

Autism Spectrum Disorders and Mental Health in Australia

perception, administration, challenges and outcomes

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Introduction

A first challenge for this report is to establish that people with autism spectrum disorders (ASD), in addition to needing services that are ASD-specific and services from the disability sector, also need to access mental health services.

Australian Governments separate ASD as from mental health. Before the last federal Budget two leading national ASD organisations, Autism Aspergers Advocacy Australia (A4) and the Australian Advisory Board on Autism Spectrum Disorders (AABASD) wrote to the Hon Mark Butler MP, Minister for Mental Health, asking him to adopt/support *Including, Connecting, Contributing: A Blueprint to Transform Mental Health and Social Participation in Australia* in the 2011-12 Budget. While the subject and content of the letters were undeniably about mental health, the Hon Mark Butler MP's Ministerial Liaison and Support Section responded that ...

the matter raised falls within the portfolio responsibilities of the Minister for Families, Housing, Community Services and Indigenous Affairs

The ASD community doubts decisions about mental health funding in the Federal Budget are "the portfolio responsibilities of the Minister for Families, Housing, Community Services and Indigenous Affairs", rather than the responsibility of the Minister for Mental Health or the Minister for Health (either or both).

A4's letter to the Hon Mark Butler MP also said ...

We are concerned that Government officials in the health sector advise that "autism is not a mental illness" and [Health officials] argue that people with ASD should not receive mental health services. ...

A4 is especially concerned that Government gets advice about ASD from health professionals and administrators whose entire career involved **not treating** autism spectrum disorders. Government should be wary of advice from people who offer "professional" opinions about treatment and services for people with ASD based on inexperience with ASD, outdated inadequate information, false assumption and prejudice.

In contrast, the Independent Mental Health Reform Group, authors of *Including, Connecting, Contributing*, include and recognise the significance of ASD which makes their blueprint the most credible policy documents for mental health that we have seen.

These issues and concerns are clearly matters relating to the Health Department.

This is not an isolated example. Previously, the Health Department wrote (Answers To Estimates, Questions On Notice, Health And Ageing Portfolio, Additional Estimates 2010-2011, 23 February 2011, Question: E11-184)

Autism is generally considered as a pervasive developmental disability ...

The Health Department uses the term *disability* rather than "disorder" to mean that "autism spectrum disorders are not disorders" ... despite ASD having "disorders" in the name. This use of "disability" instead of "disorder" is important: health services policy sees "disorders" as subjects for treatment, rehabilitation, remediation and/or intervention, while "disabilities" are apparently not amenable to treatment.

Describing ASD as “disability” shows Health officials expect ASD do not respond to treatment and rehabilitation services. Apparently, officials in the Health Department regard any effort to treat ASD as futile; such efforts waste funds and resources. Health officials deny ASD are health matters.

Similarly at the state/territory level, the ACT Government’s mental health officials say, “autism is not a mental illness”. We are very keen to hear, since they claim ASD are **not** *mental* illness, which part(s) of the body the ACT Government thinks ASD affect.

Health officials send the message that PwASD should not expect to access health services, that is treatment, remediation or rehabilitation, for their ASD. In effect people with autism spectrum disorders (PwASD) are *shut out* of the health system and their advocates are *shut out* of the offices of the Health Ministers.

Apparently, the office of the Minister for Mental Health directs anything that mentions “autism” to the Minister for Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) regardless of whether it relates to mental health. The Ministerial Liaison and Support Section for the Hon Mark Butler MP directs our concerns unilaterally to the Minister for FaHCSIA is inappropriate since the Minister for FaHCSIA clearly cannot comment on the operation of the Health Department.

When pressed, Minister Butler says FaHCSIA is the “lead agency for autism” and autism is “the remit” (meaning “sole or total responsibility”) of FaHCSIA. He is apparently OK with Health as the lead agency for mental health/illness but mental health is not “the remit” of Health since FaHCSIA addresses some disability-related aspects of mental health.

These responses reflect Government’s particularly poor understanding of the complex needs of PwASD. The conduct of the Ministerial Liaison and Support Section for Minister for Mental Health demonstrates precisely the inappropriate official response that we want to raise with the Minister for Mental Health.

There could hardly be a clearer demonstration of the disadvantage described in the report, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*¹. Disappointingly, it appears that the Government did not recognise the *SHUT OUT* report as relevant to PwASD.

Health officials are wrong about ASD. We show below that ASD are clearly mental disorders that often result in severe or profound disability. Then we show that services for PwASD are effective, necessary and the state’s responsibility. We also show that the state does not provide adequate treatment and rehabilitation for PwASD; treatment and rehabilitation services provided currently are insufficient for the needs of PwASD, their families and carers.

Autism Spectrum Disorders

Autism spectrum disorders “are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills,

¹ See http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx

communication skills, or the presence of stereotyped behaviour, interests, and activities”.

Australia health professionals refer to internationally recognised manuals to diagnose autism spectrum disorders. The manuals are:

- 1) the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (1994) known as the DSM-IV ... also its “text revision” in 2000 known as the DSM-IV-TR; and.
- 2) the World Health Organisation's [*International Statistical Classification of Diseases and Related Health Problems 10th Revision*](#) known as the ICD-10.

These manuals define a group of 5 disorders (more disorders in the ICD-10) called Pervasive Developmental Disorders. Four of the five disorders in the DSM-IV are referred to collectively as Autism Spectrum Disorders. The plan in the proposed new edition, the DSM-V (due for publication in 2012 or 2013), is for a singular Autism Spectrum Disorder.

Since the DSM-IV (1994) was published, the remaining Pervasive Developmental Disorder, called Rett's Disorder, has been identified as a specific genetic disorder.

The internationally recognised references on mental disorders clearly class ASD as *disorders* or *syndromes*, not as a *disability* as Health officials claim.

The DSM-IV (1994) and DSM-IV-TR (2000) classify mental disorders on five “axes”. The classification system is meant to “help plan treatment and predict outcomes”. Disorders classified on Axis I are *Clinical Disorders* and *Other Conditions That May Be a Focus of Clinical Attention*.

The DSM-IV-TR puts Pervasive Developmental Disorders on Axis I. Clearly the DSM-IV-TR classes ASD as mental disorders (note, “disorders” is part of their name). In 1994, the authors of the DSM-IV changed the classification of ASD from Axis II in the DSM-III to Axis I. This can hardly be clearer, ASD are generally expected to be a “focus of clinical attention” but this may be outside the knowledge of Health officials whose professional training was prior to 1994 (if they have not maintained their professional knowledge adequately).

The Australian Bureau of Statistics, in its Survey of Disability, Ageing and Carers classifies autism under the Type of long-term condition reported/ Mental and Behavioural disorders/ Code 0532 Autism and related disorders (including Rett's Syndrome and Asperger's syndrome). This equates to F84.0, F84.1, F84.2, F84.3, F84.4 and F84.5 in the ICD 10 – all of which it classes as disorders.

The authors of the report *Including, Connecting, Contributing* are recognised experts in mental health. In their document, these experts clearly regard autism as a mental health issue.

The Health Department has responsibility for funding some diagnoses and allied health services as part of the *Helping Children with Autism* package. The ASD community would be interested to know the future of this program. Clearly any responsibility for ASD in Health has little or no future if the Minister's office just dumps all communications relating to ASD in the bureaucratic black hole it has created for ASD treatment, rehabilitation and remediation.

There is a substantial argument that many experts in the field of mental illness regard ASD as a mental illness or mental disorder. Clearly, ASD are distinct from the other categories of mental disorders and therefore require some specific and distinct types of services.

Recommendation 1. Australian Governments recognise that autism spectrum disorders are mental disorders of a distinct type.

The number of people diagnosed with ASD, both in Australia and overseas, increased rapidly for 20-30 years. ASD prevalence was reported as 10 per 10,000 around 1994. In 2009, ASD prevalence in Australia exceeded 1% of school students.

In its Answers To Estimates, Questions On Notice, Health And Ageing Portfolio, Additional Estimates 2010-2011, 23 February 2011, Question: E11-184, the Health Department wrote (http://www.aph.gov.au/senate/committee/clac_ctte/estimates/add_1011/doha/184.pdf) ...

... The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

Frankly, it needs a supreme effort of diligent indifference for the Health Department to remain ignorant of increasing ASD diagnoses in Australia. Taxpayers must be alarmed that, even when prompted by the Senator's direct question, Health officials did not pick up on major concerns over the increase in the reported prevalence of autism spectrum disorders in Australia and overseas.

The Health Department falsely claims that it "is not aware of any major shifts in prevalence of autism". On 7/8/2007, an email² from the Department's Director of Children and Youth Mental Health Programs Section to staff in FaHCSIA (subject: Summary Paper on Autism Spectrum Disorder Proposals from DOHA, importance: High) said ...

Of very great concern is the increase in the reported prevalence of autism spectrum disorders in Australia and overseas. A recent Australian study in the Barwon region of Victoria found a 10-fold increase in the prevalence of autism diagnoses over a 16-year period. ...

Contrary to the response it gave to Senator Fierravanti-Wells, the Department of Health and Ageing was aware of "very great concern" about "major shifts in the prevalence of autism in Australia".

The effect of ASD and its growing prevalence on the community is largely unrecognised but in 2007 the AIHW estimated that in 2003, autism ranks second for boys aged 0-14 years as the "burden of disease and injury"³ (8th for girls since 4 times as many boys are diagnosed with ASD).

The ABS estimates of the number of Australians with ASD from the Survey of Disability Ageing and Carers (SDAC) from 1998, 2003 and 2009 are shown

² See http://www.dpmc.gov.au/foi/docs/ips/disclosure_logs/2011-068_80_Interagency_email_re_summary.pdf page 6

³ See Begg S, Vos T, Barker B, Stevenson C, Stanley L & Lopez A 2007. *The burden of disease and injury in Australia 2003*. Cat. no. PHE 82. Canberra: AIHW. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442459747>

below, along with data from Centrelink and FaHCSIA’s Carer Allowance from 2004 to 2010. (Note: Carer Allowance is for children up to 16 years of age).

Table 1 People with autism spectrum disorders in Australia

Age	ABS SDAC			Centrelink: Carer Allowance						
	1998	2003	2009	2004	2005	2006	2007	2008	2009	2010
0-4	1000	1200	3500	1539	1665	2035	2200	2593	3130	3618
5-9	10500	8200	19400	6434	7196	8535	10101	12014	14194	16689
10-14		10800	19200	5729	6695	8251	10102	12196	14527	17332
15-19	1700	3900	11400							
20+		6200	9091							
Total	13200	30400	64600							

The ABS SDAC data shows the number of Australians with ASD more than doubled from 1998 to 2003 and from 2003 to 2009. Similarly, Centrelink Carer Allowance data also shows the number of children diagnosed formally with ASD and registered for Carer Allowance doubled in the 5 years from 2004 to 2009 and 2005 to 2010.

Typically there is a 4:1 ratio of males: females for ASD.

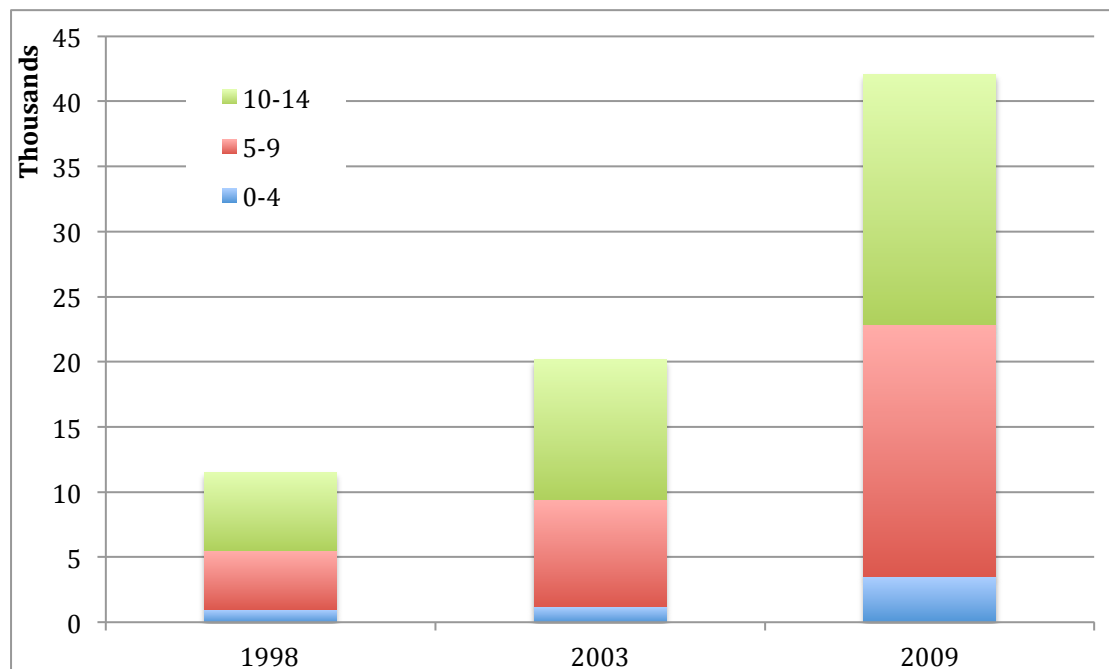


Figure 1. Autism estimates from the ABS SDAC

Note that the ABS SDAC estimate of the number of people with autism in 2003 is about 60% higher than the number of children getting Carer Allowance in 2004. In 2009, the two data sources are closer together. The ABS SDAC data for 2009 is closer to Carer Allowance figures for 2009.

Centrelink data for Carer Allowance shows the following recent steady increases in children with a formal diagnosis of ASD in Australia.

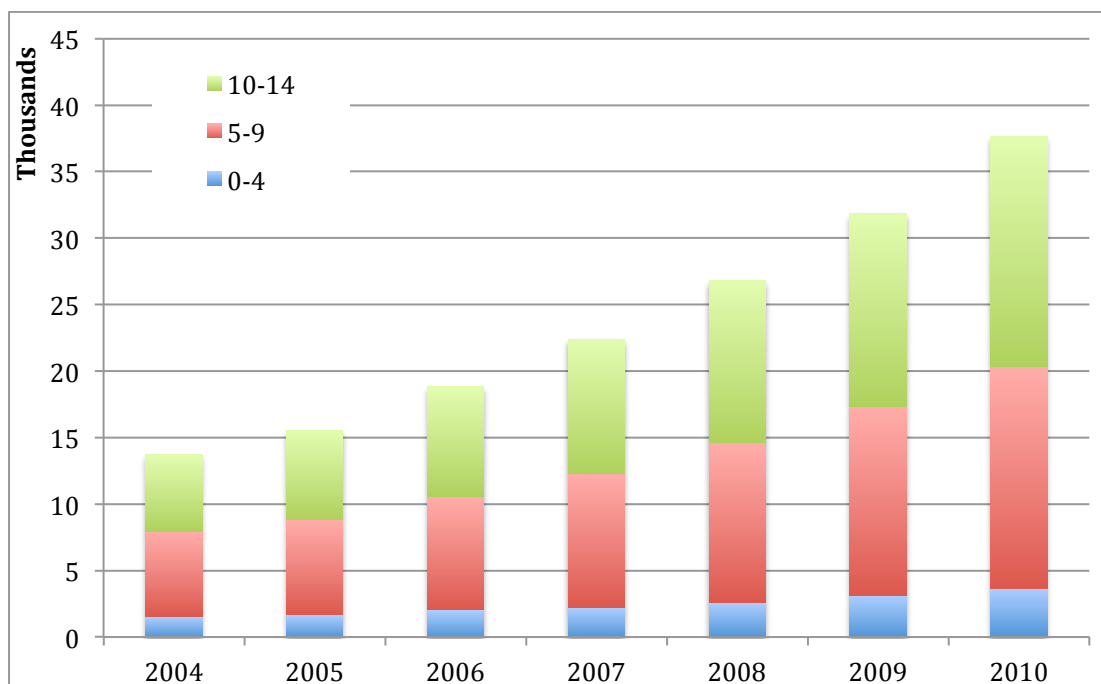


Figure 2. People with Autistic or Asperger's Disorder getting Carer Allowance

In 2010, around 1% of children aged 5 or 6 years were diagnosed formally with an autism spectrum disorder and were registered to receive early intervention through FaHCSIA's *Helping Children with Autism* initiative.

The number of Australian children diagnosed with an autism spectrum disorder has been increasing at around 15% per year for at least 20 years. This means the number of children diagnosed with an autism spectrum disorder doubles every 5 years.

If ASD prevalence continues to double every 5 years there will be very noticeable effects on the community. Table 2 below shows the proportion of children who will be diagnosed with ASD if growth continues at the same rate into the future.

Table 2. ASD school-age prevalence, growing 15% per year

year	Prevalence	Description
2010	1%	<i>Already exceeded!</i>
2015	2%	ASD exceeds intellectual disability ... ASD becomes the biggest single disability type in children. One student with ASD on average in every mainstream class in public schools (50% of all students attend public school and 100% of students with ASD in public schools since private schools rarely enrol students with ASD, average class size ~25)
2020	4%	2 students with ASD on average in every mainstream class in public schools.
2030	16%	1 in 6 children with ASD, 1 in 3 families affected. ASD has greater economic impact than climate change or the ageing population ...

Some people claim increased ASD prevalence, a worldwide phenomenon over at least 20 years, is due to the Australian Government's recent introduction of the Helping Children with Autism package. Such a claim is just ludicrous.

Government officials and some "experts" in autism claim increasing ASD prevalence is due to diagnosis of milder cases. This claim ignores available data.

The ABS SDAC data also shows that most of diagnoses are of people with severe or profound disability. The AIHW reviewed the 2003 ABS SDAC. They reported that

Autism and intellectual impairment were associated with high proportions of severe or profound core activity limitation—87% and 75% of children with these respective conditions also had a severe or profound core activity limitation.

<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453529>

The ABS recently released its analysis of its 2009 SDAC data⁴. The ABS reports that PwASD experience statistically poorer outcomes than people with disabilities generally in the areas of:

- Disability ... "of people with autism, 74% reported having a profound or severe core activity limitation (that is, they need help or supervision with at least one of the following three activities - mobility, communication or self-care)"
- Communication ... "the greatest challenges for people with autism lay with communication. There were 68% of people with autism reported having a profound or severe communication restriction, meaning they either cannot understand or be understood by others at all, or has some difficulty being understood or understanding others (it may be they communicate more effectively using sign language or some other non-verbal form of communication)"
- Education ... for example, "Of people with autism who had finished school, 77% had not completed a post-school qualification. This is well above the rate for both the rest of the population with disability and people with no disability"
- Employment ... "autism also correlates with restrictions in participating in the labour force. In 2009, the labour force participation rate for people with autism was 34%. This compares with 54% labour force participation rate for people with disabilities and 83% for people without disabilities"
- Disability services ... "there were 15,400 people with autism needing more help with communication (understanding or being understood by others) and 22,600 needing more help with cognitive or emotional tasks (managing their emotions and/or behaviour)"

⁴ <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features12009?opendocument&tabname=Summary&prodno=4428.0&issue=2009&num=&view=>

Contrary to recognised diagnostic practice, some Australian Governments do not regard autism as a “primary diagnosis”. For example, Official X⁵ said,

... for some people, the primary diagnosis may actually be an intellectual disability diagnosis rather than an autism diagnosis.

See <http://www.autismaspergeract.com.au/node/126>

In the DSM-IV-TR, Pervasive Developmental Disorders including autism spectrum disorders are classified on Axis I of the DSM-IV-TR multi-axial classification scheme. Intellectual disability (called *mental retardation* in the DSM-IV-TR) is classified on Axis II. Official X, who manages a specialist unit for ASD diagnosis, should know that according to the DSM-IV-TR, ASD are always the primary diagnosis relative to intellectual disability.

Government officials and some autism “experts” say that autism/ASD diagnoses are increasing because diagnostic criteria have changed. This is simply not true. The DSM diagnostic criteria for ASD have not really changed since 1994 (the tiny change to the criteria for diagnosing PDD-NOS⁶ in 2000 had minimal affect).

In 2009, around 1% of school students were formally diagnosed with ASD and receiving Carer Allowance on this basis. The Carer Allowance data for South Australia closely matches client data for Autism SA. This provides a degree of confidence as these data are collected through completely different processes. And the latest ABS SDAC data corroborates the substantial increase and the seriousness of ASD diagnoses across the nation.

Recommendation 2. Governments recognise autism spectrum disorders a) are primary mental disorders, b) involve severe and pervasive impairment by definition, and c) are being diagnosed in increasing numbers.

Treatment and recovery

It is said, “there is no cure for autism” and “autism is life long” (see Annex A). The following explores the possible intent and accuracy of this statement.

Autism Speaks (see <http://blog.autismspeaks.org/2011/11/21/11-myths-about-autism/>) says:

7. Myth: People with autism will have autism forever.

Truth: Recent research has shown that children with autism can make enough improvement after intensive early intervention to “test out” of the autism diagnosis. This is more evidence for the importance of addressing autism when the first signs appear.

There are no drugs or surgery for treating ASD.

⁵ to avoid naming a particular individual, this report refers to the manager of a government agency responsible for providing therapy and ASD diagnosis services in one of Australia’s territories as Official X. The official is not from the Northern Territory.

⁶ See <http://www.psych.org/MainMenu/Research/DSMIV/DSMIVTR/DSMIVvsDSMIVTR/SummaryofPracticeRelevantChangestotheDSMIVTR/PDDNOS.aspx>

Typically, the extended message seeks to make the additional points:

- the usual medical approaches (drugs, surgery, radiation, ...) offer no treatment for ASD;
- appropriate intensive ASD-specific treatment/intervention can reduce/minimise the symptoms and achieve substantial improvements for most children with autism; and
- “experts” cannot predict reliably which treatment/intervention or combination of methods will produce the best outcome for a particular child.

Unfortunately, some government administrators and decision makers use the statement that “there is no cure for autism” to deny children with ASD access to state funding for best practice treatment for their ASD. For example, Official X advised a Minister for Disability that

Autism is not a curable condition and early intervention services can only work to provide improved coping mechanisms for both the individual and the family.

Official X’s view is seriously out of step with the available evidence and expert opinion. Recognised authorities in the field of ASD agree that best practice for ASD usually minimises symptoms and substantially improves long-term outcomes. Rarely is it true for a child with ASD that “early intervention services can **only** work to provide improved coping mechanisms”.

Having someone with this view managing early intervention/therapy for autism/ASD is like putting someone who objects to blood transfusions in charge of a blood bank, or appointing an atheist as Pope.

Currently, there are posters that say, “there is no cure for brain cancer” ... but the health system does not decide, in the case of brain cancer, “services can only work to provide improved coping mechanisms for both the individual and the family”. Official X, Australian Governments and their health systems should not discriminate against PwASD based on a particularly negative misinterpretation of the available evidence.

There are fears that families are vulnerable when their child has just been diagnosed and they may make quick and uninformed choices with negative outcomes. Apparently, the usual intent of claims that “autism is life long” is to convince families, soon after their child’s diagnosis, that treatment and remediation is difficult and has varied outcomes; they should discount any claim of a quick fix for their child’s ASD.

People with an actual knowledge of ASD observe that effective treatments for ASD can be made available for children with ASD. For example, in relation to research

The results suggest that early intensive behavioural intervention is an effective form of treatment for children with autism.

Roberts & Prior, page 45.

Using the word “spectrum” shows ASD are a range of disorders with differing effects on individuals with these disorders. The DSM-IV-TR and its predecessor, the DSM-IV, say all these disorders involve severe or profound impairment.

Some people have extreme disability due to their ASD while some peoples' diagnoses lie closer to a diagnostic borderline/cut-off.

Few PwASD in Australia can access appropriate treatment and rehabilitation.

Evidence of substantial improvements in PwASD due to appropriate intervention is incompatible with the claim that "there is no cure for autism". Some people, whose ASD is within "striking" distance of the diagnostic borderline, respond to treatment. Some people who get appropriate treatment and rehabilitation improve to a degree that they no longer meet the diagnostic criteria for ASD.

Whether people whose improvement (due to effective therapy) moves them across the diagnostic borderline/cut-off for ASD can/should be described as "cured" or "recovered" from their ASD is a matter of interpretation. Many of these people still have some residual symptoms of ASD though their remaining symptoms are not the "severe impairment" that the diagnostic criteria demand. These people may be on the *autism spectrum* but they lost their *disorder* ... possibly using their remaining autistic features as strengths. Importantly, they function more independently in their home, their school and their community. Some of them make substantial contributions to their community and even their nation.

Issues of "recovery" or "cure" invoke massive emotions among clinicians, service providers and some families. Initially, the controversy was a dispute between rival treatment approaches. Roberts & Prior said (p9)

There is universal agreement that behavioural interventions have produced positive outcomes for children with autism that are well supported by research. Few other treatment programs have been subjected to the level of research scrutiny that has been applied to behavioural interventions. However, there continues to be controversy about particular behavioural interventions and programs, concerns about methodological issues, and differences in the interpretation of research findings. This controversy revolves around (a) claims that behavioural programs can lead to 'recovery' of children with autism, (b) recommendations by some service providers that ABA and DTT approaches should be used to the exclusion of all other methods, (c) and concerns that the intensity of treatment may not be appropriate for all children and families.

and (p48)

Claims for 'recovery' or 'cure' have led to the most controversy. There seems little contention that IBI programs produce positive outcomes for children with autism. Mesibov (1993) stated that it is not surprising that such intensive intervention should result in positive and lasting results, particularly as behavioural approaches have been used effectively with children with autism for many years. However, the extent of the positive outcomes reported in studies of some intensive behavioural intervention programs, particularly those that claim to produce 'normal' functioning, is questionable.

Evidence that treatment could 'lead to recovery' can be challenging for people who spent much of their professional life working with people with autism without their clients showing as much improvement. Naturally, people with so much personal investment passionately defend their own efforts to ensure best outcomes for PwASD. There are parallels in how other neurosurgeons respond to Dr Charlie Teo's work and the term "success" (see

<http://sixtyminutes.ninemsn.com.au/webchats/269545/the-outsider-charlie-teo>).

There is still no agreement whether *no longer meets the diagnostic criteria* means “recovery”. It appears that many people accept that the possibility of “positive outcomes” through intensive ASD-specific treatment (early intervention) but they may not have really thought about whether a subsequent review could remove a diagnosis.

Evidence continues to emerge that appropriate treatment produces positive outcomes where some children lose their diagnosis of autism. Helt, Kelly, et.al. (2008) report that children who are diagnosed when they are particularly young then treated intensely and immediately ...

between 3% and 25% of children reportedly lose their ASD diagnosis and enter the normal range of cognitive, adaptive and social skills.

People who say that “recovery” should mean the *total elimination of all symptoms* of autism need to

1. explain how their standard would be tested/satisfied in practice, and
2. justify that treatment should continue beyond the point where a person no longer meets the diagnostic criteria for a *disorder*.

The Department of Health and Ageing website hosts documents providing advice on early intervention (treatment, rehabilitation, education, services) for young children with autism spectrum disorders.

- 1) Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia (see <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-r-autrev>).
- 2) M. Prior and J. Roberts (2006), *Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Best Practice*, see [http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/\\$File/autbro.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/$File/autbro.pdf).

Please note that this is Health advice, not FaHCSIA advice. At the very least, this shows that the Health Department has a role in early intervention treatment for children with ASD.

The Health Department’s guidelines for best practice for children with ASD say a child with autism needs a minimum of 20 hours of individualised intensive ASD-specific early intervention per week over a period of at least two years.

Note that 20 hours per week for 50 weeks per year is 1000 hours per year.

Currently, no part of the health system in Australia funds best practice early intervention for children with autism spectrum disorders.

The early intervention part of the Commonwealth Government’s *Helping Children with Autism* package was intended to contribute to best practice for children with autism.

There are several problems with the implementation early intervention component of the HCWA package. Particular criticisms include:

1) Not based on evidence-based treatment

The criteria for getting on the FaHCSIA early intervention panel do not depend on providers delivering treatments that are recognised as effective for autism spectrum disorders.

The initial requirement of FaHCSIA's implementation of the early intervention model involved face-to-face service delivery by the clinician. Clinician face-to-face delivery is not the approach used in establishing that intervention is effective. Such an approach is relatively expensive and is unnecessary.

2) Lack of intensity

Service providers on the FaHCSIA panel charge at least \$120 per hour. So \$6000 per year provides just 1 hour a week, or 5% of what the Government advises is best practice.

This level of input from a clinician would be adequate supervision in the deliver of an established early intervention program for an individual child

3) Lack of a trained workforce

In Australia, very few allied health professionals are trained to deliver effective early intervention for children with ASD. There is a whole section on this below.

4) Unclear treatment pathways

Even "experts" with years of experience cannot agree on which early intervention approach to start with for an individual child ... yet families are under pressure to make this decision as soon after their child gets an ASD diagnosis as possible.

Were Government to fund early intervention to a level with the potential to improve a significant fraction of children with ASD to a point where they no longer meet the diagnostic criteria for ASD, then most families whose children lose their diagnosis of ASD would willingly forego benefits like Carer Allowance.

Best practice early intervention for autism spectrum disorders

The Health Department published Prior & Roberts (2006), *Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Best Practice*, see [http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/\\$File/autbro.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/$File/autbro.pdf) that says each child with ASD needs a minimum of 20 hours of intensive ASD-specific early intervention for a minimum of two years. Currently, children can only access such a service if their parents can organise and fund the service.

COAG published its *National Early Childhood Development Strategy -- Investing in the Early Years* (see http://www.coag.gov.au/coag_meeting_outcomes/2009-07-02/docs/national_ECD_strategy.pdf and

http://www.deewr.gov.au/Earlychildhood/Policy_Agenda/Pages/EarlyChildhoodDevelopmentStrategy.aspx).

It says ...

The shared vision of the Commonwealth and state and territory governments is that by 2020 all children have the best start in life to create a better future for themselves and for the nation.

If this really means **all** children, including the 1% (perhaps 4% by 2020) with ASD, then steps towards providing best practice early intervention need to be taken very soon. The current *Helping Children with Autism* program needs to deliver complete evidence-base early intervention programs (rather than a small part of a program) if it is to provide “the best start in life” for individual children with ASD.

Recommendation 3. Governments ensure all children with ASD can access best practice early intervention for their ASD.

Recommendation 4. Governments monitor the performance of all funded early intervention services for children with ASD using consistent measures to establish developmental benchmarks for children with ASD and the outcomes of the early intervention programs/services they access.

The benefits from analysing the monitoring data and using the knowledge gained wisely could be enormous.

Treatment and rehabilitation are more than early intervention

Various researchers have reported that people with “developmental delays” experience particularly poor health outcomes; worse outcomes than the embarrassing health outcomes of Australia’s indigenous population. For example, researchers report that people with “developmental delays” suffer on average from 2 undiagnosed chronic health conditions ... with chronic pain being one of the more common afflictions.

Australian Governments need to improve significantly health services for people with developmental delays (for example, see <http://au.news.yahoo.com/thewest/a/-/wa/9857115/parents-blame-hospitals-for-failing-to-save-son/>) including PwASD.

Many students with ASD struggle with the behavioural requirements of their schools. Schools do not have the behavioural support that their students with ASD need. The courts do not enforce discrimination law; they do not require schools to make even reasonable adjustments to their behaviour management policies for students with ASD (see *Purvis v NSW* and *Walker v Vic*).

FaHCSIA and the disability sector do not provide this kind of service and support.

Students with ASD experience high levels of co-morbid diagnoses such as attention deficit, epilepsy, intellectual disability, psychosis, stress, anxiety,

depression and challenging behaviour. These conditions may be exacerbated through their ASD.

Unfortunately, there are a surprising number of mental health services that simply refuse to offer any mental health or clinical service for PwASD. A person with ASD may be denied treatment for their psychosis, depression, anxiety, etc. because they have ASD. We have not heard of people with diabetes or in a wheelchair being denied treatment for mental illness on the grounds of their co-morbid condition(s).

PwASD often develop inappropriate or “challenging” behaviours when they are placed in inappropriate settings, if they are bullied, mistreated or stressed in some way. Rather than getting the appropriate clinical services and support, this often leads to further abuse ... including inappropriate and unnecessary physical restraint (see <http://a4.org.au/a4/node/371> and <http://a4.org.au/a4/node/372>).

None of the relevant Government agencies take responsibility. Health departments say it is an education or disability issue. The education system in Australia is not required to support these children. Many students with ASD are restrained (sometimes locked in a completely inhumane cage or wrestled to the ground by up to three staff with specific “Personal Assault Response Training (PART)”) or suspended from school for extended periods.

The disability sector does not usually have the clinical expertise to treat challenging behaviour in PwASD. For example, Official X said, “We do not actually use [behavioural] intervention” (see <http://www.autismaspergeract.com.au/node/126>).

Official X says, “early intervention can only improve coping”. This shows the belief that clinical services for PwASD do not improve functioning of PwASD. Official X regards clinical services for PwASD as a waste of time; that therapy resources are better used for clients with disorders/disabilities other than ASD.

“Positive outcome” deniers (like Official X) should not control government policy and resource allocation relating to PwASD.

Research shows clear benefits to appropriate treatment for ASD. For example, appropriate programs are important once a person with ASD leaves school.

We examined whether exiting high school was associated with alterations in rates of change in autism symptoms and maladaptive behaviors. Participants were 242 youth with ASD who had recently exited the school system and were part of our larger longitudinal study; data were collected at five time points over nearly 10 years. Results indicated overall improvement of autism symptoms and internalized behaviors over the study period, but slowing rates of improvement after exit. Youth who did not have an intellectual disability evidenced the greatest slowing in improvement. Lower family income was associated with less improvement. Our findings suggest that adult day activities may not be as intellectually stimulating as educational activities in school, reflected by less phenotypic improvement after exit.

J. L. Taylor, M. M. Seltzer (2010) *Changes in the Autism Behavioral Phenotype During the Transition to Adulthood*, J Autism Dev Disord (2010) 40:1431–1446.

ASD and ATAPS

ATAPS is not intended to provide best practice for young children with ASD. For young children, the “maximum of 12 sessions per calendar year - six time-limited sessions with an option for a further six sessions following a mental health review by the referring GP” means ATAPS offers an inadequate service for children with ASD. It is not a service model that meets the needs of PwASD.

Most students and adults with ASD need psychology and behaviour support services. People with Asperger’s Disorder often need, but are denied, appropriate CBT and/or ABA.

Families who try to access psychology services for PwASD through ATAPS come across a number of barriers.

- 1) There are very few psychologists who have the required knowledge, skills and experience in treating people with autism/ASD. Some of those who have the best skills are not qualified clinical psychologists but are recognised behaviour analysts. There is a major workforce issue described below.
- 2) GPs do not know who to refer to or even what type of service their clients with ASD need.

The Australian Psychologist Society website has a “find a psychologist” service (see <http://www.psychology.org.au/FindaPsychologist/>). The following table summarises the number of psychologists listed (after removing duplicates) at example location on 22/7/2011 for “Autism” and “Asperger’s syndrome” for a child aged 5-12 years. This shows there are very few relevant psychologists in some locations.

<i>location</i>	<i>50km radius</i>	<i>200km radius</i>
HOBART, TAS, 7000	2	2
PERTH, WA, 6000	5	5
ADELAIDE, SA, 5000	6	6
WAGGA WAGGA 2650	1	8*

* the APS website thinks Canberra is within 200km of Wagga Wagga, but Google Maps says it is 245km.

The therapy approaches listed for most of the psychologists that the website identifies do not address the needs of students wanting clinical services for their ASD. For example, behaviour and behavioural intervention is a serious issue for many school age children with ASD. Following a story on the ABC’s 7.30 Report (see <http://www.abc.net.au/7.30/content/2011/s3219518.htm>), the APS said ...

Dr Rebecca Mathews, psychologist and manager of practice standards at the Australian Psychological Society said: "Challenging behaviours in people with disabilities can arise for a number of reasons and we need to take the time to assess each individual's social, emotional and psychological needs to ensure that they receive appropriate support to avoid these distressing incidents. It is misguided to just blame staff, who deserve better training and support to help them provide the best possible care and services to people with disabilities."

http://www.psychology.org.au/news/media_releases/20may2011/

The APS website does not identify any psychologists as skilled in Applied Behaviour Analysis (ABA) ... ABA does not even seem to be a therapy approach that the APS recognises on its website.

PwASD cannot access appropriate psychologists when there are no appropriately trained psychologists to access.

ASD Administration

For too long, the “stove pipes” of Government Administration have focussed on “treatment” for mental illness and “care and support” for disabilities. Governments in Australia deny people with autism the health services (treatment and rehabilitation) they need and that is their right (under international law, though not under Australian law).

There are signs that Governments in Australia are starting to address the disability aspect of mental illness. The number of people receiving services through the CSTDA or NDA (see Figure 3. below) more than doubled from 2004 to 2009 ... though there is still a long way to go.

The health system must appreciate that appropriate treatment and rehabilitation can remediate the level of disability. This in turn improves patient independence and participation, reduces long-term service and support costs, and decreases the cost of ASD to the community.

In relation to disability, the World Health Organisation says

People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments.

http://www.who.int/disabilities/world_report/2011/en/index.html

Governments are reluctant or just refuse to recognise the nature of ASD as distinct from other types of disability. Governments expect PwASD to get by with services designed for other disabilities.

... As far as possible, services to people with a disability are provided as part of the services available to all ACT residents.

The additional support services required by people with a disability are not generally classified by diagnostic category, but by need. People with autism and a co-morbid intellectual disability are usually assessed as having severe or profound disability and high support needs. Therefore the increases in funding for disability and therapy services directly benefit people with autism and their families.

But this is more fantasy than reality. In the latest ACT Budget disability funding (see www.treasury.act.gov.au/budget/budget_2011/files/press/30_press.pdf) is to expand:

- after-school care services that are reluctant to take challenging students with ASD (since the Commonwealth’s scheme in the ACT provides a limited service strictly for students in wheelchairs);
- existing programs for school leavers with a disability (with long waiting lists and are mostly unsuited to clients with ASD);
- emergency accommodation for people with a disability (often unable to safely accommodate PwASD);
- a pilot program of therapy assistance⁷ in schools that provides physiotherapy for students (people do not access physiotherapy services for their ASD); and
- the taxi subsidy scheme (mainly unavailable for PwASD).

While there are items in the ACT Budget that address the specific and distinct needs of some types of disability, there is very little to address the needs of PwASD ... or to expand services for the rapidly growing number of PwASD in the ACT. So claims that funding for people with disabilities helps all people with a disability including PwASD are very misleading.

Some overseas Governments recognise and address these issues.

Box 3.2. Health inequalities experienced by people with disabilities

The Disability Rights Commission in the United Kingdom formally investigated premature deaths among people with learning disabilities or mental health problems and local reports of unequal access to health care between 2004 and 2006.

People with long-term mental health problems – such as severe depression, bipolar disorder, or schizophrenia – and learning disabilities, such as autism:

- Had more chronic health conditions than the general population. They were more likely to be obese and have heart disease, high blood pressure, respiratory disease, diabetes, strokes, or breast cancer. People with schizophrenia were nearly twice as likely to have bowel cancer. Although the recording of people with learning disability in primary care settings was poor, higher rates of respiratory disease and obesity in this population were indicated.
- Developed chronic health conditions at a younger age than other people. For example, 31% of people with schizophrenia were diagnosed with heart disease under the age of 55, compared with 18% of others with heart disease.
- Died sooner following diagnosis. Five years following a diagnosis of heart disease (adjusting for age), 22% of people with schizophrenia and 15% of people with bipolar disorder had died, compared with 8% of people without serious mental health problems. The pattern was similar for stroke and chronic obstructive pulmonary disorder.

⁷ Note that Official X claims, contrary to national and international experts, that “early intervention services can only work to provide improved coping mechanisms”, in other words the government does not aim to treat, rehabilitate or remediate children’s ASD.

Social deprivation was a major contributor to these health inequalities, and people with mental health problems and learning disabilities were at a high risk of poverty. The lack of health promotion, service access, and equal treatment were also cited as significant barriers. Disabled people identified fear and mistrust, limited access to general practice lists, difficulty negotiating appointment systems, inaccessible information, poor communication, and diagnostic overshadowing. Service providers identified issues such as fear, ignorance, and inadequate training.

Responses to the study were positive. Prominent health care professionals endorsed the findings. The British Medical Association established training for medical students, and nongovernmental organizations ran campaigns on health inequalities. The British government introduced incentives to encourage people with learning disabilities to undergo health checks and strengthened guidance for mental health-care workers. The Health Care Commission in association with RADAR – a disability NGO – undertook further work to explore disabling factors in health care and to produce guidelines on good practice and criteria for future health care inspections.

http://www.who.int/disabilities/world_report/2011/en/index.html

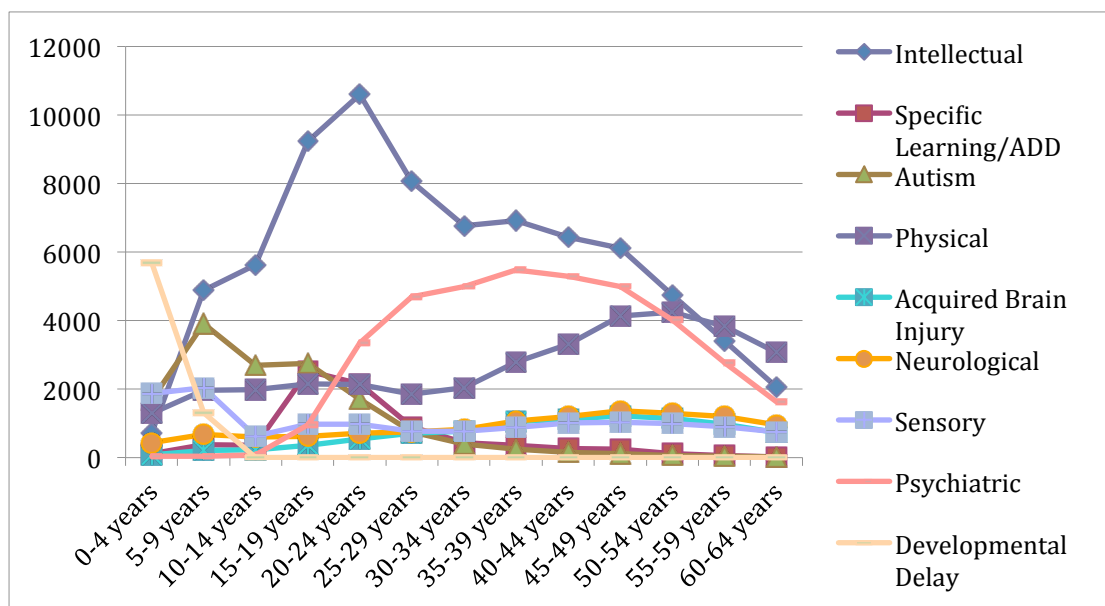


Figure 3. CSTDA data 2007-08 from <http://www.aihw.gov.au/data-cube/?id=6442475000>

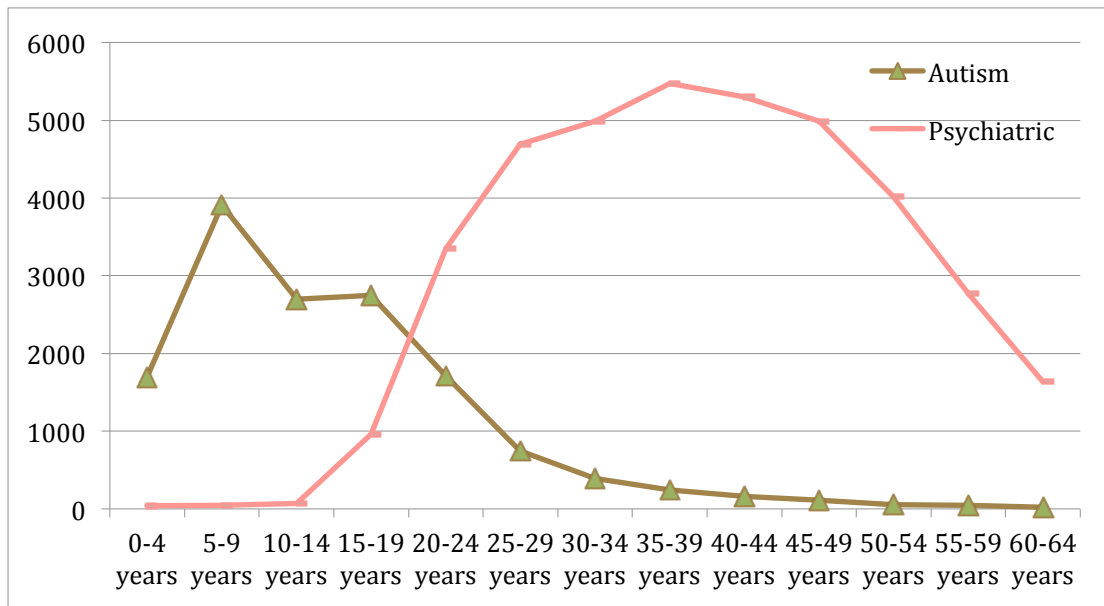


Figure 4. CSTDA data 2007-08 ... just ASD and Psychiatric

The shape of this graph, showing ASD drops off when “psychiatric” conditions cut in, is consistent with the observation⁸ from the UK that many adults in the mental health system or with mental health issues have undiagnosed ASD.

In Australia, people with a disability experience high levels of poverty: a recent report ranks Australia 27th out of 27, far worst of the OECD countries (see <http://www.pwc.com.au/industry/government/publications/disability-in-australia.htm>).

The data for 2007-08 is the most recent data on the AIHW website that gives a 5 year age breakdown. When contacted, the AIHW provided a file with 5-year age breakdown for 2008-9.

The following table shows the number of people with autism who received services via the CSTDA/NDA compared to the number registered with Centrelink for Carer Allowance⁹.

	0-4	5--9	10--14
<i>CSTDA/NDA</i>	1,951	4,443	3,044
<i>Carer Allowance</i>	3,130	14,194	14,527
	62.3%	31.3%	21.0%

⁸ <http://www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys/autism-spectrum-disorders-in-adults-living-in-households-throughout-england-report-from-the-adult-psychiatric-morbidity-survey-2007> or <http://a4.org.au/a4/node/189>

⁹ this result is worse if the number of PwASD who get any service is compared to the ABS estimate of ASD prevalence.

Since the vast majority of disability support in Australia is provided through the CSTDA/NDA, this shows that relatively *few people with autism spectrum disorder get any disability services at all* for their severe and pervasive disability through the Government's main means of providing disability services.

Note: the AIHW reports that 15% of people with "autism" change their primary diagnosis in the 15-25 year age range. It appears that people with autism change their diagnosis from "autism" so they can access services that are denied to people with "autism", for example the ITAS service in the ACT.

Service coordination

For most PwASD in Australia, their ASD is untreated and life-long. Their ASD is associated with severe or profound disability. Their service requirements are complex. Many of the services they needs simply do not exist.

No one can coordinate services that just do not exist.

Governments are creating plenty of pseudo-services whose purpose is to inform families about "available services". Families turn up to these "information services" and are told either there is no appropriate service or the services that might be of limited assistance have extensive waiting lists. In many cases, the family already knew this.

Families end up having to take the scraps of what service is available at the time. The Productivity Commission and families agree that the existing disability service and support system is primarily crisis driven.

Existing disability services are uncoordinated. The Productivity Commission is completely accurate when its opening words of its *Disability Care and Support Draft Report* (Feb 2011) are ...

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.

and

The disability support 'system' overall is inequitable, underfunded, fragmented, and inefficient and gives people with a disability little choice. It provides no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall no disability system in any jurisdiction is working well in all of the areas where change is required.

The central message of this draft report is that a real system for people with a disability is required — with much more and better-directed money, a national approach, and a shift in decision-making to people with a disability and their carers.

For example, a child in the ACT or NSW (possibly other states) trying to access both Commonwealth and ACT Government funded clinical services has to see different clinicians funded from each level of Government. The former ACT Minister for Disability either does not understand the need and just refuses to

fund therapy services operating in the community, so the ACT's services are incompatible with the Commonwealth *Helping Children with Autism* package. The Minister is not interested even when the community-based service providers are significantly better value for money. The Minister is disinterested in helping families to access the complex services children with ASD need.

In the ACT, the community has been asking for years for proper behavioural support for students with ASD. The ACT Government decided in its latest budget to introduce a therapy assistance scheme in schools. The highest priority for students with ASD needing therapy assistance is behavioural therapy that helps keep them in school. But the ACT Government says

We probably do not see this program as having a strong behaviour management component. The focus will be on speech pathology, physiotherapy and occupational therapy, rather than psychology, social work and behaviour management

see <http://www.autismaspergeract.com.au/content/therapy-schools>).

While ASD prevalence has grown significantly over the last 20-30 years, there has been no effort to coordinate services. Since Government agencies at both state/territory and the federal level are reluctant or just refuse to be responsible for service planning and coordination, the situation is now disastrous.

Recommendation 5. The Commonwealth Government create an agency that is responsible for ensuring people with ASD get the diagnosis, treatment, rehabilitation, education, employment, accommodation and all other relevant services and support that they need; and that the agency provide detailed reporting to the community on the outcomes for people with ASD, their families and carers.

Autism and mental illness policy

Some states have “dual diagnosis” units for people with Intellectual Disability and mental illness (for example, see <http://www.health.act.gov.au/health-services/mental-health-act/mental-health-services/specialty-services>).

Typically, these services exclude people with a dual diagnosis of ASD and mental illness. A significant (and growing) number of PwASD also have intellectual disability and mental illness but dual diagnosis units may deny them services because of their ASD.

PwASD and other mental illnesses may have nowhere to go to get treatment for their mental illness.

The Government is wrong about autism not being a mental illness or mental disorder. This prejudice and discrimination against people with autism denies PwASD in Australia access to crucial services. And through its refusal to treat PwASD appropriately, it imposes a substantial burden on the community as a whole.

There is some evidence, largely ignored by mental health services, that parts of the population of people who respond poorly to mental health treatment actually have mental illness with comorbid ASD. Their outcomes can be substantially improved if their ASD is recognised and treated.

There is also evidence that adults with undiagnosed ASD do particularly poorly. A recent study in the UK said ...

“The recent report by the National Audit Office on supporting people with autism through adulthood suggests very little recognition and service provision by local authorities or the NHS for adults with autism spectrum disorder.

“Within the health and social care sectors, professionals will be interested to see that despite their high levels of need, people with autism spectrum conditions in this survey are not accessing support services for mental or emotional problems in any greater numbers than the general population. This does beg some questions about whether services, as currently configured, are meeting the needs of this group of people.”

Autism Spectrum Disorders in adults living in households throughout England, 2007: report from the Adult Psychiatric Morbidity Survey, 2007 is at (www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07)

People caring for a person with ASD experience significant stress. For many, this leads to mental illness. A Victorian study¹⁰ showed:

... Having a child with ASD places considerable stress on the family. Primary caregivers of a child with ASD from a regional and rural area in Victoria, Australia (N = 53) were surveyed concerning their child with ASD, family functioning (adaptability and cohesion), marital satisfaction, self-esteem and coping strategies. Results suggest that these caregivers had healthy self-esteem, although they reported somewhat lower marital happiness, family cohesion and family adaptability than did norm groups. Coping strategies were not significant predictors of these outcome variables. Results highlight the need for support programmes to target family and relationship variables as well as ASD children and their behaviours, in order to sustain the family unit and improve quality of life for parents and caregivers as well as those children. “

Carers have difficulty getting treatment for their mental illness. They may not be able to get care for their caree with ASD while they get treatment and recuperate from their mental illness.

Conduct of health authorities

The office of the Minister for Mental Health sent the letter from A4 about mental health aspects of ASD (mentioned previously) to the Minister for FaHCSIA. FaHCSIA has not acknowledged receiving the letter, nor has it responded to the

¹⁰ Higgins, D. J., Bailey, S., Pearce, J. (2005) *Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder*, *Autism*, vol. 9, no. 2, pp. 125-137.

issues and concerns expressed in the letter. The community's concerns about ASD expressed to the Minister for Mental Health are lost in a bureaucratic "black hole". The Government ignores the concerns of the ASD community.

Recommendation 6. The Government and its Ministers respond to community communications and concerns about autism spectrum disorders (instead of stuffing them into bureaucratic "black holes" hoping they will never be seen or heard of again).

The advice provided by the Health Department in relation to Budget Estimates Question E11-184 and the Minister for Mental Health's letter to A4 might not be correct. If the members of the Health Department who provided this information/advice are qualified professionals, then their conduct should be examined. Their conduct as public servants may not meet public service standards.

Recommendation 7. The Commonwealth Government review the conduct of its officials who have informed and advised it on Autism Spectrum Disorders (such as the Health Department's response to Budget Estimates Question E11-184 and for the letter sent to A4) against a) public service standards of conduct, and b) the relevant professional standards for those individuals.

The roles and responsibilities of the Health Department in relation to autism spectrum disorders should be reviewed. The Government should consider properly whether the Government should provide treatment and rehabilitation for people's autism spectrum disorders ... after all, treatment and rehabilitation are rights under the UN Convention on the Rights of the Child.

Autism Spectrum Disorders have become a substantial contributor to the national burden of disease and injury over the last decade. It should be included in the Health Departments planning and reporting on national health and wellbeing.

Access to Ministers

At GetUp's post-Budget mental health forum, Minister Roxon said from her position on the panel that she would meet Mr Buckley, the Convenor of A4, to talk about workforce and other issues affecting PwASD. After the forum, Mr Buckley requested a meeting with the Health Minister. The Minister's office acknowledged but has not responded to our meeting request.

Recommendation 8. Both the Health and the Mental Health Ministers meet and discuss Autism Spectrum Disorders with people in the community who know about Autism Spectrum Disorders (instead of getting opinions from people in their Health Department who apparently specialise in not knowing about Autism Spectrum Disorders).

The Attorney General has not responded to A4's open letter about human rights and legal processes for PwASD (see <http://a4.org.au/a4/node/375> and <http://a4.org.au/a4/node/381>).

Funding services for autism spectrum disorders

Funding for people with autism spectrum disorder does not reflect the significance of ASD in the community. Funding in the health sector for the treatment and rehabilitation is almost non-existent.

The AIHW report¹¹ says autism spectrum disorder rank 15th burden of disease and injury for males (Table 3.4), 2nd for boys aged 0-14 years and 8th for girls. Autism prevalence has more than doubled since then so autism spectrum disorders are expected to rank around 5th highest for all males, close to top for boys and 5th for girls.

Recommendation 9. Governments increase funding substantially for treatment, rehabilitation, epidemiology, research, community awareness and workforce development for autism spectrum disorders.

The Education and Disability sectors are left to do what they can for PwASD.

The Productivity Commission says the disability sector is

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.

Typically, Governments try to provide support in mainstream/community settings with a fraction of the resources needed. The usual result is disaster and lasting disappointment.

There have been some successes in the disability sector using inclusive practices. People often assume (incorrectly) that success for people with a disability generally also means it will work for PwASD. But far too often the opposite is true ... things that work for people with a disability and normal communication usually fail for PwASD. It is important that people recognise that PwASD form a separate group to people with other disabilities as their brains function in a different way. So strategies for other disabilities frequently do not work for ASD.

The Government is concerned about the diminishing employment rates for people with a disability. Employment of people with a disability will not improve while Governments persist in their simple-minded view that the people with a disability are the problem. The problems are the employers and the lack of leadership.

The education sector is also underfunded, unskilled and disorganised in relation to educating students with ASD.

¹¹ Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD, 2007. *The burden of disease and injury in Australia 2003*. PHE 82. Canberra: AIHW.

Caring family as safety net

The discussion paper to “consider the costs, benefits and governance of a National Disability Insurance Scheme” (see http://www.fahcsia.gov.au/sa/disability/pubs/policy/National_Disability_Insurance_Scheme/Pages/default.aspx, Table 22, page 77) estimates a person with “constant support needs” costs \$100,000 per year for 64 hours of support per week. A person with “frequent support needs” costs \$50,000 per year for 64 hours per week.

There are 168 hours in a week, not 64.

Most PwASD have severe or profound disability. While there are some PwASD who can live relatively independently with the right supports, most adults with ASD have “constant support needs”.

The cost of salaries and on-costs for providing a sufficient level of support for 24 hours per day, seven days per week and for 52 weeks per year is over \$460,000 per year. This includes all the penalty rates and covers holiday periods, etc. This is the equivalent cost for the support that a family provides for a person with a severe disability and “constant support needs”.

While there are economies of scale in grouping several people with a disability together and sharing some of the support, Government policy is to not do that. Governments are ideologically opposed to aggregating people with a disability into a common setting. They and their “inclusionist” supporter see any form of colocation of people with disability as segregation. So the policy ideal is to get families to support individuals with severe disability separately and in complete isolation from their peers, despite freedom of association being a basic human right.

If a Government provided \$100,000 for 64 hours per week of support, the family would still be still providing \$360,000 worth of support for the remaining 104 hours of the week and holidays, etc. Family members who are primary carers for PwASD endure working conditions that are well outside the working conditions of paid carers.

Many carers want to participate in the workforce. This is often difficult or impossible.

A student with ASD attends school for 30 hours per week. Some students who cannot function independently may need to attend out of school care while their carer(s) are at work (although the Commonwealth’s out of school care program in the ACT is only provides a small number of places strictly for students in wheelchairs).

Government does not provide people with “constant support needs” (needing to be supervised 24 hours per day, 7 days per week, every week) 64 hours of support per week. Currently, a student with severe disability who is about to leave school is offered minimal support. As I write this, the ACT has offered just 12 hours per week of support for my son. If we lived in NSW, the NSW Government claims we would be offered 30 hours per week of support or around \$26,000 per year of funding.

A person caring for a person with severe or profound disability in their home provides a service worth over \$430,000 per year. This does not include the value of the accommodation, transport and other services that carers usually provide at no cost to the Government or the community.

Note that reducing support from 30-40 hours per week to 12 hours per week when a person with ASD leaves school forces the carer out of employment.

Caring for a person who needs constant support is very stressful. Carers also experience particularly poor health and experience mental illness at much higher than normal rates.

Coordination of mental health services

Early intervention

The Health Department advises that children with autism need early intervention. The Commonwealth Government provides a small fraction of the early intervention that children with autism need through the *Helping Children with Autism* package.

Some states also offer some form of early intervention.

For example, the ACT Government offers a trivial amount of early intervention. It offers its early intervention in a manner that is essentially incompatible with the Commonwealth scheme.

The ACT Government is determined to maintain its incompatible system that requires families that want to use both Territory and Commonwealth funding to see two separate therapy teams: a therapy team from Therapy ACT and a different team funded by the Commonwealth and possibly from other sources. The ACT Minister responsible for disability has demonstrated that she does not understand or recognise that the way the ACT Government runs its therapy service is the problem.

Mental health services in school settings

School age students spend 30 of their waking hours per week in school settings. For students with ASD, schools settings are often extremely stressful.

Students with ASD often have mental health issues in school settings yet there is little or no coordination of mental health services within school settings.

Mental health and ASD

Governments have sought to coordinate services for people with a dual diagnosis of intellectual disability and mental illness.

If ASD is not regarded as a mental illness and included in the treatment system for mental illness, then coordinated service structures are needed for a dual diagnosis of ASD and mental illness.

Researchers report high levels mental health issues among PwASD.

In our study group, 70% had experienced at least one episode of major depression, and 50% had suffered from recurrent depressive episodes. Anxiety disorders were seen in about 50%. Psychotic disorders and substance-induced disorders were uncommon. In conclusion, young adults with autism spectrum disorders are at high risk for mood and anxiety disorders. To identify these conditions and offer treatment, elevated vigilance is needed in clinical practice.

Tove Lugnega, Maria Unenge Hallerbäck, Christopher Gillberg (2011) *Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome, Research in Developmental Disabilities, 32, 1910–1917.*

The prevalence and range of psychiatric disorders are increased in people with ASD, including those with intellectual disability. Risk factors for psychiatric disorders in this group include genetic factors, communication problems, loneliness and low self-esteem. Mental health problems may be difficult to assess, and range from attention deficit hyperactivity disorder (ADHD) and tic disorders to psychotic and mood disorders, and catatonia. Prevalence of ADHD and tic disorders is increased in people with ASD. While the presentation of depressive and bipolar disorders may be similar to that in the general populations, depression may be associated with onset of or increase in maladaptive behaviour. In contrast to checking, cleaning or counting compulsions seen in people with obsessive-compulsive disorder (OCD), people with ASD may engage in repeating, hoarding, touching and tapping behaviour. ASD has been proposed as a non-specific neurodevelopmental marker for childhood onset schizophrenia and it is recognized that psychotic symptoms may be difficult to establish in the presence of ASD. Interestingly, catatonia has been reported in up to 17% of young people with ASD referred to a national centre. It is important to disseminate available evidence on psychiatric treatment for people with ASD, while recognizing the need for further research on treatment and outcome measures.

Muthukumar Kannabiran, Jane McCarthy (2009) *The mental health needs of people with autism spectrum disorders, Psychiatry 8:10.*

An Australian presentation that shows the types mental health issues PwASD experience; and that people in the mental health sector can appreciate and understand mental health issues for PwASD is available at http://www.cheri.com.au/documents/Mental_health_issues_in_ASD_web.pdf.

Mental Health Workforce

In Australia, ASD are not considered part of the mental health sector, so mental health professionals are not trained to diagnose or treat people's ASD.

Parents describe encounters with incredible psychiatrists who can de-diagnose Asperger's Disorder in 5 minutes without even seeing the patient.

FaHCSIA prefers that allied health workers who provide early intervention funded through the *Helping Children with Autism* package are members of a “multi-disciplinary team”.

An unfortunate reality is that few allied health professionals had more than an hour of lectures on autism/ASD in their entire degree. Simply, this is nowhere near enough training and experience for them to be able to provide best practice for children with ASD.

Many parents, within weeks of their child’s ASD diagnosis, have more knowledge than the allied health professionals who are trying to advise them ... the allied health professionals just do not know enough to supervise an intense ASD-specific program of clinical treatment over a two year period.

Allied health professionals are not trained in the ASD-specific programs that children need, the evidence-based ASD-specific programs described in the Roberts & Prior review.

For example, Australia has far too few professionals trained and practiced in Applied Behaviour Analysis (ABA). These are the skills needed to provide much of the clinical services and support for PwASD.

Even if a family finds its way onto the “find a psychologist” section of the APS website (see <http://www.psychology.org.au/FindaPsychologist/Default.aspx?ID=1204>), they cannot even use the website to find an appropriate behaviour specialist because it is not a category listed on the website.

Australia Governments need to recognise the international qualification in behaviour analysis (see <http://www.bacb.com/>). The Australian tertiary education sector needs to ensure it trains an appropriate workforce of qualified professionals.

The tertiary education sector needs to ensure the workforce it trains, both as new graduates and in professional development, addresses the needs of the community in the allied health sector. Currently, training in treatment, rehabilitation and remediation of autism spectrum disorders is grossly deficient: for example, it bears no relationship to the estimated burden of disease and injury.

Recommendation 10. That Government ensure a sufficient number of allied health professionals are trained to provide a) appropriate and effective intensive ASD-specific early intervention programs, and b) clinical level behavioural services for people with ASD in homes, schools, accommodation, employment and other relevant settings.

Similarly, speech pathologists, occupational therapists, school counsellors and teachers need appropriate training to work with children with ASD.

Recommendation 11. Governments ensure people with ASD can access and afford appropriate and effective allied health services to treat and rehabilitate their ASD.

The advice from the Health Department, authored by Roberts & Prior, has omissions and biases.

In the USA, ASD are mostly addressed in an education context because public health is notoriously weak. USA law (since 1975) demands that all children can access an effective education, so developmental disorders that affect a child's learning have to be addressed in the education system if they are not addressed effectively outside the education system.

As discussed previously, the Health Department's guidelines for best practice advises children with autism need 20 hour per week. In their review, Roberts & Prior do not reference the USA's National Research Council review of the Committee on Educational Interventions for Children with Autism chaired by Catherine Lord that recommends children with autism get 25 hours per week. The review, titled *Educating Children with Autism*, was published in 2001. Volkmar, in his video on ASD treatment from 2010 (see <http://www.youtube.com/watch?v=2rK3cl1bVY>), points out that this eminent committee recommends

... Educational services should include a minimum of 25 hours per week, 12 months per year, in which the child is engaged in systematically planned, developmentally appropriate educational activity aimed toward identified objectives. Where this activity takes place and the content of the activity should be determined on an individual basis, depending on characteristics of both the child and the family. (page 200)

The current workforce is deeply divided over treatment approaches.

Among clinicians in Australia, there are those who regard ABA as essential, and those to deeply distrust anything to do with ABA (despite the published research). For example, the Health Department's review of early intervention for autism says

The authors of a report by the British Columbia Health Technology Assessment (BCOHTA, 2000) have suggested that Lovaas and his research colleagues have not limited their effectiveness claims to achieving developmental gains.

But the BCOHTA Report was discredited on these issues. The Supreme Court of British Columbia, in *Auton et al. v. AGBC 2000 BCSC 1142*, said

[41] Dr. Bassett is a Senior Medical Consultant with the B.C. Office of Health Technology Assessment Centre for Health Services and Policy Research ("BCHOTA") at U.B.C. BCHOTA is funded by the Provincial Government for the purpose of "promoting and encouraging the use of assessment research in policy, planning and utilization decisions by government, health care executives and practitioners." BCHOTA was asked by the Crown to provide "an assessment of the effectiveness evidence" regarding Lovaas Autism Treatment for pre-school children with autism.

...

[44] The Executive Summary of the BCHOTA Report begins with the following statement:

This systematic review examined whether early intensive behavioural therapy for children with autism results in normal functioning, or essentially a cure. The scientific validity of this curative claim is central both to legal proceedings brought on behalf of several children in British Columbia against the Province seeking an intensive behavioural program; and to cost-benefit analyses and clinical guidelines used for planning autism treatment programs.

[45] The BCHOTA Report reiterates that Drs. Lovaas and McEachin claim that their treatment "normalized or cured children with autism." As noted earlier, neither Dr. Lovaas nor Dr. McEachin -- nor the petitioners -- assert such a claim.

[46] The BCHOTA Report criticizes the Lovaas study because it used a small number of children and further suggests that the reported findings of benefits may have been achieved by assembling a high-functioning group of autistic children. Dr. Bassett was unable to suggest how one would assemble a high functioning group and agreed, in cross-examination, that he was unaware of any evidence to contradict Dr. Baer's opinion that such a selection could not be made.

[47] While the BCHOTA Report criticizes the methodology of the Lovaas and McEachin studies and the absence of replication at length, it adds little if anything to the existing debate in the scientific journals on the subject.

[48] The BCHOTA Report exhibits an obvious bias towards supporting the Crown's position in this litigation. That detracts significantly from its usefulness.

[49] The BCHOTA Report does acknowledge the fact that behaviour therapy, or ABA, is accepted as a benefit to children with autism. Its authors agree that early intervention with behavioural treatment can help to alleviate autistic symptoms in many if not most autistic children. Dr. Bassett testified that he was unaware of any government-funded programme in B.C. that provided behavioural therapy.

The book, *Science for Sale*, is a detailed account of the evidence given in this court case (see <http://www.skfbooks.com/content/products/sfsaw.php>).

It is disappointing that experienced professionals and the Health Department are not reliable in their presentation of the key evidence relating to the treatment and outcomes of ASD.

The workforce for treating and rehabilitating PwASD cannot be effective while it continues to fight over issues like this.

Online services for ASD

Once the workforce issues relating to ASD are addressed, access to online services could be very helpful in delivering services for PwASD.

A considerable amount of service could be delivered based on video technologies such as video recording of a person's skill acquisition and behaviour, and video conferencing with families, teachers and therapists.

eHealth systems should include disability services and information. People with a disability and their families report that disability service providers require frequent repetition of personal, disability and health information ... or their records are incomplete, out of data and sometimes inaccurate. Better coordinating health and disability information would improve services and simplify the lives of some of the most stressed members of our community.

Human Rights and the legal system

The National Inquiry Concerning The Human Rights Of People With Mental Illness, the Burdekin Report¹², was one of the first major acts of the Human Rights and Equal Opportunities Commission when it was created. It said ...

It is also important to note that while the severity and duration of different forms of mental illness vary substantially, the resulting disability may effect the individual for long periods of time.

People with mental illness may also experience significant disability. The relationship between mental illness and disability is poorly understood in Australia. Only recently have Australian Governments addressed the needs that people with mental illness have for services for their disability.

Australian Governments are yet to appreciate that people with mental illness have the right under international law to life, treatment, rehabilitation, education, justice, freedom from discrimination, right of association, etc.

The legal system in Australia has particularly poor responses to mental illness. One only has to look at how badly the legal system treats its own senior members with mental illness (see http://www.lawyersweekly.com.au/blogs/top_stories/archive/2011/06/15/nsw-magistrate-with-mental-illness-fights-for-career.aspx and <http://www.abc.net.au/news/2011-05-24/nsw-parliament-to-decide-bipolar-magistrates-future/2728748>) to realise that people with mental illness who come before the law in this country have no real prospect of having their rights respected.

The World Health Organisation says (see http://www.who.int/disabilities/world_report/2011/en/index.html)

Disability is a human rights issue (7) because:

¹² see

[http://www.humanrights.gov.au/disability%5Frights/inquiries/mental/Volume%201%20\(Text%20and%20pics\).pdf](http://www.humanrights.gov.au/disability%5Frights/inquiries/mental/Volume%201%20(Text%20and%20pics).pdf) and [http://www.humanrights.gov.au/disability%5Frights/inquiries/mental/Volume%202%20\(Text%20and%20pics\).pdf](http://www.humanrights.gov.au/disability%5Frights/inquiries/mental/Volume%202%20(Text%20and%20pics).pdf)

- People with disabilities experience inequalities - for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.
- People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.
- Some people with disability are denied autonomy – for example, when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability.

PwASD in Australia are ...

- denied equal access to health care in *Woodbury & Ors v ACT*
- denied equal access to education in *Purvis v NSW* and *Walker v Vic*
- denied equal access to employment
- subject to abuse as they are 4 times more likely to experience bullying in schools ... and there are many anecdotal reports of bullying in the workplace and in the community.
- subject to prejudice and disrespect on the part of Government officials who regard ASD as “untreatable” (see the views of Official X above)
- subject to prejudice and disrespect in the legal system, for example on the part of the Judge in *Walker v Vic*
- regarded as legally incompetent (see <http://www.abc.net.au/news/2011-06-22/vulnerable-disabled-children-need-better-protection/2767922>)

Australian law denies the most vulnerable children access to the law. The legal system demands standards of evidence that many PwASD (and intellectual disability) just cannot achieve. The Disability Discrimination ACT should protect these vulnerable children from being ignored by the legal system, but it fails abysmally.

Australia is signatory to the UN treaties on the Rights of the Child and the Rights of Persons with a Disability. But Australia refuses to implement the provisions of these treaties. Australians with a disability do not have the Human Rights protections they need: in this regard Australia’s legal system is a cynical exercise in public relations and political self-delusion.

In the USA, early intervention and behaviour management for students with autism have been part of the education system since 1975. USA law gave every child in USA the Right to access effective education. This means every US child with ASD also has a right to effective and appropriate early intervention needed to prepare the child to learn effectively in an appropriate education placement.

In Australia, the law protects Governments that cannot be bothered providing any treatment or rehabilitation for ASD (see the decision on seven health, education and disability services matters described in *Woodbury and ors v ACT, DT4 2007*). Just in relation to processing delays, the ACT Human Rights Commission Annual Report 2008-09 says ...

In 2007 the Discrimination Tribunal also made a decision about events a decade earlier concerning children with autism: *Woodbury & Ors v ACT*. The Commission is

alarmed that such unreasonable delays are contrary to administrative law as well as human rights principles.

The Commonwealth Attorney-General does not respond to our requests to meet. The ACT Government completely ignores community concerns and the ACT Attorney General refuses to discuss anything to do with the “unreasonable delays ... contrary to administrative law” and these breaches of “human rights principles”.

Australia has a long way to go before every child, especially children with autism spectrum disorders, have a right to an effective and appropriate treatment and rehabilitation (see Article 24, UN Convention on the Rights of the Child) that would result in equitable education outcomes and participation in their community and employment.

Acknowledgements and Apology

Members of both the A4 Management Group and the Autism Asperger ACT Political Action Group made many suggestions that improved this report.

The Commonwealth Government persists in not funding any peak body for ASD, so the resources available to the ASD community to prepare reports such as this are extremely limited. The author of this report apologises that this report is not of the quality we had hoped. This report is prepared in haste using extremely limited resources, mainly members of a national grassroots organisation volunteering their time, effort and expertise. Most of those involved in preparing this report have a more than fulltime role caring for a person who is severely or profoundly affected by ASD.

Recommendation 12. The Commonwealth Government should fund a peak body for Autism Spectrum Disorders to provide appropriate and timely information, policy guidance and submissions to Inquiries.

List of Recommendations

- Recommendation 1. Australian Governments recognise that autism spectrum disorders are mental disorders of a distinct type.*
- Recommendation 2. Governments recognise autism spectrum disorders a) are primary mental disorders, b) involve severe and pervasive impairment by definition, and c) are being diagnosed in increasing numbers.*
- Recommendation 3. Governments ensure all children with ASD can access best practice early intervention for their ASD.*
- Recommendation 4. Governments monitor the performance of all funded early intervention services for children with ASD using consistent measures to establish developmental benchmarks for children with ASD and the outcomes of the early intervention programs/services they access.*
- Recommendation 5. The Commonwealth Government create an agency that is responsible for ensuring people with ASD get the diagnosis, treatment, rehabilitation, education, employment, accommodation and all other relevant services and support that they need; and that the agency provide detailed reporting to the community on the outcomes for people with ASD, their families and carers.*
- Recommendation 6. The Government and its Ministers respond to community communications and concerns about autism spectrum disorders (instead of stuffing them into bureaucratic “black holes” hoping they will never be seen or heard of again).*
- Recommendation 7. The Commonwealth Government review the conduct of its officials who have informed and advised it on Autism Spectrum Disorders (such as the Health Department’s response to Budget Estimates Question E11-184 and for the letter sent to A4) against a) public service standards of conduct, and b) the relevant professional standards for those individuals.*
- Recommendation 8. Both the Health and the Mental Health Ministers meet and discuss Autism Spectrum Disorders with people in the community who know about Autism Spectrum Disorders (instead of getting opinions from people in their Health Department who apparently specialise in not knowing about Autism Spectrum Disorders).*
- Recommendation 9. Governments increase funding substantially for treatment, rehabilitation, epidemiology, research, community*

awareness and workforce development for autism spectrum disorders.

Recommendation 10. That Government ensure a sufficient number of allied health professionals are trained to provide a) appropriate and effective intensive ASD-specific early intervention programs, and b) clinical level behavioural services for people with ASD in homes, schools, accommodation, employment and other relevant settings.

Recommendation 11. Governments ensure people with ASD can access and afford appropriate and effective allied health services to treat and rehabilitate their ASD.

Recommendation 12. The Commonwealth Government should fund a peak body for Autism Spectrum Disorders to provide appropriate and timely information, policy guidance and submissions to Inquiries.

Annex A: “no cure” and “life long” quotations

What are the treatments for autism?

There is no cure for autism, nor is there one single treatment for autism spectrum disorders. But there are ways to help minimize the symptoms of autism and to maximize learning.

from <http://www.nichd.nih.gov/health/topics/asd.cfm>

How is autism treated?

There is no cure for ASDs. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children.

From http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

Is there a cure?

There is presently no known cure for ASD. However, early intervention, specialised education and structured support can help develop an individual's skills. Every individual with ASD will make progress, although each individual's progress will be different. Progress depends on a number of factors including the unique make up of the individual and the type and intensity of intervention. With the support of family, friends and service providers, individuals with ASD can achieve a good quality of life.

From <http://www.autismspectrum.org.au/a2i1i1l237l113/what-is-autism.htm>

“Autism is a life long neurodevelopmental disorder” (from Roberts & Prior, see [http://www.health.gov.au/internet/main/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/\\$File/autrev.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/$File/autrev.pdf))

“Autism spectrum disorders (ASDs) are lifelong developmental disabilities” (From <http://www.autismspectrum.org.au/a2i1i1l237l113/what-is-autism.htm>)

Rhea Paul, Katarzyna Chawarska, Domenic Cicchetti, and Fred Volkmar, *Language Outcomes of Toddlers With Autism Spectrum Disorders: A Two Year Follow-Up*

Although autism spectrum disorders (ASDs) are characteristically life-long conditions, they show great variability in outcome. Many young children diagnosed with ASD go on to show significant deficits in academic achievement and independent living [[Howlin, 2005](#)], but others can achieve age-appropriate levels of function [[Kelley, Paul, & Fein, 2006](#); [Nordin & Gilberg, 1998](#); [Sigman, 1999](#); [Sutera et al., 2007](#); [Toth, Munson, Meltzoff, & Dawson, 2006](#)]. One of the most reliable predictors of positive outcome in ASD is the acquisition of spoken language by the end of the preschool period [[DeMyer, Hingtgen, & Jackson, 1981](#); [Gillberg, 1991](#); [Howlin, 2005](#); [Paul & Cohen, 1984](#)].

From <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2946084/>

Annex B: Course or Prognosis

Course

By definition, the onset of Autistic Disorder is prior to the age 3 years. In some instances, parents will report that they have been worried about the child since birth or shortly afterwards because of the child's lack of interest in social interaction. Manifestations of the disorder in infancy are more subtle and difficult to define than those seen after age 2 years. In a minority of cases, the child may be reported to have developed normally for the first year (or even 2 years) of life. Autistic Disorder follows a continuous course. In school-age children and adolescents, developmental gains in some areas are common (e.g., increased interest in social functioning as the child reaches school age). Some individuals deteriorate behaviourally during adolescence, where as other improve. Language skills (e.g., presence of communicative speech) and overall intellectual level are the strongest factors related to ultimate prognosis. Available follow up studies suggest that only a small percentage of individuals with the disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible. The highest functioning adults with Autistic Disorder typically continue to exhibit problems in social interaction and communication along with markedly restricted interests and activities.

DSM-IV-TR

Prognosis

There is no known cure. Children recover occasionally, so that they lose their diagnosis of ASD; this occurs sometimes after intensive treatment and sometimes not. It is not known how often recovery happens; reported rates in unselected samples of children with ASD have ranged from 3% to 25%. Most autistic children can acquire language by age 5 or younger, though a few have developed communication skills in later years. Most children with autism lack social support, meaningful relationships, future employment opportunities or self-determination. Although core difficulties tend to persist, symptoms often become less severe with age. Few high-quality studies address long-term prognosis. Some adults show modest improvement in communication skills, but a few decline; no study has focused on autism after midlife. Acquiring language before age six, having an IQ above 50, and having a marketable skill all predict better outcomes; independent living is unlikely with severe autism. A 2004 British study of 68 adults who were diagnosed before 1980 as autistic children with IQ above 50 found that 12% achieved a high level of independence as adults, 10% had some friends and were generally in work but required some support, 19% had some independence but were generally living at home and needed considerable support and supervision in daily living, 46% needed specialist residential provision from facilities specializing in ASD with a high level of support and very limited autonomy, and 12% needed high-level hospital care. A 2005 Swedish study of 78 adults that did not exclude low IQ found worse prognosis; for example, only 4% achieved independence. A 2008 Canadian study of 48 young adults diagnosed with ASD as preschoolers found outcomes ranging through poor (46%), fair (32%), good (17%), and very good (4%); 56% of these

young adults had been employed at some point during their lives, mostly in volunteer, sheltered or part-time work. Changes in diagnostic practice and increased availability of effective early intervention make it unclear whether these findings can be generalized to recently diagnosed children.

From <http://en.wikipedia.org/wiki/Autism> 25/6/2011

Lovaas, O. Ivar (1987) *Behavioral treatment and normal educational and intellectual functioning in young autistic children*. Journal of Consulting and Clinical Psychology, Vol 55(1), 3-9.

Abstract

Autism is a serious psychological disorder with onset in early childhood. Autistic children show minimal emotional attachment, absent or abnormal speech, retarded IQ, ritualistic behaviors, aggression, and self-injury. The prognosis is very poor, and medical therapies have not proven effective. This article reports the results of behavior modification treatment for two groups of similarly constituted, young autistic children. Follow-up data from an intensive, long-term experimental treatment group (n = 19) showed that 47% achieved normal intellectual and educational functioning, with normal-range IQ scores and successful first grade performance in public schools. Another 40% were mildly retarded and assigned to special classes for the language delayed, and only 10% were profoundly retarded and assigned to classes for the autistic/retarded. In contrast, only 2% of the control-group children (n = 40) achieved normal educational and intellectual functioning; 45% were mildly retarded and placed in language-delayed classes, and 53% were severely retarded and placed in autistic/retarded classes. (31 ref) (PsycINFO Database Record (c) 2010 APA, all rights reserved)

McEachin JJ, Smith T, Lovaas OI. (1993) *Long-term outcome for children with autism who received early intensive behavioral treatment*. Am J Ment Retard. 1993 Jan;97(4):359-72.

Abstract

After a very intensive behavioral intervention, an experimental group of 19 preschool-age children with autism achieved less restrictive school placements and higher IQs than did a control group of 19 similar children by age (Lovaas, 1987). The present study followed-up this finding by assessing subjects at a mean age of 11.5 years. Results showed that the experimental group preserved its gains over the control group. The 9 experimental subjects who had achieved the best outcomes at age 7 received particularly extensive evaluations indicating that 8 of them were indistinguishable from average children on tests of intelligence and adaptive behavior. Thus, behavioral treatment may produce long-lasting and significant gains for many young children with autism.

Glen O. Sallows and Tamlynn D. Graupner (2005) *Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors*, American Journal On Mental Retardation Vol 110 (6): pp417-438

Abstract

Twenty-four children with autism were randomly assigned to a clinic-directed group, replicating the parameters of the early intensive behavioral treatment developed at UCLA, or to a parent-directed group that received intensive hours but less supervision by equally well-trained supervisors. Outcome after 4 years of treatment, including cognitive, language, adaptive, social, and academic measures, was similar for both groups. After combining groups, we found that 48% of all children showed rapid learning, achieved average posttreatment scores, and at age 7, were succeeding in

regular education classrooms. Treatment outcome was best predicted by pretreatment imitation, language, and social responsiveness. These results are consistent with those reported by Lovaas and colleagues (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993).

Mordre M, Groholt B, Knudsen AK, Sponheim E, Mykletun A, Myhre AM. (2011) *Is Long-Term Prognosis for Pervasive Developmental Disorder Not Otherwise Specified Different from Prognosis for Autistic Disorder? Findings from a 30-Year Follow-Up Study.* J Autism Dev Disord.

Abstract

We followed 74 children with autistic disorder (AD) and 39 children with pervasive developmental disorder not otherwise specified (PDD NOS) for 17-38 years in a record linkage study. Rates of disability pension award, marital status, criminality and mortality were compared between groups. Disability pension award was the only outcome measure that differed significantly between the AD and PDD NOS groups (89% vs. 72%, $p < 0.05$). The lower rate of disability pension award in the PDD NOS group was predicted by better psychosocial functioning. The lack of substantial differences in prognosis between the groups supports a dimensional description of autism spectrum disorder, in line with proposed DSM-V revision.

<http://www.ncbi.nlm.nih.gov/pubmed/21713590>

Helt M, Kelley E, Kinsbourne M, Pandey J, Boorstein H, Herbert M, Fein D. (2008) *Can children with autism recover? If so, how?* Neuropsychol Rev. 18(4):339-66.

Abstract

Although Autism Spectrum Disorders (ASD) are generally assumed to be lifelong, we review evidence that between 3% and 25% of children reportedly lose their ASD diagnosis and enter the normal range of cognitive, adaptive and social skills. Predictors of recovery include relatively high intelligence, receptive language, verbal and motor imitation, and motor development, but not overall symptom severity. Earlier age of diagnosis and treatment, and a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified are also favorable signs. The presence of seizures, mental retardation and genetic syndromes are unfavorable signs, whereas head growth does not predict outcome. Controlled studies that report the most recovery came about after the use of behavioral techniques. Residual vulnerabilities affect higher-order communication and attention. Tics, depression and phobias are frequent residual co-morbidities after recovery. Possible mechanisms of recovery include: normalizing input by forcing attention outward or enriching the environment; promoting the reinforcement value of social stimuli; preventing interfering behaviors; mass practice of weak skills; reducing stress and stabilizing arousal. Improving nutrition and sleep quality is non-specifically beneficial.

Sutera S, Pandey J, Esser EL, Rosenthal MA, Wilson LB, Barton M, Green J, Hodgson S, Robins DL, Dumont-Mathieu T, Fein D. (2007) *Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders.* J Autism Dev Disord.;37(1):98-107.

Abstract

A diagnosis of autism spectrum disorder (ASD) is usually taken to be permanent. In this study, 13 two-year-old children with ASD lost the diagnosis by age 4, at which time they scored within the normal range on standardized measures of cognitive and adaptive functioning. No differences were found in symptom severity, socialization, or communication between children who lost the ASD diagnosis and children who did not, but children with PDD-NOS were significantly more likely than those with full autistic disorder to move off the spectrum. The clearest distinguishing factor was motor skills at age 2. Results support the idea

that some toddlers with ASD can lose their diagnosis and suggest that this is difficult to predict.

E. Kelley, L. Naigles, D. Fein (2010) *An in-depth examination of optimal outcome children with a history of autism spectrum disorders*, Research in Autism Spectrum Disorders
Volume 4, Issue 3, Pages 526-538

Abstract

Previous research has suggested that some children with autism spectrum disorders (ASD) may improve to such an extent that they lose their diagnosis, yet little research has examined these 'optimal outcome' children in depth. We examined multiple aspects of functioning in a group of 13 optimal outcome (OO) children, matched on age, gender, and non-verbal IQ to a group of typically developing children ($N = 14$) and a group of high-functioning children with ASD who still retained a diagnosis on the autism spectrum ($N = 14$). These children were tested on average about eight years after they had been diagnosed (OO = 93 months, HFA = 94 months). Unlike their high-functioning peers with ASD, the OO group's adaptive and problem behavior scores fell within the average range. They also showed average language and communication scores on all language measures. The HFA group, however, continued to show pragmatic, linguistic, social, and behavioral difficulties. The OO children tended to have been diagnosed at younger ages and were significantly more likely to have received intensive early intervention. Although the high-functioning children with ASD continued to show difficulties in the behavioral realm, the individuals in the OO group were functioning within the average range on all measures. Future research should address how this optimal outcome is achieved.

From <http://www.sciencedirect.com/science/article/pii/S1750946709001408>

Annex C: ACT Government position on autism

Following is some information about the position of the ACT Government and its pronouncements relating to autism spectrum disorders. Some members of A4 happen to be familiar with the ACT Government's position in detail so it has been chosen as an illustrative example from the state/territory level of government.

The ACT Government wrote, "autism is not a mental illness". Clearly, ASD are mental illness. The ASD community in the ACT is very concerned that the ACT Government is basing its policy and service provision on seriously incorrect information about ASD.

The ACT Government drafted a Mental Health Charter. Every point in the draft charter claimed people with mental illness have rights: people do not have any rights in relation to services for their mental illness including ASD. Nor is the ACT Government taking any steps to provide them with appropriate rights. The ACT Government's claims are clearly wrong. The ACT Government has not responded to Autism Asperger ACT's submission (see <http://www.autismaspergeract.com.au/node/208> and <http://www.autismaspergeract.com.au/node/207>) on its draft Mental Health Charter.

The Head of Therapy ACT told the ACT Select Committee on Estimates (25 May 2010) ...

for some people, the primary diagnosis may actually be an intellectual disability diagnosis rather than an autism diagnosis.

See <http://www.autismaspergeract.com.au/node/126>

The diagnostic manual for mental disorders, the DSM-IV-TR, classifies mental disorders on one of five axes. It puts primary disorders on Axis I. The DSM-IV-TR puts Pervasive Developmental Disorders, including the group of disorders referred to as autism spectrum disorders, on Axis I of its multi-axial classification scheme. Intellectual disability (called *Mental Retardation* in the DSM-IV-TR) is classified on Axis II. According to the DSM-IV-TR, autism is always the primary diagnosis relative to intellectual disability.

The Head of Therapy ACT, who is responsible for specialist ASD diagnosis service, should know "autism" is a *primary diagnosis* before intellectual disability (*Mental Retardation*).

The Head of Therapy ACT sees other types of disability as more important than "autism" in planning and providing services for people with a disability in the ACT.

The Head of Therapy ACT's view is one of extreme scepticism about children with ASD making significant improvements. It is not appropriate that anyone with such extreme and unorthodox views manages services that are essential for PwASD. Such views do not have a place in deciding how state (and Commonwealth) funds provide services for PwASD.

The Head of Therapy ACT told the ACT Select Committee on Estimates (25 May 2010)

We do not actually use the ABA [behavioural] intervention method ...

<http://www.autismaspergeract.com.au/node/126>).

Expert advice shows that most children with ASD benefit from having at least part of their program provided using ABA methods (for example, many of the best research outcomes listed in Annex B: Course or Prognosis above are from ABA methods).

Also, the former¹³ Minister for Disability, Ms Burch, said ...

We seem to be concentrating on a model of care that provides 20 hours of intense intervention and I think it is the ABA model. There is no jurisdiction—as I understand, no state or territory funds that model of care. I know it is a model of care that is a particular interest of a particular stakeholder, but no state or territory funds that model of care.

<http://www.autismaspergeract.com.au/node/156>

Rather than ABA being “a particular interest of a particular stakeholder”, most experts regard ABA as the method-of-choice for anyone with a disability (not just ASD) who has challenging behaviours.

In relation to therapy for children with ASD, the ACT Government said ...

It is actually intended to reflect work in the home that the family can do, work at school that the teacher can do, work in a variety of settings. It is important to make sure that people understand what are the appropriate responses. And I think we did actually clarify that with the authors of the report. The intent is that it does not actually have to be with a therapist. It is that a broad therapeutic approach is applied.

<http://www.autismaspergeract.com.au/node/126>

Rarely can a teacher provide individual attention, let alone achieve anything like 20 hours per week, for an individual student. Teachers are not trained or resourced to work this way.

A member of Autism Asperger ACT made a Freedom of Information request for all information, documents and communications relating to any attempt of a member of ACT DHCS to “actually clarify that with the authors”. The result shows the Department has no evidence of even trying to clarify these matters with Roberts & Prior, the authors that the Department referred to.

Roberts & Prior know that few families can provide 20 hours per week of effective ASD-specific intense early intervention for each child with ASD ... especially one parent families with multiple children. The ACT Government shows an alarming lack of awareness of the needs of families and contempt for the truth.

¹³ the latest Ministerial reshuffle in the ACT abolished the title “Minister for Disability”.

The Head of Therapy ACT claims ...

... there is quite a deal of research now that the most effective intervention is done by families and is done in circumstances where the child is naturally, rather than in a fairly artificial therapy environment, because one of the hallmarks of autism is an inability to generalise.

<http://www.autismaspergeract.com.au/node/126>

Again, the Head of Therapy ACT has just not understood the research. Many children with ASD need to learn skills initially in a structured and non-distracting setting ... in what the Head of Therapy ACT describes derogatorily as “a fairly artificial therapy environment”. In order for a child with ASD to generalise their skills, which is essential to achieve performance in the “normal range” as described above (and that the Head of Therapy ACT denies is a possibility), ABA (and many other ASD-specific) practitioners ensure children with ASD practice skills, and may get some skill development, in naturalistic setting (see http://en.wikipedia.org/wiki/Autism_therapies#Pivotal_response_therapy).

Many researchers say outcomes are better for a child when family interactions with a child are consistent with the child’s clinical program. This does not mean that the child’s family should be the primary agent delivering their child’s program of intense ASD-specific early intervention, as the ACT Government claims.

Ms Burch also said ...

The ACT Government Social Plan sets out a commitment to the principles of inclusion. As far as possible, services to people with a disability are provided as part of the services available to all ACT residents.

<http://www.autismaspergeract.com.au/node/127>

The Health Department has advice that is specific to students with ASD saying ...

Reviews of the literature indicate that general and special educators have mixed reactions to inclusion related to the efficacy of implementation and the degree of administrative support, resources and training they have received (Danne, Beirne-Smith, & Latham, 2000). Inclusive education requires significant resources to implement; complaints of lack of resources are ubiquitous. Studies in NSW indicate that teachers feel they lack the necessary time, skills, training and resources to implement inclusive practices (Wright & Sigafos, 1997). For principals, the negation of previous enrolment rights and/or practices may become a major source of conflict with parents (Bailey & Du Plessis, 1998).

Roberts & Prior, page 85

As a cost-cutting measure and contrary to advice, the ACT Government tries to impose inclusive education for as many students with ASD as possible ... without the required administrative support, resources and staff training.