<b>32</b>
<b>2.5 Unmet need and employment services .....</b>	<b>34</b>
<b>2.6 Unmet need and supported accommodation .....</b>	<b>35</b>
<b>Section 3 - Interface between Health and Disability Services for persons with ASD .....</b>	<b>36</b>
<b>3.1 Health Needs.....</b>	<b>36</b>
3.1.1 Health needs for children with ASD .....	36
3.1.2 Health needs for children with ASD and the tax system.....	36
3.1.3 People with ASD pushed into private services .....	36
3.1.4 Medicare and the cost of treating ASD.....	37
3.1.5 Health and ASD .....	37
<b>3.2 ASD healthcare hardships.....</b>	<b>37</b>
<b>3.3 Mental Health and ASD .....</b>	<b>38</b>
3.3.1 Mental health of people with ASD, .....	38
3.3.2 Misdiagnosis .....	38
3.3.3 Mental health of carers .....	38
3.3.4 Mortality and the interface between health and disability services.....	39
<b>Section 4 - Interface between Aged Care and Disability Services for persons with ASD .....</b>	<b>40</b>
<b>Section 5 - Case study from overseas .....</b>	<b>41</b>
<b>Overseas Examples of good Practice for people with ASDs.....</b>	<b>41</b>
The Judevine Centre for Autism <a href="http://www.judevine.org">http://www.judevine.org</a> .....	41
Jay Nolan Centre. <a href="http://www.jaynolan.org/">http://www.jaynolan.org/</a> .....	42
Attractive homes.....	43
Happy people caring for happy people .....	43
Supportive Communities .....	44
<b>Appendix A – Full text from Letter to Editor, A4 Newsletter, June 2006.....</b>	<b>45</b>

## **About Autism Aspergers Advocacy Australia, A4**

A4 is a grassroots advocacy group of approximately 1000 members around Australia. A4 represents people with autism spectrum disorders, their families and associates. A4 generally operates as a “virtual” organisation. It’s policies and positions are guided by a steering committee of some 20 members comprising adults with ASD, parents of children with ASDs and professionals.

Further information about A4 can be found at our website <http://www.a4.org.au/>

## **Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) causes lifelong disability. The term “Autism Spectrum Disorder” encompasses the disorders of Autism, Aspergers Syndrome and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). All these disorders are characterised by developmental difficulties in Language and Communication, Social interaction and Imagination, which affect all areas of life. An individual’s degree of impairment can vary from mild to severe and may also vary according to situation. Autism is a brain disorder and causes lifelong disability. The cause is unknown and there is no cure. ASD is not an intellectual disability.

Some of the difficulties commonly experienced by persons with ASD are:

Difficulty with communication; some people have no speech, restricted or disordered speech including inappropriate use of tone, pitch and intonation and; difficulty understanding others; impaired or no understanding of aural and/or non-verbal communication such as facial expressions and gestures.

Difficulty forming and maintaining relationships with people: individuals may seek social contact but not have the skills to develop or sustain relationships – they may appear aloof, or even too interested.

Difficulty interpreting the environment. Everyday sights, smells, tastes and textures may be overwhelming, causing confusion or distress.

Unusual behaviours: Often people with ASDs exhibit behaviours that appear to be rigid and controlling. They may appear to be eccentric or use complex rituals or routines to order their lives.

ASD is not caused by poor parenting as was once believed. Families usually experience extreme stress coping with the daily challenges of their child’s suffering.

Autism can usually be diagnosed between 18 months and 3 years of age. Milder forms can remain undiagnosed for several years preventing individuals from accessing early childhood intervention.

Prognosis is significantly improved by early diagnosis, specialised interventions and ongoing support. Without appropriate support, the life of persons with ASD is severely affected.

ASD can no longer be considered a rare disorder. The Federal Senate committee reporting on Education of students with a disability (December 2002) said “Over the whole of Australia between 0.6 per cent and 1 per cent of children are affected by autism or a related disorder.”

## Summary and Recommendations

A4 welcomes this opportunity to make a submission to the inquiry into the CSTDA and raise issues that we believe are relevant to Australians with Autism Spectrum Disorders (ASDs). Our submission deals only with the Current Multilateral CSTDA. In spite of the good intentions and positive words, it is the experience of A4 members that the CSTDA is a deeply flawed arrangement for people with ASDs that have not delivered its objectives. By any measure, current outcomes for Australians with ASDs are poor.

For example, the AIHW update Bulletin issue 42, July 2006 notes that “autism, while having a lower prevalence than asthma, was strongly associated with severe or profound core activity limitation—an estimated 87% of children with autism also had a severe or profound core activity limitation.”

AIHW data show that less than one third of children (4981 children according to AIHW) with autism receive CSTDA services.

Our examination of the effect and intent of the CSTDA identifies issues relating to:

- Disability Advisory bodies
- Dual pivotal roles for State and Federal governments
- Inclusion
- Legislation supporting the CSTDA and affirmation of human rights
- Generic versus specialist services
- Disability quality standards

We identify health issues for people with ASDs relating to mental health, misdiagnosis and premature death.

In summary, our recommendations are as follows;

### ***Disability Advisory Bodies***

- Disability Advisory bodies that operate in an open and transparent fashion – information about their consultations with the community and representations to government to be freely available to the community.
- Advisory Bodies that represent the full range of disability, including people with ASDs.

### ***Dual government roles***

There is an urgent need for a single point of accountability from government– not handballing of responsibility between layers of government.

### ***Inclusion***

- Consistent definitions of inclusion in State and Federal agreements and laws.
- Recognition that specialised supports and infrastructure are required for inclusion.
- Recognition that inclusion can be at conflict with other important rights for people with ASDs (eg education).

### ***Generic versus Specialist Support***

Recognition that traditional disability supports generally don't meet the needs of people with ASD.

### ***Legislation***

- Consistent definitions of disability in all Australian laws and agreements that includes ASDs.
- Consistent entitlements in all Australian Laws.
- Access to due legal processes including higher levels of appeal and independent, binding arbitration.
- Removal of the assumption that some people cannot or should not exercise their rights.

### ***National Quality Standards***

Observance of National Quality standards and monitoring of performance against the standards.

## **Unmet needs**

- Alternative arrangements for specialised services with clinical focus eg. via Medicare.
- Clearly identified responsibility for providing evidence based interventions.
- Recognition that interventions can be a lifelong need.
- Recognition that group living arrangements can be unsuitable for people with ASDs.

## **Health care**

- Better understanding of ASDs in the health professions.
- Understanding that people with ADS their families and carers should enjoy good mental health outcomes.
- Address issues of misdiagnosis.
- Address issues of premature death for people with ASDs.

## **Conclusions**

A4's submission and government data highlights the serious inadequacies of the CSTDA for people with ASDs of all ages. A4 is concerned for the human rights of Australians with ASDs.

At best, services for people with ASDs are adhoc, fragmented and dysfunctional at worst they are non existent The heavy reliance on user pays private services (including those with a specialist clinical focus) means that it is difficult to meaningfully measure the effectiveness of services for people with ASD funded under the CSTDA.

A4 believes that the current human rights crisis for Australians with ASD warrants a step change improvement rather than a slower evolutionary change. We approach the next CSTDA with trepidation., we do not want more of the same with some "fine tuning".

In particular we highlight that thecurrent "one size fits all" model of inclusion does not work for people with ASDs. A4 supports the principle of including people with ASD in their community, but observes that the essential expertise, preparation and resources for including people with autism spectrum disorders effectively are rarely available. In practice, government and its agents use "inclusion" as an excuse to cut funding and expertise to a level where services are ineffective. They avoid providing necessary services and then blame the outcomes on the people, their disability, their families and the workers at the coalface.

People with ASDs lack the social resilience to trail blaze a path to inclusion in discriminatory environments. Their families and carers, overwhelmed by their caring responsibility, cannot navigate systems of arbitration that are rarely binding. A4 seeks a better alternative to the current complaints driven model for overcoming discrimination.

A4 has particular concern for Australian children with ASDs. We know that current funding arrangements, policy and practice does not prepare children with ASDs for independent adulthood. It is profoundly unjust that Australian children with ASDs are needlessly allowed to develop profound and lifelong disability for lack of effective interventions.

To some degree, the difficulties faced by children with ASD are warehoused by preschool and education services. The impact of this strategy is not felt until the child enters adulthood unable to function in the community or find employment. A4 anticipates even greater pressure on disability services for adults with ASDs in the future as a result of the increased rate of diagnosis of ASDs. We seek a new CSTDA that accepts responsibility for the human of newly diagnosed children **and** the thousands of Australians with ASDs denied help under the existing arrangements. It is appropriate to offer effective interventions to people with ASDs of all ages.

A4 believes there is much work to be done by CSTDA signatories to address the gap between the words in the CSTDA and reality. We recognise the need for a whole of government approach and welcome the recent commitment of Christopher Pyne (Parliamentary Secretary to the Minister for Health and Ageing) to work on a substantial autism package for next year's budget. We now look to other areas of government to make a similar commitment.

A4 knows that people with ASDs have the capacity to be productive members of the community. The inability to live up to this potential because of government policy and practice is a significant source of grief and anguish to people with ASDs their families and carers.

A4 would welcome the opportunity to participate further in the development of the next CSTDA. We would welcome the opportunity to participate in the Committees public hearings.

## **Section 1 - Examination of the Effect and Intent of the Current Multilateral CSTDA**

This submission studies the effect and intent of the current multilateral CSTDA which expires 30<sup>th</sup> June 2007. It is beyond the resources of A4's volunteers to examine the intent and effect of prior agreements and bilateral agreements.

We identify and discuss areas of intent within the current multilateral CSTDA that we consider especially pertinent to the obstacles faced by people with ASDs their families and carers. Where possible we have provided case studies and documents to support our arguments. Identifying material in the case studies has been removed at the request of contributors to preserve privacy.

The areas of intent in the CSTDA, which A4 considers pertinent to ASD, are:

1. The views of people with disability and their families and carers should inform government policy and that these views are communicated to government via state and federal disability advisory bodies;
2. People with disability will be accorded fundamental human rights by inclusion in the community. This is not specifically stated but we assume that it is inferred by the statement that "communities will be enriched by inclusion of people with disabilities";
3. That State and Territory legislation encompasses the spirit of the CSTDA, Disability Services Act and the Disability Discrimination Act;
4. UN Declaration of Rights of Disabled Persons is Reaffirmed;
5. Some people not able to exercise their rights – a very dangerous and limiting assumption. It does not belong in the CSTDA;
6. Generic services will meet the special needs of persons with disability;
7. Disability Services will be governed by disability quality standards.

## 1.1 Disability Advisory Bodies

### **Recommendations:**

- *Disability Advisory bodies that operate in a more open and transparent fashion – information about their representations to government to be freely available to the community;*
- *Process of recruitment into disability advisory by an open process;*
- *Representation of the full range of disability including people with profound social and communication impairments;*
- *Open processes of consultation with the community.*

The CSTDA Multilateral Agreement states that:

“ “Disability Advisory Bodies” means the groups that advise their respective Minister on issues that affect people with disabilities, their families and carers.”

The preamble to the CSTDA agreement was written in consultation with Federal and State disability advisory bodies.

Participation in advisory bodies is at the invitation of government. We do not know what advice these bodies provide to government in respect of people with ASDs their families and carers. We do not know if they represent the range of views and experiences of people living with ASD, their families and carers.

People with ASDs struggle to have their disability recognised in law and in policy. We don't know if this is because:

- disability advisory bodies advocate for people with ASDs but that the government won't listen or;
- the bodies simply do not advocate for people with ASDs because there is not sufficient representation to give ASD a voice.

The internet publishes some information about Disability Advisory Bodies and some websites include profiles of the members. It was not possible to identify the range of disabilities represented on all the councils around Australia because information for many states was incomplete or did not include member profiles. A summary of the information published on the internet for Disability Advisory Bodies around Australia is tabulated below.

<b>Body</b>	<b>#members &amp; # members with ASD experience</b>	<b>Meeting dates published for 2006?</b>	<b>Community Consultation dates for 2006 published?</b>	<b>Most recent report</b>	<b>Comment</b>
National Disability Advisory Council <a href="http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/representation-ndac.htm">http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/representation-ndac.htm</a>	15 includes 1 parent of a child with ASD.	No	No	Community consultation report dated May 2004.	An end of term report is written every 3 years.
Disability Council of NSW <a href="http://www.disabilitycouncil.nsw.gov.au/page/members.html">http://www.disabilitycouncil.nsw.gov.au/page/members.html</a>	17, no ASD representation evident although some members do not state disability experience.	No	No	Strategic plan covering 2002 to 2005.	Most recent news dated 2004. Several position papers published. No strategic or annual plan for 2006.



Body	#members & # members with ASD experience	Meeting dates published for 2006?	Community Consultation dates for 2006 published?	Most recent report	Comment
Disability Council of Queensland <a href="http://www.communities.qld.gov.au/community/disabilitycouncils/dcq/index.html">http://www.communities.qld.gov.au/community/disabilitycouncils/dcq/index.html</a>	11, 2 members have affiliation with people with ASD.  Several regional disability bodies reporting to DCQ – membership profiles not published.	No	No	No reports published.	No information about the activities of the DCQ available.
Northern Territory Disability Advisory Council <a href="http://www.nt.gov.au/health/facs/DAC_advisory_council.shtml">http://www.nt.gov.au/health/facs/DAC_advisory_council.shtml</a>	16 members, 4 individuals, the rest organisational representatives, disability experience not stated.	No	No	No reports published.	Comprehensive terms of reference published including council's responsibilities and processes. No information about council's activities.
WA - Ministerial Advisory Council on Disability <a href="http://www.dsc.wa.gov.au/2/266/83/Council_Members.pm">http://www.dsc.wa.gov.au/2/266/83/Council_Members.pm</a>	14, including a parent of a child with a developmental disability.	No	No	2006 document of current issues.	Publish a current annual report – which is comprehensive.
SA – Disability Advisory Council <a href="http://www.dfc.sa.gov.au/disability-services/documents/DAC%20Info%20DFCWebsite.pdf">http://www.dfc.sa.gov.au/disability-services/documents/DAC%20Info%20DFCWebsite.pdf</a>	15 members, disability experience not stated.	No	No	No reports published.	Role of council stated but no other info available.
Tasmania	There is no disability advisory body for Tasmania				
ACT - Disability Advisory Council <a href="http://www.dhcs.act.gov.au/DisabilityACT/AdvisoryCouncil/Publications.htm">http://www.dhcs.act.gov.au/DisabilityACT/AdvisoryCouncil/Publications.htm</a>	12 members, including one parent of child with developmental delay.	No	No	Budget proposal 04/5.	Response to 2004 budget published.  Publishes some terms of reference.
Disability Advisory Council of Victoria	12, no ASD representative.	No	No	“Accessible Place, Accessible State 2020”. Recommended Policy Outline for the Victorian Government.	Participation and partnership guide 2005 published.  Terms of reference published.

Based on this information, we make the following general observations:

- The members of disability advisory bodies are outstanding individuals making an important contribution. We do not question their integrity or commitment. We do not doubt that many members of disability advisory bodies face significant obstacles in their own lives as a result of disability.
- As far as we can tell from published member profiles, members of disability advisory bodies with disability are mostly those with physical or sensory impairments. The profiles tell us that many members with disability can manage challenging and demanding careers. We could not identify any member of a disability advisory body who has ASD or a profound social and communication impairment. We hope it is not simply assumed that they are incapable of participating directly in a disability advisory body. We think it is fair to ask if people with ASD and their carers are represented by organisations where the experience mostly relates to conditions that do not impair social functioning, communication or result in challenging behaviour. We could not identify any direct representation from a person incapable of verbal communication or incapable of sitting in a room full of people.
- Most carer representatives can combine their caring responsibility with challenging careers, running their own business or tertiary study. We cannot tell if there is any representation from a carer who must closely supervise a person with profound disability 24/7 to the extent that they can never have a proper night's sleep or participate in paid employment.
- Most Disability Advisory bodies publish little if any information for the community about with whom they consult and the advice they pass on to government on behalf of persons with disability (WA - Ministerial Advisory Council on Disability is a notable exception).
- Consultation opportunities for the community are not advertised on the web sites. Meeting dates of the advisory bodies are not published. The community cannot inform the advisory body.
- Information about the selection criteria for membership of disability advisory body's are not published on the web sites.
- With the exception of Victoria, the web sites state that the roles of all the disability advisory bodies are primarily to represent the views of persons with disability to government. This is consistent with the CSTDA.

### 1.1.1 Case Study – The Disability Advisory Council of Victoria

In respect of the last point The Disability advisory Council of Victoria (DACV) website states “ Our principal purpose is to provide advice to the Victorian Minister for Community Services on issues concerning people with disabilities **in order to assist the Victorian Government achieve its stated policy objectives** as detailed in the [Victorian State Disability Plan 2002-2012](#). <http://www.dac.vic.gov.au/>

As far as we can tell from information published on the Internet, DACV is the only council with the extra responsibility of helping government implement its policy objectives. The terms of reference for the DACV are published on the Internet (see [http://www.dac.vic.gov.au/documents/dacv\\_tor.rtf](http://www.dac.vic.gov.au/documents/dacv_tor.rtf)). Here we find the statement that:

“Major functions of the Disability Advisory Council are to:

- Communicate effectively with people with disabilities in Victoria, Government, Government departments and the broader community;
- **Raise community awareness of the rights of people with a disability and the role of government, business and the community in promoting these rights;**
- Consult and work with the National Disability Advisory Council, other State and Territory Disability Advisory Councils/Bodies and local government Disability Advisory Committees;
- Monitor the implementation of strategies for promoting inclusiveness, enhancing community participation and reducing barriers for people with a disability; and
- Report annually on its activities to the Minister for Community Services.”

We are uncertain about the raising of community awareness of the role of government in promoting the rights of persons with disability. What does this mean and is it appropriate for the DACV to promote government to people with disability?

The following statement from the DACV website that:

“In 2005 the DACV took an active interest in the development of disability action plans. The DACV was represented on Government department DAP reference groups and committees, and reviewed nine State Government department draft disability action plans.”

**“In 2006 the DACV will continue to support the Victorian State Government departments and Local Government Authorities by promoting the progress and achievements of the disability action plans. The DACV’s plans include forums for public sector employees and executive officers, the publication of an achievements report and quarterly e-bulletins to share examples of best practice.** The DACV will also establish a reference group of Victorian Public Servants with a disability.”

We believe that the promotion of government achievement is already richly resourced and it is unnecessary for government to divert the scant resources of the DACV to this area especially if this prevents the DACV from consulting people with disabilities.

The DACV website provides no information regarding its other role of consultation with people in the wider community with disabilities for the purpose of informing government. We found no advertised community consultations or any information about the representations made to government by DACV on behalf of persons with ASD. The DACV reports to the Victorian Community Services Minister and these reports are not published on the DACV website. The two publications on the DACV website suggest that the DACV is very focussed on specialised supports for people with physical or sensory disability relating to access to the built environment and generic services.

- <http://www.dac.vic.gov.au/documents/accplace2020.pdf>
- [http://www.dac.vic.gov.au/documents/pp\\_guide.pdf](http://www.dac.vic.gov.au/documents/pp_guide.pdf)

The role played by DACV in the enactment of the controversial Victorian Disability Bill 2006 strongly suggests that DACV represents a very narrow range of views and experiences on disability.

The exposure draft of the Victorian disability bill attracted substantial criticism especially from carers, people with mental illness, psychiatric disability, autism and their advocates. Of key concern to autism advocacy groups was the Bill’s mandate for restrictive interventions to be used on people with a disability. These interventions include chemical restraint, physical restraint and solitary confinement without due legal processes and access to appropriate and binding arbitration or complaints resolution.

The non complaint or aggressive behaviour that can be typical for a person with severe or poorly managed autism makes these people a prime target for the Bill’s Restrictive intervention provision.

Additionally, autism advocacy groups voiced their concerns about the lack of provision of specialised services to effectively treat and manage autism spectrum disorders.

Submissions from the community regarding the draft disability Bill were published on the Victorian DHS website [http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionfour/submissions\\_exposure\\_draft?open](http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionfour/submissions_exposure_draft?open)

We believe that even the most favourable reading of the submissions could not conclude that community endorsed the Bill. We are not alone in this view.

For example, a media release by Victorian Council of Social Services says; ‘While we congratulated the Victorian Government on its commitment to review of the disability legislative framework, we have also raised ongoing concerns with Minister Garbutt about important aspects of drafts of the Bill’, ‘Our chief concerns have been with the Bill’s ability to protect the rights of people with disability to services, planning and adequate accommodation, as well as the rights of families and carers of people with disability,’ Cath Smith, VCOSS CEO.

[http://www.vcooss.org.au/VCOSS\\_docs/media\\_releases/2006/MED08\\_05\\_2006.htm](http://www.vcooss.org.au/VCOSS_docs/media_releases/2006/MED08_05_2006.htm)

Therefore it was disappointing and surprising that during parliamentary debate the Government countered criticism about lack of community support by tabling a letter from Dr Rhonda Galbally written in her capacity as Chair of DACV, strongly endorsing the disability Bill. Dr Galbally’s letter is reproduced below...

From Rhonda Galbally, chair of the Disability Advisory Council of Victoria

Dear Minister Garbutt

As Chair of the Disability Advisory Council of Victoria and someone who has worked for the rights of people with a disability and their families for more than 30 years I would like to offer my strongest support for the new disability act.

I believe that a single piece of disability legislation will create a stronger and more coherent Victorian government approach to disability. It is pleasing to see that the government has followed the international trend of moving away from specialist service provision according to diagnosis. An individualised planning and support approach will ensure that people receive support based on their individual need within the context of their relationships with families, friends and the broader community.

I would like to congratulate the Victorian Government on the introduction of an independent complaints mechanism and the creation of the Disability Services Commissioner, the Disability Services Board and a Senior Practitioner. The introduction of these new initiatives will ensure that there is scrutiny of service provision and provide additional protection for people with a disability with complex medical and behavioural needs.

I would also like to highlight the mandating of disability action plans (consistent with the Disability Discrimination Act) within state government, statutory bodies and local government. This will enable government and local councils to systematically identify and address barriers that prevent the full participation of people with disabilities into the community. Disability action plans will also provide practical strategies to achieve tangible change, including improved access to community infrastructure and universal services.

I would like to thank the Victorian Government for the leadership it has shown in developing the disability legislation and look forward to the implementation of the new initiatives.

Yours sincerely



Dr Rhonda Galbally AO  
Chair, Disability Advisory Council of Victoria  
30 March 2006

It is very hard to understand why the DACV would so warmly endorse a bill that many others including the ASD community legitimately and publicly criticised.

<http://www.parliament.vic.gov.au/downloadhansard/pdf/Assembly/Autumn%202006/Assembly%20Extract%2030%20March%202006%20from%20Book%203.pdf> page 777, Thursday March 30<sup>th</sup> extract book 3.

## **1.2 Dual Roles and Cooperation between Governments**

### **Recommendations:**

- ***One layer of government to have overall accountability – not handballing of responsibility between layers of government;***
- ***Accountability for the provision of specialist services with a clinical focus.***

The CSTDA says that State and Federal governments will both perform pivotal roles in advancing the rights of persons with a disability. It also says that State and Federal governments will work cooperatively.

It is a law of physics that an object supported by more than one pivot cannot move - every pivot prevents the movement of the other pivots.

One of the biggest obstacles faced by people with ASDs is that governments sharing responsibility respond to criticism and complaint by reverting to practiced positions, handballing the problem to the other layer of government. People

living in crisis want governments to work constructively with each other to resolve clearly identified problems – sadly this does not happen for people with ASDs.

ASD is a clinical disorder. It is classified on Axis I of the DSM-IV. This means that experts regard ASD as a condition that warrants clinical attention. The Health system regards autism as a disability and that clinical issues should be provided for in the disability sector. The disability sector says the CSTDA does not provide funding for services with a specialist clinical focus. People with ASD are stuck in no-mans land.

It is the overwhelming experience of A4 members that neither State nor Federal governments working together or independently are meeting the health, education, accommodation or intervention needs of people with ASDs. At best services are fragmented, inadequate and adhoc. At worst the services are non existent. Our experiences are validated by government's data, for example; disability data published by the Australian Institute of Health and Welfare for users of all CSTDA-funded services, 2003-04 clearly shows that of all disability categories, ASDs are the most likely to result in severe or profound impairment.

Despite some good intentions, the CSTDA is in reality an all care and no responsibility arrangement for people with ASDs. The lack of a single government body accountable for the outcomes of the CSTDA is a significant barrier to effective democracy for persons with ASDs.

The following example illustrates the difficulty of dual pivotal roles.

QUESTIONS IN WRITING, Autism Spectrum Disorder, (Question No. 1660)

Question: Ms George (Throsby) asked the Minister for Health and Ageing, in writing, on 2 June 2005:

“What Commonwealth funding and programs are targeted at assisting children and adults diagnosed with ASD”

Answer: Mr Abbott (Warringah—Minister for Health and Ageing)

“The answer to the honourable member's question is as follows:

The Australian Government assistance for those with autism and their carers is provided through the government's mainstream health, welfare, education and financial assistance programs. For example, assistance is available through Medicare attendance items, which can be used for the treatment of autism by medical practitioners.

“The provision of early intervention and education services in relation to autism is the responsibility of State and Territory governments. Their disability, health and education programs have components that include the care, treatment and education of those with autism.”

## 1.3 Inclusion

### **Recommendations:**

- **Consistent definitions of inclusion in State and Federal agreements and laws;**
- **Recognition that specialised supports and infrastructure are required for inclusion;**
- **Accountability for needs based funding of specialised supports for inclusion for people with ASDs;**
- **Measurement of inclusion outcomes for people with ASDs;**
- **Recognition that generic models of inclusion can be at conflict with other important rights for people with ASDs (eg education).**

The preamble to the CSTDA states that:

“The Agreement is based on the premise that communities are enriched by the inclusion of people with disabilities and that positive assumptions about the gifts and capacities of people with disabilities, including those with high support needs, are fundamental to their experience of a good life and to the development and delivery of policy, programs and services.”

This statement infers rather than explicitly spells out that people with disability are afforded their human rights by participation in the community. A4 believes that it is not always true that people with ASD are afforded human rights by “inclusion” in Australian communities.

We understand the premise to be that people with disability have a basic right to experience a good life - and without inclusion, that won't happen. The emphasis on “inclusion” follows from a proposition or assumption that people with a disability who are “included” in the community have increased independence, positive outcomes and experience life like people with less or no disability.

We know from experience that “inclusion” to an “inclusion idealist” means full support combined with culture change, but far too often “inclusive practice” just dumps people with ASD in an unprepared setting with little or no support.

A4 supports the principle of including people with ASD in their community, but observes that the essential expertise, preparation and resources for including people with autism spectrum disorders effectively are rarely available. In practice, government and its agents use “inclusion” as an excuse to cut funding and expertise to a level where services are ineffective. They avoid providing necessary services and then blame the outcomes on the people, their disability, their families and the workers at the coalface.

Legislation and policy emphasising the “inclusion” proposition to the exclusion of other human rights (such as the Victorian Disability Act 2006) disadvantages the most vulnerable members of the community. For many people with autism, the one-size-fits-all “inclusion” model is utterly inadequate.

A4 believes that people with ASD and their families have important and unique issues to rise with respect to inclusion. The social/behavioural and communication impairment characteristic of ASDs are significant barriers to inclusion in Australian communities for people with ASDs. We want the CSTDA to serve all people with disability, not just those who benefit purely from generic inclusive practices.

### 1.3.1 Positive Assumptions and Challenging Behaviour

It is the common experience of people with ASD that Australian communities are often unwilling to “make positive assumptions about the gifts and capacities of people with disabilities” when the disability or mismanagement may have negative social or behavioural consequences. Inadequate disability supports exacerbate these problems as highlighted in the following case study taken from NSW Legislative Assembly Hansard 15/10/2003, page 3928.

Ms GLADYS BEREJKLIAN (Willoughby) [5.28 p.m.]: I mention a matter of immense concern. On Monday 29 September my constituents, Mr and Mrs Mudge of Middle Cove, approached my office justifiably upset after they were advised that funding which had been provided to their 24-year-old intellectually handicapped daughter and stepdaughter, Jackie, to provide 25 hours of supervision per week would be withdrawn by the Department of Ageing, Disability and Home Care. As upsetting and as shocking as the news of the withdrawal of this funding is for my constituents, equally concerning are the circumstances in which my constituents were advised of this decision, the lack of notice provided, and, according to the department's own admission, a complete lack of concrete options for support to be provided through other agencies.

The facts surrounding this case are intensely personal. However, after numerous attempts to reverse this ill-thought out decision, my constituents feel they have little choice but to have this issue raised in Parliament so the future of their daughter, Jackie, and of many others in similar situations in this State might be considered. Jackie has been diagnosed with Asperger's syndrome, part of the autistic disorder spectrum, as well as mild intellectual disability, functioning at a level lower than 99.9 per cent of the population. That diagnosis was made approximately 11 years ago. Asperger's syndrome is characterised by severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behaviour, interests and activity. Socialisation is Jackie's lowest area of functioning. In particular, her interpersonal relationships are at the level of a seven-year-old and her coping skills are at the level of seven years and eleven months.

Regrettably, because of her condition, Jackie recently found herself in court due to incidents involving her neighbours. As a result she was charged with malicious damage and the victim sought an apprehended violence order [AVO] against her. After four court appearances the malicious damage charge was dismissed and the magistrate considered it inappropriate to burden Jackie with the imposition of an AVO because of her disabilities. It is important to note that the magistrate made his decision on the basis that Jackie would continue to be supported by her parents and the Autism 100 Program. I raise this issue to demonstrate that people in her situation are in need of constant care. Jackie has tried to seek gainful employment but was not able to retain the jobs she had managed to successfully apply for.

Jackie, and many like her, need multidimensional support. The funding that Jackie's parents received from the Department of Ageing, Disability and Home Care [DADAHC] was to support the care she received from Autism 100. Jackie's parents are in despair as to what withdrawal of the funding might mean. They both work full time and are conscious that they will not be around forever. When I asked my constituents what reason was given for the withdrawal of funding, they indicated that they had not been given one, apart from the fact that DADAHC was withdrawing support to families in similar circumstances.

I was shocked to learn of the way in which my constituents had been advised of the withdrawal in funding. To date they have not received anything formal in writing. They informed me that an officer from the department knocked on their front door to verbally advise them of the department's decision. The only other acknowledgment arrived via an informal email from a departmental officer in which the officer stated:

As you are aware, interim funding will cease as of 30 Sept 2003 therefore support services for Jackie will also cease from that day onward. The same situation applies to other clients.

I am concerned about what this withdrawal of funding means for the many families in the circumstances I have highlighted today. I am concerned about the lack of transparency in the making of the decision, how it was communicated to the families and the lack of subsequent support. What are people such as the Mudges to do? Without the structured environment that occupies a lot of her time and expert supervision and care, Jackie and everyone she associates with will be exposed to risk. I ask the Minister for Community Services in another place to immediately address this issue and to inform the House of the Government's position. I have been advised that interim funding arrangements may be available for another three months of supervision at a significantly reduced level: 25 hours per week down to 8 hours per week. That will simply delay the inevitable. The inevitability of this decision is placing additional stress on families who have more than enough to cope with already. The State Government must act now to address this serious matter. I look forward to the Minister's response.

### 1.3.2 Definition and Standards of Inclusion

There is a wide range of standards for inclusive practice in Australian communities and organisations. Unfortunately lack of funding for professional integration support means that “inclusion” may simply refer to the right to occupy the same physical space as people who have no disability.

“ a teacher from the early intervention centre visited ‘A’ at kinder. ‘A’ spent most of his time playing by himself in the corner with the same toy. Kinder can’t cope with him”

It can be the expectation of government funded service providers that inclusion for children with ASD will not occur unless families foot the bill....

“when we applied to for ‘J’s’ integration support we were told that because he could walk through the door, he did not need a full time aide. Only children in wheelchairs are funded for full time aides. ‘J’ could not safely attend 4 yo kinder without a full time aide so we had to pay the extra wages. Because ‘J’ is non-verbal and severely autistic and we wanted him to benefit from his kinder year, we had to provide a lot of training and professional support to the aide. Wages and training cost us nearly \$5,000 for the year on top of the kinder fees. The professionals who visited ‘J’ at kinder said they found the kinder teacher very difficult to work with. She was reluctant to change anything and we had to be very persistent“

Part 3, Interpretation of the CSTDA contains no definition of “inclusion”. A4 believes that “inclusion” should not be left open to negative interpretation. A4 would like to see a definition of inclusion included in the CSTDA such as:

Inclusion – the participation of people with disability in educational, social, recreational, vocational and community environments according to their needs and choices. Inclusive settings are places where people with disability have their individual differences and choices recognised and their differences and choices are provided for by making adaptations and/or modifications to procedure and/or activities and/or environments. Inclusion may require the provision of specialised supports such as staff, communication aides, equipment, transport, education, training and building modifications. Inclusion may also require the education of other service users as to appropriate supports for their peers.

### 1.3.3 Opting out of inclusion

Of great concern are service providers who opt out of inclusion for people with ASDs:

“The kinda music teacher refused to have a representative from X (early intervention centre) at the meeting. Then changed the time of the meeting to “now” with her assistant as the third person, so I could not even have ‘P’ or a friend with me. I was crying before the meeting started due to anxiety. Basically they said that ‘D’ did not meet certain criteria for the music program (despite 3 other kids with ASD already being in there). The criteria weren’t explained to me; they are not published and appear to be regarding behaviour. I was told he could attend if I fund an aide myself. I offered to be the aide and that was refused (no parents are allowed to attend the music program). The behaviour of concern was regarding distress at change and I offered solutions to this (ie. writing a note to pre-warn) and I was told that “I bent over backwards for ‘D’ last year and I am not going to be bothered doing that this year” When I suggested that ‘X’ were offering me support but she had refused them, she replied; “X are not going to interfere with my program”. .....

I got legal advice from a private solicitor and from the disability legal service. They agreed that ‘D’ was discriminated against and that we had a case for compliant. We considered complaining to equal opportunity board but thought because the teacher obviously does not want to teach our son in a way that he would learn then we now don’t want him in the music program and so why bother waiting and going through all that hassle...

I hate the fact that the process of complaining about discrimination is so involved and lengthy that it puts you off doing it. I hate how this woman has got what she wanted -not having ‘D’ in the music program.”

Another case study about opting out of inclusion:

“I went to check out a local school for my son. When I phoned to ask about parent tours I was told that the principle likes to meet with prospective families and would be happy to tell me about the school and show me around. When I introduced myself I mentioned that ‘J’ already attended an autism special school. The principle started the meeting by asking how much money would my son get for integration support. I didn’t know so the principle said I should go away and find out from the department of Human Services. He said I needed to have realistic expectations about my son’s inclusion at the school. I said I thought ‘J’ would qualify for a lot of support because he qualifies for the maximum level of funding at special school. The principle told me that the government rarely provides enough funding for high needs children in mainstream schools. He indicated that the meeting was over and asked if I had any questions. “Yes” I said, “can you please tell me about your school?”



These 2 case studies highlight inadequate arrangements in place to advance the inclusion of people with ASDs. The first story illustrates how the Disability Discrimination Act does not deter discrimination. The expectation that inclusion will occur by relying upon complainants to drive cultural change is unrealistic.

The overwhelming demands of raising a child with ASD in Australia means that families often cannot assert their child's rights by formally complaining. Secondly, families are reluctant to place their children in programs that don't want them. It is understandable that parents will not put their child "in the firing line" to make a point or to force a change in the community. Children with ASD do not have the social resilience to "trail blaze" a path to inclusion in discriminatory environments.

### 1.3.4 Inclusion and Education

As already stated, A4 strongly supports meaningful inclusion for people with ASDs. However we highlight potential conflict between acquiring an educational outcome and participation in regular classes typical of Australian mainstream schools. Children with ASDs can find it very difficult to cope with the noise, movement and social environment of the classroom. The stress they experience in the mainstream classroom can prevent them from learning the curriculum and often results in difficult behaviour. Children with ASDs, unlike their peers, often do not find the playground a welcome break from the classroom. The unstructured play, reduced adult supervision, unspoken social rules, noise and activity can be very confusing and overwhelming for a child with ASD. These problems are compounded if the child is the target of bullying – sadly this is common for children with ASDs. Australian researcher Dr Verity Botroff, Flinders University commented on the RURAL HEALTH EDUCATION FOUNDATION program,

"...one of the concerns I have from the research certainly that I have carried out and it has been a three-year project, is that 100 per cent of the children we were working with were victimised and bullied, and those reports came not just from the children themselves but from parents and from teachers and I think that that really needs to be addressed on a total school situation and just to remember that the child is not always going to be aware that they are being victimised. I can give you just one example of that to finish: we realised that one child was being verbally abused, physically abused on the way to school and eventually when the adults got to hear about it they asked, "Well, why didn't you tell us?" and the child just said "I thought that's what happened when you went to school"

Program 502 transcript, Learning Difficulties and Child Behaviour:Autism Spectrum Disorder

Broadcast live on 22nd March 2005. The full transcript can be found at <http://www.rhef.com.au/programs/502/502.doc>

When students with ASD are placed in mainstream classrooms, accountability procedures should be required to ensure that the student receives environmental and teaching supports appropriate to individual needs. A4 acknowledges that some schools (or individual teachers) manage quality inclusion for students with ASDs. There is a high degree of goodwill in these schools and usually a strong partnership between parents, the school and the wider school community.

Sadly, quality inclusive practices in mainstream schools tend to be available on an adhoc basis. Some families are forced to travel widely (even move interstate) to find a supportive school environment for their child with ASD. Other families simply must put up with inclusive practice that causes tremendous anguish and stress for their child. Too often a lack of funding is cited as the reason that supports according to need are unavailable in Australian schools. Education and welfare can be severely compromised. Expulsion and suspension from school is not uncommon for Australian students with ASD.

### 1.3.5 Children with ASD and Inclusion

In relation to children with ASD, the generic inclusion proposition can be false. Most children with autism do not "pick-up" social skills through "inclusion", they do not observe and imitate the social conduct of their peers. It is like trying to teach swimming through "inclusion" in the top water polo team. The approach immerses a child who cannot swim among skills that are remote and unrecognisable. If the child does not drown, he/she will be demoralised, possibly traumatised and may never want to return to the water. "Inclusion" can result in especially negative outcomes for people with an autism spectrum disorder, a group who have, by definition, particularly poor social skills.

The limited resources available to provide disability services for children with autism mean that services do not and cannot properly prepare children with autism for "inclusion". Government and service providers focus mainly on generic "inclusion" so services lack the specialised knowledge and skills needed to support children with ASD when they are "included" in community services. For example, the Victorian Government implemented a statewide "inclusion" model for preschool children with disability. Funding is such that no child can spend more than 2 hours per week at an early intervention centre. Parents are offered kindergarten and daycare to compensate for limited early intervention.

Autism specialists agree that pre- school-age children with ASD need intensive ASD-specific early intervention. Children with ASD need specific instruction in speech & language, social skills & behaviour, to observe & imitate peers, attending to & following instructions, etc. Research shows “intensive” means starting with a minimum of 20 hours per week. Effective programs integrate children with ASD progressively into mainstream settings where they are supported to practice the skills they needed for successful inclusion.

The Victorian model denies children with autism an effective opportunity to acquire the skills they need to benefit from their “inclusion”. The Output based funding Model is discussed further under the heading Generic Services versus Specialist Services.

The Association for Children with a Disability observe there are 8,500 students in Victoria with, or at risk of developing, extreme problem behaviours. And one third of these have Asperger syndrome. A4 anticipates this outcome will continue to worsen as children with even less early intervention flow through to schools.

The focus on “inclusion” in the CSTDA does not address essential services for children with autism. As the CSTDA is meant to address the essential needs of people with a disability including children with autism, and for children these needs are not met here or elsewhere, the CSTDA fails to provide services that assist children with autism as intended.

Children with ASDs can suffer badly in mainstream schools as highlighted in the following case study – a letter published in the A4 newsletter (The full text of this letter is in Appendix A)

Issue 3, June 2006 Page 10 of 19

Dear Sir,

We are writing to express our disappointment at the way in which the school handled the management of our son during the 2000 school year.

Our son was diagnosed . . . with Asperger's Syndrome in October 1999.

We took immediate steps to make the school aware of the situation, given that he was starting Year 7 in 2000. At the transition meeting with staff from the school and the Primary School, we were assured because of our son's needs the necessary Negotiated Curriculum Plan would be in place from day one. We were also advised that our son would be put into a class which would focus on children with special needs, but not a “special” class as such. We were told the teacher was a special education teacher, and that a support teacher would also be on hand to help.

Shortly after the start of Term 4 we felt we had no choice but to withdraw our son from the school, for the following reasons:

- The school's failure to implement many if not all of the suggested strategies provided by us, based on a sound knowledge of the management of an Asperger child.
- The school's failure to maintain any of the implemented strategies for anything more than a few weeks, contrary to all published material on Asperger Syndrome - provided to the school – that Asperger children require continuity, not “set and forget” strategies.
- The school's failure to protect our son from systematic bullying and harassment or to acknowledge that he was the target of systematic bullying and harassment.
- The school's failure - to the extent of reluctance - to make itself aware of Asperger Syndrome and of strategies to help our son. This ranged from declining to purchase the acknowledged authoritative texts, to declining to attend or make someone available to attend a two-day weekend authorised workshop in June on handling Asperger Syndrome at nearby . . . (It was mentioned to us that one of the teachers had tennis on Saturdays.) The school also seemed reluctant to invite a representative from the Autism Association to address the teachers, despite such a person being available, and despite offers by the association and repeated requests from us. The school also declined to contact our son's previous school or his tutor, a qualified special education teacher himself - both of whom were willing to offer strategies and/or work with his teacher in helping our son.

Much of this neglect resulted in our son developing serious behavioural problems, which seemed to surprise no one with any knowledge of Asperger Syndrome. Except of course the school, and the school handled the situation poorly. The school's response was, not surprisingly, to suspend our son on a number of occasions. The school's solution was – with consultation - to set in place strategies, many of which were simply left to fall away within weeks.

The cycle of harassment and bullying, with our son responding with more violence or threats of violence against a group of boys - one in particular - would then begin again, and we were back to square one.

### 1.3.6 Replacing a Clinical Diagnosis with a Moral Diagnosis

Many people with ASD struggle because policy makers struggle to accept social impairment as a legitimate disability. Where generic inclusion is not working, the clinical diagnosis is often set aside in favour of a moral diagnosis.

There are many people with ASD who find social settings confusing and distressing, even though they may crave social contact. Some can only cope with solitude or limited exposure to social settings, especially where they have not had the benefit of intervention and support.

Where inclusion decisions rest with a parent or carer, many families do not insist upon inclusion when their child will find it distressing. Other adults and children having fun in the “inclusive” setting that is upsetting for a person with ASD can find this hard to understand. Some people think that people with ASD just have bad manners or were badly raised. They may think that if the child were more firmly disciplined inclusion would not be difficult. Another common attitude is that parents who choose not to have their children in inclusive settings are backward thinking, unenlightened folk who are the cause of their child’s problems. This is very unfair. It is natural and proper for parents to protect their child from humiliating or distressing environments.

Where “inclusion” is attempted and fails, systems quickly revert to denial of responsibility, punishment and exclusion (without fair processes and rights of appeal). The CSTDA and supporting legislation does little to address this issue. “Failing” to meet the social demand of the inclusive setting is especially worrying in jurisdictions such as Victoria where the strengthened responsibilities that the Disability Act 2006 imposes on people with ASD may lead to further penalty.

## 1.4 Generic Services versus Specialist Services

### *Recommendations:*

- *Recognition that people with ASD needs specialist support to use generic services;*
- *Provision for specialist support.*

It is the experience of A4 members that generic services generally do not meet the needs of people with ASDs. In order to benefit from generic services, people with ASDs often need the support of specialist services. When government does not provide specialist support for people with ASDs, the need does not go away. People are simply driven into private services or go without help. People with ASDs deprived of specialist support often develop very challenging behaviours and may also acquire a secondary disability of mental illness.

Further, people with ASDs are often ineligible for disability services from any provider. For example the Victorian DHS report ‘Responding to people with multiple and complex needs in July 2003’ identifies the:

“lack of targeted responses to individuals with autism spectrum disorders, particularly Asperger’s Syndrome. These people are often identified as falling into service gaps, frequently deemed ineligible for both mental health and intellectual disability services.”

### 1.4.1 Children with ASD and Specialist Services

The insistence upon generic services rather than specialist services with a clinical focus can have profound and lifelong consequences for children with ASDs. The amount of specialist intervention for Australian children with ASD defies available evidence about effective early interventions for ASDs.

“It is now widely accepted that between 15 and 25 hours of specific intervention is adequate, ... In the typical programs of today, a child may spend time in individual therapy, in preschools with support, in special playgroups, and in home-based interventions. Services available differ between areas, and **in Australia there are no government- funded programs providing the recommended amounts of intervention.** There is a need for increased government financial support for early intervention programs.”<sup>1</sup>

---

<sup>1</sup> J. Wray, N. Silove & H. Knott, (Apr 2005) *Language disorders and autism* MJA, **182**:7, pp354-360.

**“most young children with autism in Australia do not receive intensive behavioural intervention programs** — partly because such programs are not recommended by many health professionals and partly because of their prohibitive cost for families”<sup>2</sup>

The results is that most families of children with ASD self-fund specialist therapies with a clinical focus. They hope to prepare their child for some success in school, and later for a degree of independence in adulthood. The Victorian Government’s “Autism in Victoria” Report<sup>3</sup> found that Victorian families with a preschool child with ASD spend large amounts of money accessing whatever private services they can afford. The report showed each year:

- 3% spend more than \$40,000,
- 6% spend \$20,000 to \$40,000.
- 12% spend \$10,000 to \$20,000, and
- 63% spend \$1,000 to \$10,000.

Any measure of the effectiveness of “inclusive” practices must include this burden, this extra “autism tax”, that it imposes on families of children with ASD. The amount spent indicates the desperation experienced by Australian families and lack of help available to their child under the CSTDA and health system. Lack of parent expertise in the treatment of ASDs may even compromise outcomes

“Programmes in Australia are frequently parent directed, as opposed to clinic directed, which may compromise outcome if expert supervision is inadequate. Parent directed programmes rely on parents to organize recruitment, training and supervision of therapists; clinic directed programmes organize recruitment, training and supervision of therapists from the clinic base. Families mortgage their homes and access superannuation funds to finance these programmes.”<sup>4</sup>

The CSTDA needs to recognise the special status and needs of children with disability. The CSTDA needs definitions of early intervention.

The CSTDA needs to recognise that inclusion is not early intervention or treatment for ASD. The attached document shows differences between the Victorian service models for early intervention and kindergarten for a preschool child with ASD. We have not analysed all the different service models for each State and Territory and acknowledge the possibility that some States have better services than others.












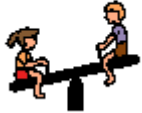




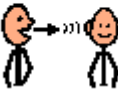

---

<sup>2</sup> J.J. Couper, A.J. Sampson (May 2003) *Children with autism deserve evidence-based intervention*, MJA, **178**, pp424–425.

<sup>3</sup> Crewther (2003) *Autism in Victoria: An Investigation of Prevalence and Service Delivery for Children Aged 0–6 Years*, Department of Human Services, Melbourne, Victoria (allegedly available from [www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)). A summary of the report is available at [http://www.ecis.vic.gov.au/bhcv2/bhattach.nsf/images/ecis\\_autism\\_in\\_vic/\\$file/autism\\_in\\_vic.pdf](http://www.ecis.vic.gov.au/bhcv2/bhattach.nsf/images/ecis_autism_in_vic/$file/autism_in_vic.pdf).

<sup>4</sup> J.J. Couper (2004) *Who should pay for intensive behavioural intervention in autism? A parent's view*, J. Paediatr. Child Health **40**, pp 559–561

1.4.2 Specialist early intervention for autism is different from kindergarten – Victorian Service Models

Early Intervention	Kindergarten
Class size	
<p>small class</p> 	<p>big class</p> 
<p>1:1 teaching</p> 	
Staff	
<p>Special Ed. Teacher</p> 	<p>Teacher</p> 
<p>Assistant</p> 	<p>Assistant</p> 
<p>Psychologist</p> 	<p>2 x 3    1 + 4</p> 
<p>Occupational Therapist</p> 	<p>Integration Support ?</p> 
<p>Speech Pathologist</p> 	
<i>Parent involvement</i>	
<p>with my parents</p> 	<p>on my own</p> 
<i>Curriculum</i>	
<p>I can play</p> 	<p>how do I play ?</p> 
<p>more breaks</p> 	
<p>slower</p> 	
<p>visual teaching</p> 	<p>verbal teaching</p> 
<p>repetition</p> 	

## 1.5 The CSTDA, Legislation and Affirmation of Human Rights

### **Recommendations:**

- **Consistent definitions of disability in all Australian laws and agreements;**
- **Recognition of ASDs as a distinct disability in the definitions;**
- **Consistent entitlements in all Australian Laws commensurate with identified needs;**
- **Access to due legal processes including higher levels of appeal and independent, binding arbitration;**
- **Removal of the assumption that some people cannot or should not exercise their rights.**

The CSTDA states that ... “the spirit of this Agreement encompasses the Principles and Objectives outlined in the Disability Services Act 1986 (Commonwealth), Disability Discrimination Act 1992 (Commonwealth) and complementary State and Territory legislation. The rights of people with disabilities under the United Nations Declaration of Rights of Disabled Persons are reaffirmed.”

We assume that the above statement infers that the CSTDA and Australian laws will be consistent with each other and the United Nations Declaration of Rights of Disabled Persons.

This is a positive sentiment. However, clauses in the CSTDA and Australian laws referring to human rights and disability carefully avoid the creation of an enforceable legal obligation to uphold human rights.

An Australian with a disability experiencing breaches of Human Rights are unlikely to find protection under Australian disability legislation and unlikely to have access to the court system or other avenues of binding arbitration. As far as A4 is aware, Australia’s Human Rights and Equal Opportunities Commission (HREOC) mostly advises complainants with ASD that they are unable to progress their complaint.

In any event, we note that the Australian legal system cannot uphold a human rights offence. For a time Australian citizens were able to benefit from the provisions of international treaties. The Australian High Court ruled, in the Teoh case, that the entry into a treaty by Australia creates a 'legitimate expectation' that the Government and its agencies will act in accordance with the terms of the treaty, even where those terms had not been incorporated into Australian domestic law (see [http://www.dfat.gov.au/treaties/workshops/treaties\\_global/jennings.html](http://www.dfat.gov.au/treaties/workshops/treaties_global/jennings.html)).

Subsequently, the Australian government acted to nullify this ruling. According to the webpage ...

“The Minister for Foreign Affairs, Mr Downer, and the then Attorney-General, Mr Williams, issued a joint statement in 1997\* stating that the act of entering into a treaty does not give rise to legitimate expectations in administrative law. The statement replaced a statement made by the then Minister for Foreign Affairs and the then Attorney-General in 1995.”

\* Commonwealth of Australia Gazette, No. S 69, 26 February 1997.

The case studies in this submission indicate that human rights are not affirmed in practice by the CSTDA and its supporting legislation, and that there are few, often no penalties for individuals or organisations perpetuating human rights abuse of persons with ASDs in Australia.

We highlight that important rights in employment and commerce, environmental protection, road rules etc are different from disability rights because the law relating to these areas does not rely so heavily on the goodwill of individuals, government or the community. For example, until there was legislation holding company directors’ criminally liable, environmental protection was poorly resourced and many individuals and organisations avoided their responsibility with the excuse that it was too complex and costly.

Recently enacted Australian legislation offers scant affirmation of human rights, for example

Queensland Disability Services Act 2006, Division 1 Human rights principle;

“Persons are *encouraged to have regard* to the human rights principle in matters relating to people with a disability”

This is inconsistent with Disability Service Standards, which state that;

### **“Standard 12: Protection of human rights and freedom from abuse**

The service provider *acts* to prevent abuse and neglect and to uphold the legal and human rights of service recipients.

**KPI 12.1** The service provider takes all practical and appropriate steps to prevent abuse and neglect of its service recipients.

**KPI 12.2** The service provider upholds the legal and human rights of its service recipients”

The standard says acts to prevent etc but the law in Qld only says encouraged to have regard. Clearly there is a gap between the standards and the laws that is inconsistent with affirmation of human rights.

If it is intended that Australian laws will reaffirm the rights of people with disabilities under the United Nations Declaration of Rights of Disabled Persons, A4 highlights the following legal barriers and shortfalls for people with ASDs:

- inconsistent definitions of disability in State and Federal legislation ;
- statements in State and Territory legislation that directly contradict the United Nations Declaration of Rights of Disabled Persons as it would apply to persons with ASDs.

### 1.5.1 Inconsistent definitions of disability in State and Federal legislation

ASDs are excluded from definitions of disability in the CSTDA and many relevant State and Territory disability laws.

The coverage of ASD in Australia’s disability laws hinges upon the choice and combination of words used in the different definitions of disability. Reference to impaired learning, impaired social functioning or more general descriptions such as “malfunction of any part of the body” may allow the definitions to be interpreted to include ASDs.

It is important to note that ASD is not an intellectual or neurological disability – these terms have specific meaning in the National Minimum Data set that excludes ASDs. In the NMDS there is a separate Autism category.

The range of definitions of disability across Australia is unsatisfactory for 2 reasons:

- loss of entitlement to disability services can prevent the mobility of persons with ASDs and their families;
- where disability services are provided on a discretionary basis for a person whose disability is not covered by legislation, the person may have little redress against their service provider for breaches of the law.

The table below summarises some analysis and opinion about the inclusion of ASD in some Australian disability laws.

State	Act	ASD included?
Commonwealth.	Commonwealth State/Territory Disability Agreement (Multilateral)	No
Commonwealth	DISABILITY DISCRIMINATION ACT 1992	Yes
Commonwealth	SOCIAL SECURITY ACT 1991	Yes
Victoria	Disability Act 2006	No
	Equal Opportunity Act 1995	Yes
	Intellectually Disabled Persons' Services Act 1986	No
	Disability Services Act 1991	No

To add further weight to our argument in favour of consistent definitions, we point out that ASDs are recognised in Federal support programs eg a carer of a child with Asperger’s Syndrome is eligible for Carer Allowance but state governments often deny people with Asperger’s Syndrome or ASD access to many disability services.

#### **A4 recommends that if...**

... “the spirit of this Agreement encompasses the Principles and Objectives outlined in the Disability Services Act 1986 (Commonwealth), Disability Discrimination Act 1992 (Commonwealth) and complementary State and Territory legislation. The rights of people with disabilities under the United Nations Declaration of Rights of Disabled Persons are reaffirmed.

**... then a single consistent definition of disability, which includes autism spectrum disorders (or pervasive developmental delay) is adopted in the CSTDA and all Commonwealth States and Territories legislation relating to persons with disability.**

### **1.6 Contradictions between Rights and Australian legislation**

In practice, for people with ASDs Australian disability laws protect systemic discriminatory practices more than they protect human rights. Rarely can people with ASD complain under the law. When people with ASD do complain their matters are delayed. For example, discrimination cases in the ACT relating to children with autism going back to 1997

have not been finalised. In the ACT and NSW Coronial inquests involving autism have been delayed indefinitely. Justice delayed is justice denied.

The United Nations Declaration of Rights of Disabled Persons can be found at <http://www.unhcr.ch/html/menu3/b/72.htm>

### 1.6.1 The Right to Disability Services in Australia

The United Nations Declaration of Rights of Disabled Persons states that:

8. “Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.”

For people with ASDs this means access to effective interventions to help a person minimise the impact of their ASD on their functioning. Effective interventions for people with ASDs include services with a specialised clinical focus. The services include speech pathology (for help with communication), occupational therapy (for help with sensory issues and motor skills) and psychology (for counselling, treatment of mental illness, help with human interaction/relationships with employers etc).

We have already mentioned that the provision of these services is especially vital for young children with ASD. Children need these services at least weekly over a period of years. Yet most States opt out of providing these vital clinical services leaving many families to self-fund therapies or watch their child needlessly develop a profound disability. There is no legal redress for Australian children with ASDs who needlessly develop profound disability because they were denied evidence based early intervention. There is no redress because there is no “right” to the interventions described in the United Nations Declaration of Rights of Disabled Persons.

The CSTDA notes that:

“The Commonwealth and the States/Territories acknowledge that this Agreement and any Bilateral Agreements do not apply to the provision of services with a specialist clinical focus, regardless of whether those services are provided to people eligible to receive services under this Agreement.”

Yet early interventions (which are specialist services with a clinical focus) are funded under the CSTDA – there is an NMDS category for this expenditure. A4 believe that the CSTDA must:

- acknowledge that specialist services with a clinical focus are essential for people with ASDs;
- acknowledge that specialist services need to be supported by efficient infrastructure;
- commit signatories to build and provide ongoing funding for the above either under the CSTDA or another scheme (such as Medicare);
- measure performance of services with a specialist clinical focus against relevant therapeutic (and internationally recognised) clinical standards.

Section 7 of the UN declaration of Rights of Disabled Persons says:

“Disabled persons have the right to economic and social security and to a decent level of living.”

Section 8 says: “ Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.”

The following case study from NSW highlights one example of a comprehensive failure to honour these important rights. (**NSW Legislative Council Hansard (Proof)** Extract from Transcript of Hansard 10/05/2006 (Article No.51)).

The breaches of human rights described below possibly arise from sections 19 and 24 of the NSW Disability Services Act 1993 which says:

Section 19

- (1) Payments of financial assistance are to be made from funds to be appropriated by Parliament for the purpose.



(2) Nothing in this Act requires a payment of financial assistance to be made otherwise than from funds that are available to the Minister for that purpose and, in particular, subsection (1) does not operate so as to appropriate money for the purpose of enabling such a payment to be made.

#### Section 24

(2) Nothing in this Act renders the Crown, whether in right of New South Wales or otherwise, liable to be prosecuted for an offence against this Act or the regulations.

**The Hon. JOHN RYAN** [10.11 p.m.]: This evening I would like to speak to the Minister for Disability Services on behalf of a 19-year-old young man called Paul Hill, and many others like him, who I believe are receiving ordinary service from the Department of Ageing, Disability and Home Care. Paul has autism, an intellectual disability. I first met Paul Hill in a group home at Yagoona operated by an organisation called the Bankstown Handicapped Children's Centre. He was sleeping on a two-inch thick foam mattress in the middle of winter with nothing more to cover him than a cotton blanket. His room was filthy; it had no covering on the windows to afford him a reasonable level of privacy; and he had one set of clothes—the ones he was actually wearing, consisting of a T-shirt and jeans. To wash them, he had to stand in a towel while they were machine dried.

Honourable members might recall that I raised this matter in Parliament in June 2004. As a result Paul was moved into another group home operated by the Department of Ageing, Disability and Home Care [DADHC], a place where we would expect he would receive the best possible care. But how different it proved to be! This young man was moved to a group home operated by the department in Murray Street, Bankstown. His parents have sent me a series of emails that would shock anyone who reads them. They report that when Paul moved into this group home he was always clean, his personal hygiene was on the improve, his depression was improving, and he was regularly attending a Transition to Work Program.

Within weeks of being transferred to the group home, he was refusing to attend his Transition to Work Program, and he was left isolated alone in his room, deprived of community access. Staff at his Transition to Work Program reported that he was being sent to their programs with a lunch consisting of 10 packets of potato chips. His parents took him to a general practitioner, who gave him blood tests that led the practitioner to the medical opinion that Paul was being subjected to a starvation diet. These matters were reported to the department on 20 January 2006. His parents also reported to the department that they witnessed group home staff ignore the needs of another resident in the same group home having an epileptic fit. They said that staff sat motionless in their office until it was obvious that this resident's head was "striking against an office door".

Then there were two very explicit reports about sexual assaults on Paul, including one very credible report that this young lad was homosexually assaulted by one of the group home staff. Believe it or not, every matter that Paul's parents have asked the department to address has been virtually unaddressed, including their request for the installation of a heater, or that Paul be taken to a podiatrist for treatment of an ingrown toenail, or that he attend for dental treatment. However, DADHC has found the money to install a security system that allows group home staff to sit behind a heavy duty steel door sheeted in Perspex and speak to the residents through a mesh grill.

In case any member should think that I am exaggerating, I have copies of correspondence that suggests this family have every support of the Public Guardian in regard to the complaints that they have made to the department. The latest correspondence I have received from the parents is dated 7 May 2006, is addressed to a senior member of the department's staff, and states:

Paul still does not have a heater. Can you give me some indication of just how long it will take for DADHC to provide heating for residents at Murray Street? Does Paul's cold need to progress to pneumonia before someone finally considers residents' warmth as a serious concern? Perhaps if all the managers spent a weekend in the residence we would see some changes, although I note that the carers [staff] have a nice heater in their office.

Paul reports to me that a budgie's cage is still being cleaned in the bathroom sink. His mother and I had no trouble getting him to clean his teeth on Saturday when he slept over with us, but then he didn't have to share the sink with bird droppings, nor did we handle his toothbrush. This is all really simple stuff. We can't understand the reticence [of DADHC staff] to comply with what amounts to basic good hygienic practices.

I understand that finally, after months and months of trying to negotiate with DADHC staff, Paul's family have requested an appointment with Ethel McAlpine, a deputy director general of DADHC. Finally, they have got almost to the top of the tree and will have the opportunity to put their case. I am begging the Minister and DADHC to finally listen to the concerns of Paul's parents. I do not understand what attitude the department's staff have towards this young man that they feel the need to freeze him every time they get the opportunity to "look after" him. Clearly he has significant concerns but the department appears to continue to ignore them. Standards that we would expect would be easily provided in DADHC homes are simply being ignored. It is high time the practices in this Murray Street group home were reviewed. I sincerely hope the Government listens to the concerns of the parents when they are put before the Minister and the Government in a few days."

## 1.6.2 Rights, Responsibilities and Restrictive interventions – The Victorian Disability Act 2006

A4 believes the recently enacted Victorian Disability Bill 2006 is an interesting case study because of its departure from many important human rights principles outlined in United Nations Declaration of Rights of Disabled Persons and the Commonwealth Disability Discrimination Act 1992.

The Victorian Disability Act 2006 can be found at [http://www.dms.dpc.vic.gov.au/Domino/Web\\_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/0B82C05270E27961CA25717000216104/\\$FILE/06-023a.pdf](http://www.dms.dpc.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/0B82C05270E27961CA25717000216104/$FILE/06-023a.pdf)

A4 believes that the Victorian Disability Act 2006 is a disturbing development for many people with ASDs and people with other disabilities relating to social or behavioural impairment because it:

- “strengthens responsibilities” for people with disability;
- mandates restrictive intervention;
- mandates inclusion as the primary “right” for a person with a disability ;
- does not recognise persons with ASDs .

We detail our concerns in relation to these points below.

### 1.6.3 Strengthened Responsibilities

We think that the Disability Act reference to persons with disabilities having the same responsibilities as other members of the community is at best not clear and at worst unnecessary and discriminatory. United Nations Declaration of Rights of Disabled Persons does not qualify those rights with responsibilities – a person does not have to earn or deserve their human rights. The responsibilities of individuals are already adequately addressed in other laws.

It is unfair to mandate that people with social impairment share the same responsibilities as other people in the community. It is profoundly unjust that the Disability Act does so when it does not recognise social impairment and consequently ASDs as a disability. This situation subjects people with ASDs to a moral diagnosis for their challenging behaviour. The Disability Bill recognises mental illness, as a disabling condition where it coexists with intellectual disability but we point out that ASD is neither a mental illness nor an intellectual disability.

### 1.6.4 Mandate of Restrictive Intervention

The Victorian Disability Act mandates restrictive interventions for persons thought to have a dual mental illness and intellectual disability. This is problematic because the Act does not allow those individuals the right to proper legal process and access to binding arbitration. Restrictive interventions take the form of chemical restraint, physical restraint and solitary confinement and are governed by the broad philosophy that

“where it is necessary to restrict the rights and opportunities of a person with a disability the intervention shall be the least restrictive **possible in the circumstances**”

**By contrast the UN Declaration on the Rights of Mentally Retarded Persons says:**

“Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain **proper legal safeguards against every form of abuse**. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.”

What is “possible in the circumstances” will depend on the attitudes, skills, level of communication, quality of care, personality traits and available resources prevailing at any point in time. “Possible in the circumstances” in practice means that restrictive interventions can be applied in a random and discretionary manner. “Possible in the circumstances” is not a “proper legal safeguards against every form of abuse”.

**Possible in the circumstances** does not give adequate protection to the rights of a person who

- Is incorrectly diagnosed and may in fact be receiving the wrong treatment for their condition –there is evidence that some people not responding to treatment for ADHD or schizophrenia actually have ASD) This is discussed further in this submission under the heading Mental Health and ASDs – Misdiagnosis.
- Is assumed to have needs that are too complex to understand.

- Is assumed to lack the intellect to understand what is happening to them.
- Is assumed to be making a moral choice to be deliberately non-compliant.
- Does not get the opportunity to tell their own side of the story, does not have the right for an alternative means of communication and does not have the right for their carer to be informed of the restrictive intervention.
- Acts out of frustration because others lack the skill or cannot be bothered to understand or accommodate their thoughts and needs.

A4 would prefer that the Victorian Disability Act said:

“A restriction to rights or opportunities may only be applied when exercising the right or opportunity poses a direct threat to the health, safety or wellbeing of the individual or others.

In determining whether an individual poses a direct threat to the health or safety of himself or others, a service provider must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk.

A service provider shall make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the provider can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations”

We call upon the CSTDA to address the profound injustice of restrictive interventions as mandated in the Victorian disability Act 2006 in accordance with the CSTDAs stated commitment to justice for people with disability.

### 1.6.5 Mandate of inclusion as the primary “right” for a person with a disability

Inclusion can be a limiting right for persons with ASD. It is wrong to assume that inclusion in the community at all times and in all circumstances subsumes all other rights such as health and education.

Forcing socially impaired people into poorly supported inclusion coupled with “strengthened” responsibility and mandated restrictive intervention is a recipe for systemic human rights abuse.

The “right” to inclusion is not backed up with a meaningful and enforceable right to preparation and ongoing support for inclusion. The right to inclusion is not backed up by a definition of inclusion in the Victorian Disability Act.

Inclusion is already mandated with fewer restrictions under the Commonwealth Disability Discrimination Act. The DDA says that reasonable accommodation must be made to facilitate inclusion. The Victorian Disability Bill says rights and opportunities may be restricted if that is all that is possible in the circumstances. We do not think that Human Rights are reaffirmed when the Victorian Disability Act undermine a Commonwealth Act. In real life and daily practice which one takes precedence?

## 1.7 National Quality Standards

### **Recommendations:**

- **Observance of National Quality standards;**
- **Monitoring of performance against the standards.**

Sections 6(3) and 6(5) of the CSTDA assign responsibility to the respective governments “to ensure that ... (c) agreed national quality standards are upheld and monitored”.

Further the DISABILITY DISCRIMINATION ACT 1992 - SECT 32 says:

“It is unlawful for a person to contravene a disability standard.”

The current version of these national standards can be downloaded from the FacSIA website [http://www.facs.gov.au/internet/facsinternet.nsf/viA/nsds1993/\\$file/nsds1993.pdf](http://www.facs.gov.au/internet/facsinternet.nsf/viA/nsds1993/$file/nsds1993.pdf)

In relation to people with ASDs, A4 believes that the national standards are more honoured in the breach than in the observance. We cite some examples below:

The first standard is about services access. The standard says, “Each consumer seeking a service has access to a service on the basis of relative need and available resources.”

Several States limit essential disability services to people with an intellectual disability. For example, DADHC in NSW says it will only provide case management for people with an intellectual disability.

The AIHW reports that people with ASD and related disorders are the most likely to report having severe or profound disability. People with autism are usually described as having complex needs and severe or profound disability.

The data available clearly demonstrates that high relative need does not mean that a person will receive a disability service.

The Disability Standards also say that services are supposed to develop entry and exit policies and procedures. Yet in many cases people do not know whether they are clients of the service or not.

The following case study is from a parent trying to access therapy services for a child with ASD in the ACT;

“Therapy ACT tells families that it will provide a particular level of service, and then simply fails to turn up. Therapy ACT has not seen my son in over 5 years, even though I have raised this issue on numerous occasions with the Minister and the Head of Department. I do not know whether he has exited the service. There is no information about his relative need. Nor would Therapy ACT have any idea what his relative need is after 5 years of not seeing a child with autism. There has been no referral to other services.”

The third national standard says “Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives”.

The same parent from the ACT says:

“About 4 years ago another agency hired a consultant to assess my son’s needs. The consultant made a number of recommendations. The agency decided to provide less than 25% of the recommended service. After 2 years, the service was independently assessed. The recommendation was that the services continue ... but the decision was made to cut the service completely.”

The above discussion and examples are by no means exhaustive. A4’s position is that even superficial examination reveals significant gaps between the disability standards and actual service standards.

Recommendations:

- Section 32 of the DDA 1992 to be enforced;
- Provision of resources so that Disability standards are met;
- Performance measurement against disability standards.

## Section 2 - The appropriateness of joint funding arrangements,

The joint funding arrangements under the CSTDA ensure that services to persons with ASDs are severely restricted or nonexistent.

The funding arrangements and the level of cooperation between governments results in keeping people serviced so they may survive. There is little provision for growth, optimism, wellbeing or positive futures and human rights for people with ASDs.

No party takes responsibility for properly funding evidence-based interventions for ASD. No party recognises that effective interventions can be a lifelong need that does not stop when a person starts school, leaves school or finds employment.

The lack of a single body responsible for adequate funding, coupled with the focus on individual inclusion has led to a lack of infrastructure to support individual needs. Services are fragmented and dysfunctional for people whose lives are already fragmented by ASD. People with ASDs and their families must constantly reinvent the wheel and expend an extraordinary amount of time, energy and money finding the help they need, negotiating with providers, coordinating the different service providers and navigating the funding schemes.

The inadequate funding arrangements for public disability services push people into the private sector where the costs are much higher.

Recouping costs through the various funding arrangements imposes an unhelpful administrative burden on people who already struggle with the activities of daily living.

The CSTDA joint funding arrangement provides impetus for one level of government to shift costs onto another. For example the Autism in Victoria Report recommends that childcare centres be used as early intervention substitutes. In early intervention centres the state government pays whereas parents pay for childcare and the commonwealth funded SNSS scheme covers the special needs cost. We have already discussed that generic services such as childcare are not early interventions for children with ASDs.

There is a disturbing attitude amongst public and private service providers that carer allowance is to be used to fund therapies.

Even more disturbing is the attitude that the high personal costs, the lost opportunities for a meaningful life, the grief and anguish experienced by Australians with ASD, is just a price that must be paid while governments avoid their responsibility. Typical excuses given by policy makers and bureaucrats is that “there will always be issues of unmet need”, “it wouldn’t be fair on everyone else if your needs were met”, “we have to consider everyone’s needs, not just yours”. The members of A4 are weary of these excuses. A4 does not believe that conditions that are profoundly unjust for people with ASDs can be justified in the name of “fairness”.

Finally, the following case study is a sobering and urgent reminder of the profound inappropriateness of the CSTD joint funding arrangements

In the case of Jason Dawes ... the following facts come from Judge Ellis in the matter from the NSW District Court known as 04/21/1041 – REGINA v DANIELA DAWES at Parramatta, Wed. 2 June 2004  
Jason Dawes was born on 2 Sept 1992.  
His autism was diagnosed in March 1994 when he was eighteen months old. His parents were advised that Jason was in need of early intervention, but [the local service] advised that they did not have a place for him. He went for years without intervention.  
Jason’s mother was required to educate, feed, toilet, bathe, entertain and love Jason. ... She constantly lived with the fact that her son had lost his best chance of acquiring later life skills because of the failure of authorities to provide appropriate intervention during his early formative years.  
Jason’s father said autism caused constant stress in the family and pervaded all their relationships, “[His mother] had to fight so hard for help for Jason – early on I couldn’t cope at all  
Judge Ellis said ... it is clear that the present system within New South Wales leaves a lot to be desired and was a significant stressor for Jason’s mother over an extended period of time.  
On 24 August 2003 ... Jason’s mother held his hand, placed her hand over his mouth and nose and held him until he ceased struggling. In so doing she took her son’s life. ... [Jason’s mother] then went into the bathroom, took a razor and severely lacerated her wrists.”

The funding arrangements made by the states to cover services with specific clinical focus are deeply flawed because they;

- are ad hoc,
- discourage clinicians from working in the public system,
- drive up costs by encouraging migration of expertise into private practice;
- create multiple layers of administration ;
- fragment service provision.

“for years we self funded our children’s therapy. Over 4 years our family spent more than \$135,000 on clinical interventions. Finally we qualified for an individual funding package of \$60 per week for each child which helped a bit. This involved paying the costs ourselves then forwarding the invoices to our case manager for reimbursement. I can claim some other costs through Medicare and some through our tax return. Managing and coordinating individual professionals into one child’s program is exhausting me. I hardly have enough energy or time to practice all the therapy at home with the children. My kids really need all their different therapies under one provider –then all the professionals could work together as a team, talk to each other and see how my kids are going with each therapy. And I could concentrate on helping my kids and being their mother rather than a case manager and administrator.”

A more satisfactory arrangement is needed. For example, evidence based clinical interventions for ASD could be fully covered by Medicare. This offers a better guarantee of service than the current funding arrangements. The philosophy of social integration and individual development contained in Australian law and the UN declaration is sound but should not be misused as an excuse not to provide essential infrastructure for people with ASD - particularly infrastructure to support the provision of services with a specialist clinical focus. It should be noted that the aim of these services is to get people functioning to their individual capacity so that they may take advantage of opportunities offered by generic services and participate meaningfully in their communities.

## 2.1 Unmet needs

### **Recommendations:**

- **Alternative arrangements for specialised services with clinical focus;**
- **Better financial support for therapy needs through Medicare;**
- **Clearly identified responsibility for providing evidence based interventions;**
- **Recognition that interventions can be a lifelong need;**
- **Recognition that group living arrangements can be unsuitable for people with ASDs;**
- **Measurement and reporting of unmet need;**
- **Recognition of the special needs of children.**

Available data shows high levels of need and high levels of unmet need for persons with ASD.

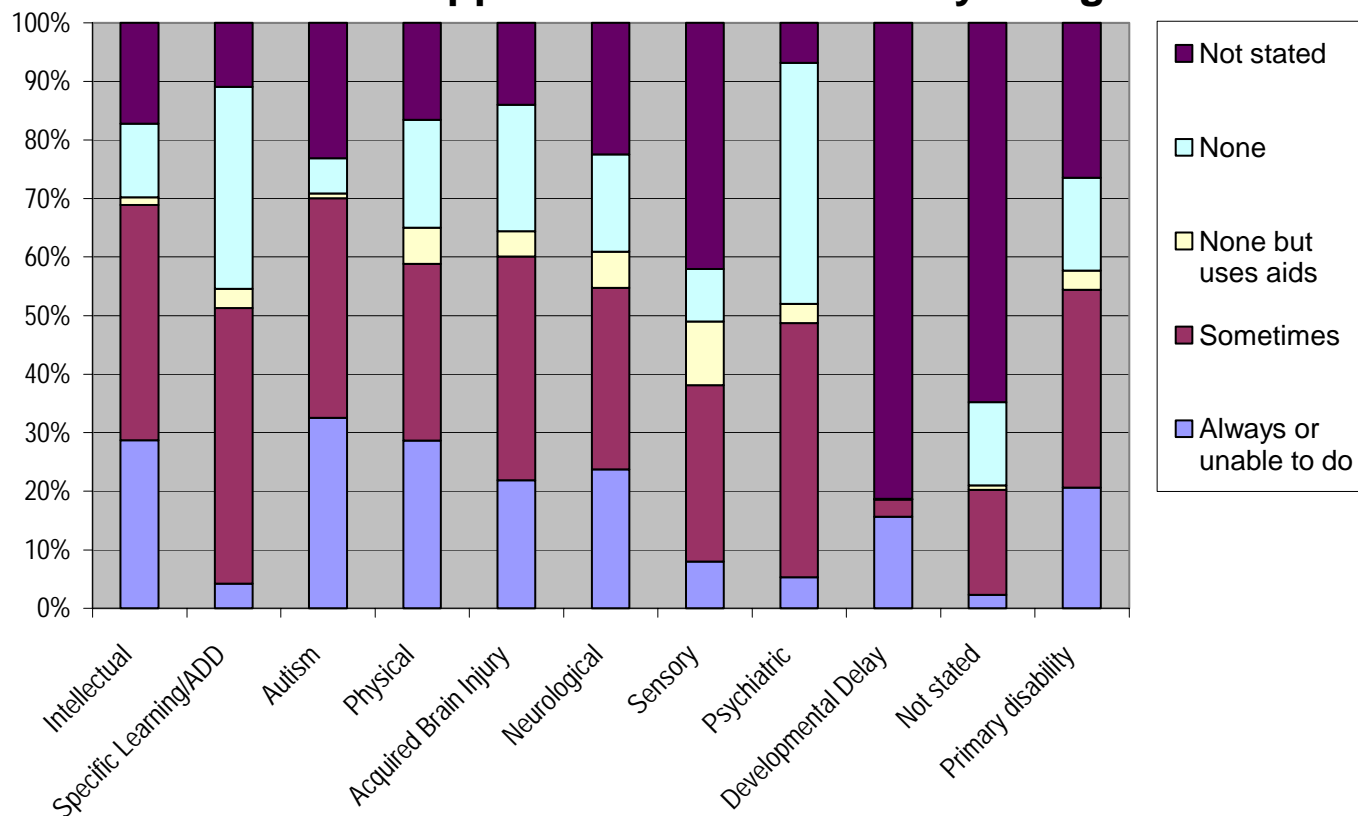
## 2.2 People with ASDs have high support needs

The following graph is prepared using interactive disability data published by the Australian Institute of Health and welfare for users of all CSTDA-funded services, 2003-04 from [http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all\\_20034](http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20034)

The graph highlights that persons with autism are the most likely of all persons with disability to fall into the “always needs help or unable to do category” for managing daily living activities.

### Need for support in activities of daily living

## Need for support in activities of daily living



### 2.3 High level of unmet need for people with ASD

There are high levels of unmet needs at all ages and stages of life for people with ASDs and their carers. We know this from anecdotal evidence from the A4 membership and because of reports of long waiting lists from specialist service providers for people of all ages and stages with ASDs.

**A4 believes that service providers in receipt of public funding should report under the CSTDA unmet needs arising from complete or partial inability to provide a service to a person with a disability. Unmet need is an important accountability measure, is a key tool for effective government planning and budgeting and should be regularly and systematically measured and reported to the public.**

### 2.4 Unmet need and children with ASD

A4 draws particular attention to the high levels of unmet need for children with ASDs. The unmet need is predominantly in the areas of diagnosis, specialised early intervention and ongoing intervention. Early diagnosis and specialised early intervention are proven methods for minimising the level of disability the child with ASD carries into adulthood.

A diagnosis of ASD is made by a multidisciplinary team of professionals. The diagnosis includes a speech assessment by a speech pathologist, an assessment of social and cognitive skills by a psychologist and a medical assessment by a paediatrician. Waiting lists for diagnosis through the public system can be up to 2 years. If private services are available, families can obtain a private diagnosis for about \$1,500. Many families opt for private diagnosis rather than waste precious time on the public waiting list since interventions often cannot be offered without a diagnosis of ASD.

The services needed by children with ASD are chronically under-resourced in the public sector. For example Victorian Hansard of 14 September 2004 Hon. D. K. DRUM ...

*“We currently have autism assessment waiting lists of well over 12 months now for the central Victorian Bendigo region, which in the last 12 months has come down from a high of over two years”*



Once the diagnosis is made, it is unlikely that Australian children will receive evidence-based intervention for their ASD in terms of the type of intervention offered and its intensity.

By evidence based interventions we refer to interventions with measurable developmental outcomes that are validated and replicated by scientific methods, subjected to peer review and published. There are interventions for children with ASD that satisfy these criteria but they are only available privately. A4 is not aware of any publicly funded early childhood intervention program for ASD in Australia that could be described as evidence based in terms of the duration, frequency and method of intervention.

The high needs and unmet needs of children with ASD are also highlighted in the AIHW Bulletin issue 42, July 2006 <http://www.aihw.gov.au/publications/aus/bulletin42/bulletin42.pdf>

Reports for the 2003-4 financial year show there were 317,000 children with disability aged 0 to 14 years; this figure includes 165,000 children with severe or profound disability.

The Australian Institute of Health and Welfare published data on users of CSTDA services states that for the same period there were a total of 38,382 children aged 0 to 14 years with disability using CSTDA funded services. Of this group, 4,981 children aged 0 to 14 years have autism as their primary disability.

[http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all\\_20034](http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20034)

**Hence, government figures show that only 12% of children with disability received CSTDA services and that approximately 127,000 Australian children with severe or profound disability received no CSTDA services at all.**

The AIHW update Bulletin issue 42, July 2006 also confirms that autism is a high needs disability. It notes that “autism, while having a lower prevalence than asthma, was strongly associated with severe or profound core activity limitation—an estimated 87% of children with autism also had a severe or profound core activity limitation.

The number of Australian children aged 1 to 14 year with autism is 17,700, so there are 15,400 Australian children with a profound or severe core activity limitation caused by autism. Less than one third of children (4,981 children according to AIHW) with autism receive CSTDA services.

A key impairment of autism is communication. Communication is strongly linked to quality of life. Inability to communicate profoundly affects interactions with parents, siblings, peers and others, it profoundly affects education and employment opportunities. It is especially disturbing to note that “While 98% of children with severe or profound disability requiring assistance with communication received assistance with this activity, only 60% of these children had their need for assistance with communication fully met. In comparison, 90% of children requiring assistance with self-care had this need fully met.”

Where children have high levels of unmet needs in relation to their disability, it falls to parents to breach the gap. The AIHW bulletin 62, July 2006 says:

“An estimated 32,200 (59%) primary carers of children aged 0–14 years with a severe or profound core activity limitation provided more than 40 hours of care per week.”

Often this caring responsibility can interfere with the ability to care for other children in the family. We discuss this further under the heading Mental Health of Carers.

“Almost half (48%) of primary carers of children aged 0–14 years with a disability reported needing more support. Of these primary carers, 40% reported more respite care as their greatest need and 34% reported financial assistance as their greatest need.”

The majority (62%) of mothers who were primary carers of children aged 0–14 years with a disability were not in the labour force. This compares with 36% of other mothers of children of the same age. Mothers who were primary carers also had lower employment rates than other mothers.

The data above clearly states and reinforces what people with ASDs their parents, families and carers experience in their own lives; in summary;

- Children with ASDs are likely to have severe and profound impairments;
- The early intervention needs of children with ASDs are not met by government and many families self fund interventions;
- Parents experience high levels of physical, emotional and financial stress trying to raise a child with ASD with minimal support, the fragmented and dysfunctional nature of services is an additional source of stress for parents and child.

There should be no doubt those children with profound and severe impairments, deprived of effective clinical interventions grow into adults with profound and severe disabilities.

Adults with disability are unlikely to live independently in the community. They are cared for by ageing parents who will become old, frail and die on the job carrying a horrible burden of worry for their child's future to their graves.

Children with profound communication and social impairments resulting in challenging and noncompliant behaviour are a particular worry. Restrictive interventions either legal or informal are routinely targeted at these vulnerable children – especially when resources are tight. Parents are sometimes the only human rights advocates for their child.

How does this happen when Australian laws “reaffirm human rights” “strengthen rights for people with disabilities” etc? It is time for governments to deliver on their promises to respect human rights for all Australians.

## **2.5 Unmet need and employment services**

People with ASD can find it very difficult to find and retain employment. The social and communication impairment associated with ASD is a significant but often unrecognised barrier to employment. Employers and employment agencies can struggle to understand social and communication impairment, especially in a person who is intellectually very capable (for example. a person with Aspergers Syndrome).

The following case study is insightful and highlights employment difficulties for people with ASDs.

“My son is 25 and has Asperger's Syndrome. We all worked hard to make sure he had a good education, thinking that education was the key to employment. He finished year 12 in Qld with an OP 10, and went on to get his Bachelor of Multimedia at Griffith uni, in the 3 years minimum time, and with a good smattering of Credits and Distinctions, like his friends.

He attempted unsuccessfully for the next 3 years to get employment. His only success was a 5-month state funded project specifically targeting the long-term unemployed. The aim of this project was to provide experience, which would lead to employment, but while he was given very good references, and was able to do the job successfully, it did not help him pass the interview, or compete with “normal” people. He did a Certificate 4 in TESOL teaching, because he was always good with language, but the same barriers existed. He could not perform well in interviews. He began by applying for jobs using his degree. When it became obvious he would not succeed this way, he dropped his expectations, looking for anything using a computer, but equal opportunity is not equal for those with disabilities. He would never be the best for any job. Very few people understand Asperger's, and they cannot see beyond the surface of these people to realize they could have a very valuable employee. And why should they, when they can employ someone with no complications?

All this time he was using a Disability Job Provider. These people also do not understand Asperger's. He used 2 different providers, for 18 months each, and his individual case manager changed at least 3 times with each one, so there was little stability. They received their government funding, created a great deal of stress in all of us, achieved nothing for my son, and left him not wanting to try anyone else.

We had got to the stage of applying for traineeships and apprenticeships, thinking that way he could get experience and training, but he couldn't get one of those either. Because he had a tertiary qualification he was not eligible for government funding, and so no employer would take him.

I wrote to every state and Federal Minister I could, several times, as well as having personal meetings with several, explaining how Equal Opportunity discriminates against those with disabilities, how those with tertiary qualifications are further discriminated against, how there was help to train people, but those with training had no appropriate help to get jobs, how the job provider system did not help and so on. The response was always to tell me how much money was spent on disabilities, how wonderful their programmes were, but not addressing the fact that a person with a disability, but with skills and certainly with a desire to work was unable to.

Finally the Principal of the Christian School where my husband and I both work, concerned at the lack of public and government help, created a job for my son. He now has a part-time traineeship as a library aide. It is only 3 days a week, and only in term time, so he still needs his salary subsidized by the Disability Support Pension. The school was not able to access funds for this traineeship, because of my son's degree, but the costs of his training are reimbursed. He has been there for a year now- 2 terms at 1 day a week, and 2 at 3 days. He has had his annual review and did very well. He is a productive staff member (although he'll always be slow). He is honest, committed, has not had any sick leave, is studying for another qualification, etc.

The main points I want to emphasise are:

1. The government's policies of Disability Job Providers are ineffective when they and industry are not prepared to employ those with disabilities.
2. Equal Opportunity discriminates against those who can do a job, but will never be the best applicant because of their disability.
3. The conditions for traineeships discriminate against those who have higher level skills, but can't get a job using them.
4. Because of their disabilities people, if they do manage to get employment are certainly employed at a much lower level than they would otherwise be”

## 2.6 Unmet need and supported accommodation

Available data portrays a sobering picture with respect to supported accommodation and unmet need for Australians with disability. There appears to be a deliberate strategy on the part of government to deny support to aged carers of ageing people with disability.

For example in Victoria in 2006 there are “nearly 4000 people on the waiting lists for accommodation support, and over 2000 of these people on the Urgent waiting list. Victoria’s 2006-07 budget throws out a few leftovers by way of 170 additional individual support packages. The average funding would at best fund a few hours a day of support. There is no additional funding for respite. Over 1000 people on the waiting lists for accommodation support are aged 45 years or more. The current funding of services demonstrates clearly the expectation that parents will and should continue to care for their sons or daughters with disabilities in the family home until, they, the parents, become incapacitated or die.” Disability Network media release 4/6/06

The following article from the Queensland Courier Mail tells a sad story about unmet need and highlights that group living arrangements for people with social impairment can be disastrous.

May 13, 2006

### **DISABILITIES advocates have called for an investigation into the culture of Disability Services Queensland and a review of the housing of intellectually disabled people in-group homes.**

The call follows allegations a senior manager told the parents and advocates of a severely disabled man that a certain level of abuse in group homes, where intellectually disabled people lived, was to be expected.

Dianne Toohey, from the Brisbane disability advocacy agency Speaking Up For You, said on Friday her agency had referred the matter to DSQ’s complaints unit, together with a series of serious complaints about the treatment of 30-year-old Edwin Hewitt.

She said Mr Hewitt, who was profoundly intellectually and physically disabled, had been subjected to serious physical and emotional abuse for three years while living in a DSQ-operated Alternative Living Service group home in Brisbane’s east.

Ms Toohey said her agency had found that many of the attacks on Mr Hewitt by his intellectually disabled housemates had not been reported to his parents or police as required by DSQ policy.

She said she was shocked when told by a DSQ manager at a meeting to discuss Mr Hewitt’s abuse that what he experienced was commonplace in group homes.

Chief executive of Queensland Advocacy Incorporated Kevin Cocks said the Crime and Misconduct Commission should investigate DSQ.

“When does complacency, or not doing enough to protect people in a timely manner from violence, abuse and harm, become criminal or constitute official misconduct? Because this attitude is totally unacceptable,” he said.

Mr Cocks said the group housing solution adopted following the closure of large institutions – currently costing around \$100 million a year – was the cheapest way of supporting people with high support needs and should also be reviewed.

“Often people with aggressive and violent behaviours are grouped together and this immediately establishes a highly volatile, if not explosive, living arrangements – it’s setting everyone up to fail,” he said.

Our case study from overseas (see Section 5 - Case study from overseas) that presents some better alternatives to group living arrangements.

## Section 3 - Interface between Health and Disability Services for persons with ASD

### **Recommendations:**

- *Better understanding of ASDs in the health professions;*
- *Understanding that people with ADS their families and carers should enjoy good health outcomes including good mental health;*
- *Address issues of misdiagnosis;*
- *Address issues of premature death for people with ASDs.*

Like everyone else in the community people with ASDs have different health needs relating to their ASD depending on their age and stage of life. Feedback from the members of A4 indicate that people with ASDs of all ages need:

- specialist services with a clinical focus and supporting infrastructure;
- Centres of Excellence for ASD research, teaching and intervention ;
- financial assistance for individuals and families to meet the costs of interventions for ASD.
- A home for ASD in health;
- Health professional awareness;
- Adequate Coverage for ASDs available in private health insurance.

### **3.1 Health Needs**

#### **3.1.1 Health needs for children with ASD**

The rate of early diagnosis of children with ASDs suggests an improved interface between ASD and the health system for young children. There is however significant improvement still required for children in the health system to ensure that diagnosis of ASD is made at the earliest opportunity. Early diagnosis is the only way for a child to access early intervention and thereby minimise their disability and maximise their chance of independence in adulthood.

Too often, health professionals, such as maternal child nurses and GPs, overlook early signs of ASD. A parent's early concerns are sometimes dismissed as overanxious or incompetent parenting. False assurances that everything is OK do not help and valuable time is lost. It can take a degree of persistence on the part of parents to have their toddler's developmental problems referred to health specialists qualified to make an ASD diagnosis. In the public health system, the waiting list for a developmental assessment can be up to 2 years. Once the diagnosis is made, the waiting period to receive an early intervention service can be up to 2 years. In some parts of Australia (not necessarily remote areas) there are no diagnostic or early intervention services at all for children with ASD.

#### **3.1.2 Health needs for children with ASD and the tax system**

Disability and health interface via the tax system – not a fair or equitable arrangement. The Australian Tax Commissioner had ruled that interventions for children with ASD prescribed and supervised by a medical practitioner can be medically necessary and can attract a tax rebate through the annual returns system. This ruling allows higher income families to claim a higher rebate. Parents usually find out about this ruling through word of mouth from other families with a child with ASD. They then approach their accountant with the ruling to make a claim. Although this arrangement provides a small amount of much needed financial relief to some families, it is not a fair or equitable system.

#### **3.1.3 People with ASD pushed into private services**

Lack of public health services relating directly to ASD pushes people into the private sector for allied health services. Adults with ASD, struggling to find and retain employment can find private services out of their reach. Some very limited financial relief is available under Medicare.

The tight rationing of services in the public system drives a tendency amongst service providers to provide services according to their own value judgements rather than an objective assessment of needs.

**“In the Asperger Syndrome Support Network meetings, the most common parent complaint I hear is that they are told by the health system that their child is not BAD enough to warrant any help through the system and they have to find help privately, often at their own cost ...”**

People are disadvantaged if they tell a publicly funded provider that they use private services while they languish on the waiting list. People are often told that if they can afford to use a private service while waiting for a public service they should not “burden” the public system at all. This informal and adhoc means testing is grossly unfair. These people pay taxes that fund the service they cannot access, and they may also have paid tax on the income they spend on the private service.

### 3.1.4 Medicare and the cost of treating ASD

While many people believe there is a safety net to support all Australians against high medical costs for medical services provided outside hospitals" – there is no safety net for people with ASD.

An intervention for ASD is the domain of allied health workers such as psychologists, speech pathologists and occupational therapists.

Some Medicare allied health service rebates are available for conditions treated by GPs through an Enhanced Primary Care (EPC) plan. Up to 5 allied health services per year may be used. Medicare rebates are available totalling \$220 per year for the 5 services.

However few (if any) people with ASDs are offered EPC plans and the rebates because GP’s do not treat ASD.

People with ASD and their families compensate for the lack of public services by using private services typically costing \$100 to \$200 per hour. Paediatricians say that speech pathology, psychology, occupational therapy and behavioural therapies are medically necessary for children to minimise their lifelong disability – yet these services are mostly unfunded by Medicare.

The cost of treatment for ASD is especially high for preschool children. The Victorian Government’s “Autism in Victoria” report found that of Victorian families with a preschool autistic child; ***Two out of 10 families will spend more than \$10,000 per annum (and sometimes more than \$40,000) while the other families may spend up to \$10,000.***

### 3.1.5 Health and ASD

Living with ASD is hard not only because of the disability but also because the public health system and Medicare are not equipped to deal with ASD.

Access to general healthcare is harder for children and adults with ASD because:

- High cost – Services covered by Medicare are inadequate so there is reliance on expensive private health services;
- The social, communication and sensory difficulties characterising ASD hamper effective diagnosis and treatment of illness;
- ASD, although not rare, is misunderstood by many healthcare workers.

## 3.2 ASD healthcare hardships

There is a higher incidence of some health problems amongst people with ASDs. (eg. Autoimmune diseases, epilepsy)

Routine visits to doctors and other health professionals can be hard for people with ASD and the reasons for this are varied.

Some find it difficult to process and remember spoken information and may use a monotone voice that gives a poor indication of their intelligence.

Hence, a person with ASD may find it difficult to answer questions about their health. They may not understand what they are told about their illness and how to treat it. On the other hand, a healthcare professional without a working knowledge of ASD may not communicate effectively and misinterpret what their patient says. One adult with Aspergers Syndrome said:

**“The nurse was showing me how to test blood sugar. I wanted to write it down but she said it was easy. It’s not easy for me”.**

Problems are compounded if the health professional ignores or dismisses their patient's ASD diagnosis. For example:

"My GP died. It took me 3 years to find another who would even look at the diagnostic report I took to prove that I actually do have Aspergers. One doctor said that it was grossly over diagnosed and that we would not worry about it..."

A tendency to interpret language literally and even the inability to recognise pain may also impact on access to appropriate health care.

**"When they ask, does it hurt? I reply "no it doesn't", cause to me it doesn't hurt. I worked for two weeks with a major bone in my foot broken 'cause it didn't really hurt much -till it was just a ball of bone fragments"**

Treatment which requires touch or is accessed in a noisy environment can be very difficult, for example physical examinations, dental care, treatment in emergency wards and hospital waiting rooms. There are specific strategies which must be used to assist the autistic person in accessing health care in a range of settings but these are not well known in Australia.

While paediatric staff are slowly developing awareness of ASD issues, staff in general disability support facilities or aged care often have little specific knowledge of ASDs.

### **3.3 Mental Health and ASD**

#### **3.3.1 Mental health of people with ASD,**

Mental illnesses such as anxiety disorders and depression are common for people with ASD, even young children. We believe there may be a growing reliance on medications to manage challenging behaviours for people with ASDs. We acknowledge that some people with ASD benefit enormously from the use of drugs to manage their anxiety but highlight that many drugs are not proven safe for use in children and there is some evidence that long term use of some drugs can lead to serious health complications (eg liver failure). We know of one specialist ASD school that runs an information evening to advocate use of drugs for primary aged children with ASD. We believe that drugs should be a final option considered after every other possible humane intervention and modification of personnel process, practice and procedure has been put in place. Non complaint or challenging behaviour usually happens for a reason. Even when drugs are prescribed, they are unlikely to alleviate mental illness caused by poor practises. Carers, professionals and organisations must consider how they may cause the "challenging" behaviour of a person with ASD. Government policy should encourage best practice communication and behavioural management rather than promote reliance on drugs. Good practice takes more time and greater skill. It costs money. Restricted resources can create the circumstances for a mental illness in a person with ASD.

#### **3.3.2 Misdiagnosis**

Some researchers provide evidence highlighting the misdiagnosis of mental illness, which is really ASDs. For example: S. Edwards, C. Bennett (Nov 2002) *Assessing for Autism Spectrum Disorder in adults with psychotic illness and intellectual disability*, World Autism Congress, Melbourne, say they examined ...

"a group of 25 adults who had been receiving treatment for psychotic disorders but with a less than optimal response. After assessment ... it was found that they had diagnoses within the autism spectrum that had not been previously identified".

"In Schizophrenia the typical sensory disturbance is hallucinations and these are normally auditory ... Most mental health workers will screen for auditory hallucinations with the question 'Do you hear voices?' To which many people with Autism and intellectual disability will respond 'Yes' reflecting either a concrete, literal answer (as we all do hear voices in the absence of hearing problems) or a desire to give the 'right' answer that the examiner seem to be looking for." [p5].

#### **3.3.3 Mental health of carers**

The oxford dictionary provides 2 definitions of respite:

"respite – interval of rest or relief";

"respite – delay permitted before discharge of an obligation or suffering of a penalty".

It is disturbing to observe a change in the meaning attached to "respite" for Australian carers. It is more like the second definition, a crisis service offered to people on the verge of breakdown rather than a rest offered to promote quality of living for carers and those for whom they care.

Terms and conditions for Australian carers of people with high support needs are not conducive to good mental health. Studies have shown that there are high levels of depression in mothers caring for a child with ASD. Many mothers reported that they needed medication to cope with depression and felt that they were unable to care properly for the other children in their family. These problems can only be exacerbated by lack of disability services.

Gray (2003) found that mothers were much more likely to claim that their child's autism had severely affected their emotional well being. Indeed, many mothers had experienced enough distress to require psychotherapy and/or medication. In cases where the sibling of a young child with disabilities is a preschooler, the parents themselves are likely to be in the initial stages of adjustment to the reality of the child's disabilities, resulting in fewer quality interactions with the preschooler than usual (Lobato, 1985). Consequently, these children may be particularly vulnerable to feelings of confusion and isolation which can lead to developmental difficulties.

Gray D. (1993) Perceptions of stigma: the parents of autistic children. *Sociology of Health and Illness*, Vol. 15 (1), pp. 102-120

Lobato D. (1985) Brief report: preschool siblings of handicapped children impact of peer support and training. *Journal of Autism and Developmental Disorders*, Vol. 15 (3), pp. 345-350

The right to family life is an important human right and is important to quality of life for both carers and the person they care for. It is unjust that Australian carers are forced to relinquish "normal" relationships with their family because of their "disability carer" role. Terms and conditions for many Australian carers would not be lawful in any Australian workplace. People want lives that are calm and over which they feel they can exercise a reasonable degree of control. Denying people reasonable control over their lives guarantees poor mental health.

### 3.3.4 Mortality and the interface between health and disability services.

Figures published by AIHW show that in Australia for 2003-4 there are only 77 Australians with ASD aged over 50 years receiving a CSTDA service. This is a sobering figure. It appears that lifespan is significantly shortened by ASD.

*Insight to this alarming statistic is provided by The Victorian, Medical Committee on Client Mortality (MCCM) (Intellectual Disability).* Their report *A Review of Client Mortality 1999-2001* says:

"During the period 1 January 1999 to 31 December 2002 the Medical Committee on Client Mortality (MCCM) reviewed the files of 79 people who had intellectual disabilities and who died whilst living in residential facilities run by the Department of Human Services (DHS). The Committee's role is to review the lifetime health care and the death of all people with intellectual disability who died whilst in the care of the DHS and to make recommendations, which will lead to improvements in standards of health care.

Additionally the report indicates that ...

#### **1.9 Probable Autism**

The reviews indicate that 13 (16.5 %) clients of the 79 reviewed had unrecognised autism. Knowledge about the nature of autism-related impairments and their consequent management is improving rapidly, to the considerable benefit of people with these problems. Lack of recognition and diagnosis denies people with these disabilities access to the benefits of this expertise.

Clearly, there is a serious problem. Specialised disability services did not recognise autism in their clients, when autism is the disorder most associated with severe or profound disability.

The report found people in this group have a **life expectancy of 46 years**, much lower than for the rest of the population. These experts say

"Some reduction in life expectancy is to be expected, but the Committee's view is that to accept this is at best complacent and at worst tends to self-fulfilment."

This information is consistent with results Nick Lennox, now the Director of the Queensland Centre for Intellectual and Developmental Disability (QCIDD) (see <http://www.uq.edu.au/qcidd/index.html>) at the University of Queensland told the AIHW. Prof Lennox told an audience at the AIHW that people with a developmental delay have on average 5.2 co morbid serious health disorders with two of those unrecognised

---

## **Section 4 - Interface between Aged Care and Disability Services for persons with ASD**

The figure of 77 Australians with ASD aged 50 years or more receiving a CSTDA service might strongly suggest that few Australians with ASD can expect to reach old age. A4 hopes the life expectancy of Australians with ASD will improve. Currently the interface between aged care and disability services is more likely to be an issue for ageing careers.

Although very little is known about autism and aging, we do know that people with autism are likely to experience considerable angst if placed in communal living situations, particularly in noisy environments. We know that under extreme stress, people with ASD can become violent and aggressive. If required to change long term routines, they can become upset and highly anxious. We know that many (due to high levels of anxiety) need space and privacy in order to relieve stress.

Based on what we do know about ASDs, the group living model for elderly Australians needing high levels of support for the activities of daily living is probably inappropriate.



## Section 5 - Case study from overseas

There are many examples from overseas of governments and services with compassion and respect for human rights for persons with ASDs.

The case study presented here is but one of many. It should be noted that the case study we present is not a statement of all needs for all people with ASDs and their families. The fact that we have chosen this example is not intended to diminish other pressing issues for Australians with ASDs their families and carers.

We do however believe that the philosophy of compassion and genuine respect described in our case study reflect the needs of all persons with ASD. A4 has chosen this case study because it is relevant to the current CSTDAs stated priorities of people with very high support needs and ageing/disability.

A4 is grateful to 'MM' for sharing this case study. 'M' is the father of an 18-year-old man who has severe autism which regularly results in episodes of very difficult behaviour at home, in respite and at school. This routinely results in the use of seclusion, physical restraint, and expulsion from school. This is distressing for the whole family and is a significant and unremitting source of stress. The family wants this self-perpetuating cycle of crisis and restrictive intervention to stop for their son. They believe their son deserves an opportunity for a happy life. The 'M' family is from Victoria and have found it very difficult to access compassionate services for their son so that he can live calmly and productively in the community. They worry about his future and what will happen when his parents can no longer advocate for and protect him.

'MM' visited the United States in June 2006 to learn more about the compassionate supported living arrangements available to adults with ASDs. 'M' is now working with several other Victorian families in similar circumstances to bring these services to Australia under private sponsorship. The coalition of families wishes to implement this service in Australia, initially without government input so that families can directly influence the scope and quality of the service. A4 believes that the experience of these families is a sad reflection on the nature of the relationship between caring families and government. Australian governments should pause to reflect upon their practical commitment to human rights for people with a disability that results in challenging behaviour.

### ***Overseas Examples of good Practice for people with ASDs***

Two (2) service providers from the United States are described, The Judevine Centre for Autism and the Jay Nolan Centre. Both centres are **specialised** services for persons with Autism Spectrum Disorders and Developmental Disabilities. Both centres provide **infrastructure** to support the individual needs of people with ASDs and their families. Funding is driven by the needs of the individual (ie. the stated needs of the person are not adjusted to fit the available funding). The person with ASD is given a funding package, which they and their family can decide how to use. The best practice providers readily attract families. This funding arrangement works because there is supporting **infrastructure**, ie the funding is not wasted reinventing the wheel, it is not wasted by multiple layers of administration.

Here is what the centres say about themselves on their websites ...

#### The Judevine Centre for Autism <http://www.judevine.org>

"For more than thirty years, Judevine Center for Autism has been a pioneer in treatment and training of individuals with autism spectrum disorders (ASD) and their families. Its programs rooted in principles of applied behaviour analysis within a social exchange framework, the Judevine Center has provided effective training and treatment to thousands of families across the world. Judevine Center has, over the years earned an international reputation as a leader in its field."

The Judevine website publishes this case study;

"Ron" will be 18-years-old next month. He had been diagnosed with ADHD among other diagnoses throughout his whole life. It wasn't until three years ago when his psychiatrist diagnosed him with Asperger's Disorder. "Ron" was struggling in his high school and had been in a classroom for students with Behavioural Disorders. He has had many "meltdowns", and both in his freshman and sophomore years he refused to return to school after the holiday break.

Now "Ron" attends the Intensive Educational Program for students with Asperger's Syndrome at Judevine Center for Autism, and he has a part time job three days a week. This year, "Ron" returned to school after the holiday break. According to his mother, life is much easier for "Ron" now that they have found Judevine.

Jay Nolan Centre. <http://www.jaynolan.org/>

“The Mission of Jay Nolan Community Services, Inc. (JNCS) is to enable individuals with Autism Spectrum Disorder and other Developmental Disabilities to live fulfilling lives as members of the community by providing support services customized to their individual needs.

JNCS, a nonprofit 501(c)(3) organization, was established in 1975 by members of the Autism Society of LA. Initially named Programs for the Developmentally Handicapped, Inc., JNCS operated a social and recreational Saturday program, group homes, and day programs.

By 1990, the group home concept that had been "state of the art" in the 1970's and 1980's, became an example of what not to do because it gave very little thought to the needs and wants of the individuals being served. Leaders around the nation in the field of disability advocacy were advocating a change to individualized, community based support services. In 1992, JNCS began changing the way it provided services. The organization closed its group homes and began providing supports to people to enable them to live in their own homes, have jobs, and participate in other valued activities during the day.

Today, JNCS provides an array of support services in Los Angeles and its surrounding counties and in Santa Clara County , offering individualized planning guided by the needs and wishes of the person receiving services and his or her circle of support.

JNCS believes that:

- • All people have capacities and gifts.
- • All people need a sense of belonging to a community.
- • All people contribute to a community.
- • Relationships and trust are equally fundamental for inclusion to happen.
- • All people can live in their own home with the right support.
- • All people should be treated with dignity and respect and have a right to privacy.
- • For all persons, self-advocacy and empowerment should be promoted.
- • All people have the right to be free from pain, coercion, and cruelty.
- • All people have the right to be heard and their ideas acknowledged.

JNCS' philosophy is based on the belief that with the right kinds of support and assistance, individuals with disabilities can pursue their hopes and dreams and live to their full potential within the community. It is an ideal of inclusion rather than exclusion and segregation.

Jay Nolan's services break down into the following categories:

- • [Family Support Services](#)
- • [Supported Living Services](#)
- • [Day Support/Supported Employment Services](#)“

Here is what ‘MM’ noticed about the supported living services for adults with ASDs when he visited both the Jay Nolan and Judevine centres ...

## Attractive homes

People with ASDs deserve to be in nice environments. They are not forced into stressful group living arrangements. They have “normal” homes in normal streets with comfortable furnishings and nice gardens. Some photos of the homes are shown below. Windows are not boarded up, rooms are not built so that they can be holed out or “contain” an out of control person with ASD. The homes belong to the resident who learns to take pride in his or her home. People with ASD appreciate nice homes and feel good when they are in pleasant surroundings – just like anyone else.



## Happy people caring for happy people

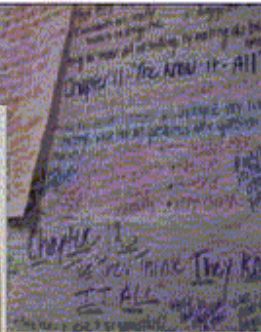
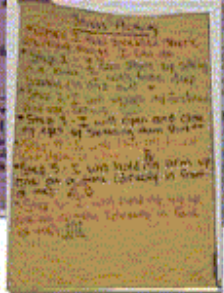
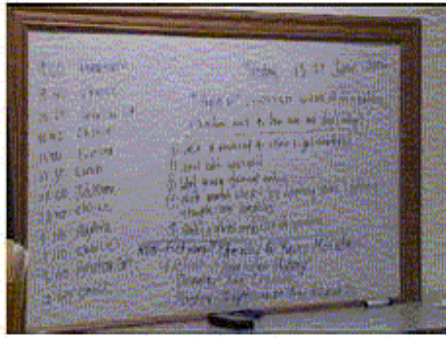
Staff genuinely regard the people with ASD they care for as equals and friends. Terms and conditions of employment (eg. living in a nice home, very high support from employer and culture of ongoing learning) support this relationship between carers and those they care for. Seclusion and restraint is used only as an emergency measure to ensure physical safety rather than a convenient or routine behavioural management tool. When Seclusion or restraint is necessary, the Mandt system is used ( see <http://www.mandtsystem.com>). When an aggressive incident occurs, carers ask, “what should I have done differently or better?”

Employees receive anger management training so that they can keep their own emotions out of difficult situations thereby minimising escalation of aggressive behaviour. There is no culture of blaming the person with a disability or their family. Challenging behaviours are recognised as part of the disability and the humanity of the individual is genuinely respected.

Individuals with ASDs receive ongoing training in communication and managing their own behaviour. Where individuals cannot talk, their need for alternative communication is respected. People with ASDs are not denied access to facilitated communication.

The images below show examples of plans and strategies for self-management developed by people who are profoundly disabled by ASD

## Fantastic Programs & Procedures



But what impressed me the most was ... the people I met ...

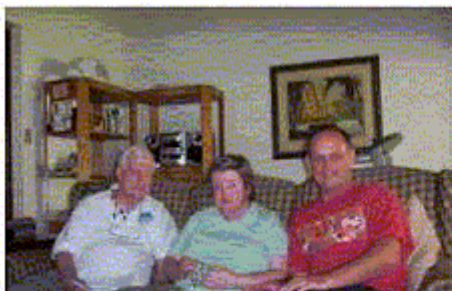
## HAPPY PEOPLE



Jean, Jim & Bob



Arty



Elderly parents looking relaxed in retirement, resting assured that their children were, happy, living in their own homes, with friends and paid support

### Supportive Communities

The supports provided to people with ASDs are underpinned by legislated entitlements in the USA; the community follows the law. The centres have the funding and infrastructure to advocate effectively in the community for people with ASDs. The advocacy is accountable back to the person with ASD and their family.

## Appendix A – Full text from Letter to Editor, A4 Newsletter, June 2006

Issue 3, June 2006 Page 10 of 19

Dear Sir,

We are writing to express our disappointment at the way in which the school handled the management of our son during the 2000 school year.

Our son was diagnosed with Asperger's Syndrome in October 1999.

We took immediate steps to make the school aware of the situation, given that he was starting Year 7 in 2000. At the transition meeting with staff from the school and the Primary School, we were assured because of our son's needs the necessary Negotiated Curriculum Plan would be in place from day one.

We were also advised that our son would be put into a class which would focus on children with special needs, but not a "special" class as such. We were told the teacher was a special education teacher, and that a support teacher would also be on hand to help.

Shortly after the start of Term 4 we felt we had no choice but to withdraw our son from the school, for the following reasons:

- The school's failure to implement many if not all of the suggested strategies provided by us, based on a sound knowledge of the management of an Asperger child.
- The school's failure to maintain any of the implemented strategies for anything more than a few weeks, contrary to all published material on Asperger Syndrome - provided to the school - that Asperger children require continuity, not "set and forget" strategies.
- The school's failure to protect our son from systematic bullying and harassment or to acknowledge that he was the target of systematic bullying and harassment.
- The school's failure - to the extent of reluctance - to make itself aware of Asperger Syndrome and of strategies to help our son. This ranged from declining to purchase the acknowledged authoritative texts, to declining to attend or make someone available to attend a two-day weekend authorised workshop in June on handling Asperger Syndrome at nearby ... (It was mentioned to us that one of the teachers had tennis on Saturdays.) The school also seemed reluctant to invite a representative from the Autism Association to address the teachers, despite such a person being available, and despite offers by the association and repeated requests from us. The school also declined to contact our son's previous school or his tutor, a qualified special education teacher himself - both of whom were willing to offer strategies and/or work with his teacher in helping our son.

Much of this neglect resulted in our son developing serious behavioural problems, which seemed to surprise no one with any knowledge of Asperger Syndrome. Except of course the school, and the school handled the situation poorly. The school's response was, not surprisingly, to suspend our son on a number of occasions. The school's solution was - with consultation - to set in place strategies, many of which were simply left to fall away within weeks.

The cycle of harassment and bullying, with our son responding with more violence or threats of violence against a group of boys - one in particular - would then begin again, and we were back to square one. The school's agenda at all times - to us at least - seemed to be to introduce strategies that would bring our son into line, into the mainstream.

Anyone with any knowledge of Asperger Syndrome knows this was never going to work.

Despite us collecting, collating and providing detailed published material on Asperger Syndrome to the school for the teachers, we firmly believe little or any of it was ever read. In fact we are fairly certain that many of his teachers didn't even bother to read his NCP.

A strategy was put in place whereby if our son's teacher could see he was going seriously offtrack, we could come and get him and take him home before trouble developed. The school seemed to enjoy using this strategy, but it seemed more of a way for the school to remove the problem rather than attempt to deal with it.

In late July, out of frustration, we contacted the Education Department ourselves to inquire if the school was accessing everything it could to help our son. We were eventually put on to XXXXX at the Department of Education, Training and Employment. We detailed the above concerns to her, and she seemed amazed that the school had failed to act on the strategies we had provided. Her support and professionalism, while maintaining the interests of our son foremost, has possibly been life saving. DETE acted in late Term 3 to ensure the correct strategies - many of which we had initially suggested in Term 1 - were put in place for the remainder of Term 3 and for Term 4, and worked with the Autism Association to ensure the strategies were

maintained and were working. The intervention was everything we had been hoping for, but unfortunately it was too late. Our son's mental state was close to breaking point because of what even he saw as the school's failure to act to prevent the constant harassment and bullying. After another incident early in Term 4 involving our son reacting violently to more bullying and harassment, followed by a suspension, we were invited to the school to discuss his re-entry.

Before attending the meeting we decided the situation was never going to improve, and we informed the school at that scheduled meeting on October 31 that he would not be returning.

There was no attempt by the school to talk us out of our decision. XXXXX from DETE then set in place a means to transfer our son to (another) High School, in transition this year and hopefully full-time next year.

A number of incidents have added insult to injury. We were asked by the school to provide a supporting letter from our son's paediatrician as to why he should be withdrawn from the school. The school's reply to Dr Lamb from the deputy principal was quite simply misleading to say the least. To wit: ... support programs ... have been developed and put into place to cater for (the student's) disability ..." "Development of these plans and strategies has involved working closely with the Director of Disability Services and representatives with expertise in Asperger Syndrome ..." "...and ..." "These plans have been developed after much consultation..." Such statements imply a pro-active stance by the school in relation to our son. This, as far as we are concerned, is far from the truth. Yes, all that was in put place, but only after we approached the Education Department in late July, and XXXXX and the DETE intervened in late August to force the school to act. The letter was both an insult to our intelligence and a flagrant distortion of the school's handling strategy for our son. Then, shortly after we withdrew our son from the school we received a letter from the school asking us to consult with them regarding a new NCP for him. Attached to the letter was an NCP for the child who had been the main instigator in bullying our son from as far back as a transition visit in 1999. We returned the NCP to the school and pointed out how inappropriate it was for another child's NCP to be sent to us. A member of the administration staff indicated to us that it was hoped we would not reveal the contents of the NCP, or even that it had been sent to us in error. Thirdly, no one from the school who was involved with our son has approached us since to inquire as to his health, his progress, or in any other way. This is despite regularly being at the school on other matters, including working in the school canteen where contact with school staff is common. We have been ignored. We feel let down, we feel humiliated, and yes, we are angry. Our son feels let down and humiliated, but at least he is getting over his anger. It has now been eight weeks since we withdrew him from the school. After visits to his paediatrician and a psychologist, and the love and support of his family, he is finally getting to the stage where he can laugh again, and not threaten to end his or even our lives at the slightest hint of criticism. Our son had a right to feel safe at school. Through the school's inability to cope with his Asperger Syndrome, and more importantly the school's lack of willingness to accept or even seek assistance until it was forced to accept help, the school quite clearly failed to create a safe environment for him. We will not know for some time how much his year at (school) has injured him. His visits to (his new school) have been very positive and we feel and hope that this move will be in his best interests.

We bring these matters to you as concerned and frustrated parents, and to place our concerns and frustrations on the record.

We would be available should you want further details or information.