Submission to
Senate Select Committee on Mental Health

from

Autism Aspergers Advocacy Australia

(www.a4.org.au)

Dear Committee Members,

Thank you for this opportunity to discuss issues affecting people with an autism spectrum disorder (ASD) and their associates (families and carers).

Autism Aspergers Advocacy Australia (A4) is a national grassroots lobby group representing people with ASD and their associates. A4 communicates directly with its members using the internet and represents a significant number of people from each state. A4 has a close relationship to the Autism Council of Australia, the peak body for the various state and territory autism associations.

A4 wishes the Committee every success with this Inquiry.

Bob Buckley
Convenor

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Summary

Responsibility for treatment for autism spectrum disorders (ASD) could belong with the health system. Diagnosis of a person’s ASD is a process of identifying a clinical disorder that requires clinical attention. And that clinical attention is a responsibility of the health system.

Autism Aspergers Advocacy Australia urges the Inquiry to identify which sector of the health system is responsible for ensuring children with ASD receive effective early intervention and treatment for their ASD.

Australian professionals specialising in ASD say ...

> “Services available differ between areas, and in Australia there are no government-funded programs providing the recommended amounts of intervention. There is a need for increased government financial support for early intervention programs.” [15]

Autism Aspergers Advocacy Australia urges the Inquiry to recognise mental health services in the form of early intervention and treatment for autism and for other mental illness associated with or arising from ASD are completely inadequate.

Unfortunately, people with ASD will still develop mental illness. Existing mental health services usually fail to provide people with ASD treatment for the mental illness they develop if they reveal that they have ASD.

Autism Aspergers Advocacy Australia urges the Inquiry to ask government to ensure that people with ASD and mental illness have their mental disorders and illnesses treated effectively.

The Burdekin Report Chapter 21 [9, pp659-677 & pp935-6] starts out quoting Professor Tonge from Monash University ...

> “There is a huge number of intellectually disabled [including autistic] people who receive no treatment for their psychiatric disorder because it is not available.”

The report says

> “Mental ill health also often results from a variety of factors which particularly affect the intellectually disabled [including people with ASD]. These include ‘lack of friends, not having valued social role, not having a job and not having a home’. ... Psychiatric difficulties confronting many intellectually disabled people are compounded by a scandalous shortage of appropriate psychiatric services.”[9, pp659-660]

Autism Aspergers Advocacy Australia urges the Inquiry to consider a program to screen mental health patients who are unresponsive to treatment for ASD.

Autism Aspergers Advocacy Australia urges the Inquiry to recommend training for all health staff teaching them to attend carefully and appropriately to the needs of people with ASD.

Introduction

In the case of Jason Dawes ... the following facts come from Judge Ellis in the matter from the NSW District Court known as 04/21/1041 – REGINA v DANIELA DAWES at Parramatta, Wed. 2 June 2004

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

Jason Dawes had autism, a mental disorder that required treatment that the state did not provide and that he did not get. The fact that authorities failed to provide appropriate intervention for his autism contributed to his parents' mental illnesses and to his death.

Many families with a child with ASD are barely surviving. Action for Autism warned the Gallop Inquiry into disability services in the ACT that urgent action is required to avoid outcomes like the Jason Dawes' death ... but nothing was done to provide people with ASD with the treatment they need. The death of Stephen Moon in the ACT followed. The lack of effective services has a profound affect on all families that have a child with ASD. The situation is similar in all Australian states and territories.

Autism Aspergers Advocacy Australia urges the Inquiry to recognise mental health services in the form of early intervention and treatment for autism and for other mental illness associated with or arising from ASD are completely inadequate.

We see the challenge for mental health service providers around autism spectrum disorders in three parts.

> First is the need to treat and rehabilitate people with ASD for the disability and dysfunction due to their ASD.
>
> Secondly, people need treatment for mental illness associated with their ASD. Many people with ASD are disabled by stress, anxiety, depression and sometimes psychosis.
>
> Thirdly, clinical levels of stress, anxiety and depression afflict many family members and carers.

We are particularly concerned that the needs of children with ASD are not being addressed. Children have particular needs, and having their needs met is provided as a Right under international law (see Annex C). Children with ASD require effective treatment for their condition.

Australian professionals specialising in ASD say ...

> “Services available differ between areas, and in Australia there are no government-funded programs providing the recommended amounts of intervention. There is a need for increased government financial support for early intervention programs.” [15]
>
> “However, most young children with autism in Australia do not receive intensive behavioural intervention programs — partly because such programs are not recommended by many health professionals and partly because of their prohibitive cost for families.”[4]

Knowledge of and attention to autism spectrum disorders in mental health services could improve the treatment and the subsequent outcomes for people with an autism spectrum disorder and another mental illness.

Service provisions for adults with ASD should also improve significantly. Several researchers report that chronic health problems in adults with “developmental delay” including ASD.

There appears to be large-scale under-diagnosis or misdiagnosis of ASD in adult Australian. Some enlightened researchers examined ...

> “a group of 25 adults who had been receiving treatment for psychotic disorders but with a less than optimal response. After assessment ... it was found that they had diagnoses within the autism spectrum that had not been previous identified” [7].
>
> “In Schizophrenia the typical sensory disturbance is hallucinations and these are normally auditory ... Most mental health workers will screen for auditory hallucinations with the question ‘Do you hear voices?’ To which many people with Autism and intellectual disability will respond ‘Yes’ reflecting either a concrete, literal answer (as we all do hear voices in the absence of hearing problems) or a desire to give the ‘right’ answer that the examiner seem to be looking for.” [7, p5].

Adults with ASD who find their way into a mental health service may receive inappropriate, ineffective and expensive treatment as a result of misdiagnosis. The researchers conclude (in the triple negative) that “in our experience it is not uncommon for people with a mild intellectual disability and a diagnosis of schizophrenia who are not responding to treatment to have an undiagnosed Autistic spectrum disorder” [7, page 8].

The subject has been raised before. The Burdekin Report Chapter 21 [9, pp659-677 & pp935-6] starts out quoting Professor Tonge from Monash University ...

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> intellectually disabled people are compounded by a scandalous shortage of appropriate psychiatric services."[9, pp659-660]

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Discussion based on the Inquiry Terms of Reference

a. the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress;

According to the Department of Health and Ageing website, the National Mental Health Strategy aims to:

- Promote the mental health of the Australian community;
- To, where possible, prevent the development of mental disorder;
- Reduce the impact of mental disorders on individuals, families and the community; and
- Assure the rights of people with mental illness.

The four items of the National Mental Health Strategy are crucial for people with ASD. Yet Autism Aspergers Advocacy Australia is not aware of any discernable commitment of resources or steps that either federal or state mental health services have taken in relation to people with ASD in respect of these aims.

The subject of responsibility raises a major issue in relation to ASD. “The division of responsibility for policy and funding” of services for ASD follows.

- Responsibility for educating students with ASD rests with education authorities.
- Responsibility for support services relating to ASD rest with states disability services.
- Responsibility for employment services rests with DEWR.

But responsibility for treatment, early intervention and rehabilitation rests with no one.

Responsibility for treatment for ASD could belong with the health system. Diagnosis of a person’s ASD is a process of identifying a clinical disorder that requires clinical attention. And that clinical attention is a responsibility of the health system.

Autism Aspergers Advocacy Australia urges the Inquiry to identify which sector of the health system is responsible for ensuring children with ASD receive effective early intervention and treatment for their ASD.

The DSM-IV [1], first published in 1994, formally recognised PDD (or ASD) as a family of clinical conditions, categorising them on Axis I with the other mental disorders. Internationally, recognition that ASD requires treatment resulted in improved early intervention and treatment regimes being provided for people with ASD.

In Australia the signs are that understanding of ASD in health administration has fallen far behind. Most health administrators regard ASD/PDD as a DSM condition categorised on Axis II as it was when most of them were trained.

Health administrators were also taught autism is a rare disorder. They do not accept that up to 1% of students will be diagnosed with an ASD by the time they leave school [2; 8].

Many health administrators regard ASD as a childhood disorder. But ASD is life-long. DSM-IV says these are severe or profound disorders. Outcome for people with ASD are particularly poor: available data shows few people with ASD are successfully employed. Currently, most students with ASD are granted a Disability Support Pension as soon as they reach the eligible age, that is before they leave school. Qualitative evidence is that the most challenging clients in supported accommodation, hence the most costly clients, are people with untreated ASD.

Best outcomes result from treating ASD. Unfortunately, existing policy and funding models do not provide effective early intervention and treatment for ASD. Best outcomes for people with ASD are also best outcomes for the community and for government. To minimise cost and maximise productivity government needs to act to ensure people with ASD have the best outcomes possible.

This lack of responsibility for ASD confuses people even at the highest levels of the Department of Health and Ageing. The sequence of messages following shows the confusion around this issue.

Alan Singh, A/g Assistant Secretary of the General Practice Programs Branch, wrote (21 December 2004) responding on behalf of the Minister to a letter specifically on the subject of treatment for autism, suggested parents of children with autism could access treatment:

"Under the Better Outcome in Mental Health Care (BOiMHC) initiative, which may be accessed through your local Division of General Practice, GPs can refer patients up to six sessions a year with a psychologist, occupational therapist or social worker, among others. An additional six sessions are also available each year, if required, following review by the referring GP."

Parents asked for information and documentation about the BOiMHC Initiative that would help them access resources provided by this initiative.

Colleen Krestensen, Director of Mental Health Strategies Section, responded in an email on 11 February 2005 with a contrary view saying:

"Can I explain at the outset that the Better Outcomes Initiative is designed to support GPs in the management of their patients with mental health conditions. The Initiative was mentioned in the correspondence to you as being one of the mainstream programs we have in the health portfolio which may be of interest to families of children with autism. The program itself does not extend to developmental disabilities and provides treatment which specifically targets mental health conditions."

Colleen Krestensen's email implies that autism spectrum disorders (often called Pervasive Developmental Disorders in the mental health sector) are "developmental disabilities". And she says the BOiMHC is for "mental health conditions" and does not extend to "developmental disabilities" that therefore are not mental health conditions in her view. This view is widely held in the mental health sector.

Parents of children with autism report that mental health professionals tell them "*Autism is a developmental disability. It cannot be treated.*"

The view, widely held among mental health professionals, that autism cannot be treated is factually wrong.

Their view arises from ignorance and fear. It is outdated. It is prejudice. It discriminates against some of the most vulnerable Australia citizen. It excludes people with autism from the community.

Contrary to the views of people working in mental health (who have minimal training at best about autism), appropriate treatment significantly improves outcomes for most people with autism. Numerous research reviews show treatment for autism is usually effective for children with autism [2; 9; 11; 12; 13].

People working in mental health in Australia lack knowledge of autism. Mental health training in Australia does not give them accurate information about autism and its treatment.

Mental health workers typically fear people with autism because they don't understand them. People with ASD behave quite differently from other people; even from people with other mental illnesses. Mental health professionals fear treating people with autism because they lack appropriate knowledge and any experience they have tells them their methods will not be effective.

Policy in the mental health sector does not provide the resources or funding for the clinical treatment that people with autism need. Nor does any other section of government. For example the CSTDA specifically prohibits using disability funding for clinical services.

So existing policy excludes people with autism from the effects of the National Mental Health Strategy. The existing policy and practice in mental health denies people with autism spectrum disorders the treatment they need so they can avoid mental illness.

Unfortunately, people with ASD will still develop mental illness. Existing mental health services usually fail to provide people with ASD treatment for the mental illness they develop if they reveal that they have ASD.

Autism Aspergers Advocacy Australia urges the Inquiry to ask government to ensure that people with ASD and mental illness have their mental disorders and illnesses treated effectively.

b. the adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;

People with ASD need their mental dysfunction addressed through:

- effective early intervention that follows immediately from a diagnosis and initial assessment;
- treatment to address issues reported by carers or detected through ongoing monitoring of the person's condition

- services that are adapted to address the needs of a person with ASD for treating other health conditions including mental illness in the context of limited or dysfunction communication skill.

International experts on treatment and care for people with ASD advise that a child with autism needs a minimum of 20 hours per week of effective autism-specific early intervention to prepare them for school[1]. Without such intervention few of them succeed[2] at school or in the community.

In Australia, most children are denied the early intervention and treatment they need for their ASD. The public health system does not provide effective treatment for ASD.

The best of the publicly funded early intervention services in Australia, provide just 2 hours per week of clinically directed program … and these services are very limited in duration. These programs claim to be evidence based but they clearly ignore the overwhelming evidence that such low intensity is ineffective.

This is like giving each cancer patient just a tenth of the treatment they need. It reduces the cost of treatment but is rarely an effective form of treatment.

These programs expect parents to make up the enormous deficit in service level. Increasingly, the service model offered requires parents of children with ASD to provide a further 18+ hours per week of specialised clinical intervention for their child's autism.

Where is the evidence that most families have the capacity and can develop the expertise required to meet this expectation? What is the effect of imposing this additional burden and expectation on families that already show signs of severe stress?

What other treatment models for severe of profound disorders treat families this way? This model of service delivery for ASD is like asking families whose child has a heart condition to attend a few lectures, view a few videos and then perform surgery and anaesthesiology on their kitchen table … call us if you have a problem.

The cost of treatment in the private health system is prohibitive for most families. Recent data [5, p31] shows 84% of families of a young child with ASD spend over $1,000 p.a. on interventions for ASD. And 21% of families spend over $10,000 p.a. with 3% spending over $40,000 p.a..

Yet the so called Medicare Safety Net covers a maximum of just $220 p.a.

People with ASD are not offered adequate early intervention. Apart from the few families who can completely fund private treatment, people with ASD do not get treatment needed to minimise or possibly prevent mental illness and challenging behaviour.

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[1] New York ??? & Education of children with autism.

[2] The DSM-IV says … ???

Australian research[3] shows people with ASD have elevated risk of mental illness. Mental health services do nothing for people with ASD to prevent their developing mental illness.

Community, respite and acute care services are unprepared and typically struggle to provide care for people with ASD. Their staff are not trained to support people with ASD and inappropriate conduct of a service can exacerbate problems.

For example, families report being called to remove their child with ASD from respite services. When this happens it usually impacts significantly on the family. And the person with ASD is highly agitated; providing a further challenge for the family.

Most mental health crisis teams/services refuse to attend where ASD is even suspected.

c. opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care;

There are enormous opportunities to coordinate services capacity to deliver much more effective treatment for children with ASD.

A major challenge in providing treatment for young children with ASD is getting sufficient one-to-one staff capacity to deliver an effective program. A coordinated approach could make much more effective use of staff who provide respite and support workers in pre-school and school settings.

In education settings, many children with ASD spend significant amounts of time in settings where they lack the social and communication skills that are prerequisites for learning. Education resources used to sustain this ineffective situation are wasted.

A coordinated approach, centred on the individual rather the services, could use existing capacity to develop prerequisite skills for learning before placing students in educations settings that they are unable to benefit from.

Similarly, students with ASD could receive the integrated treatment and education program that they need through coordinated clinical and education programs and better training and support for teaching aides, support staff in after school care and respite workers.

For older people with ASD, existing support workers and carers can be a coordinated part of the clinical team.

The capacity already exists to meet the needs of people with ASD.

Currently, Australia has the capacity to deliver the individual programs people with ASD need but we lack:

- expertise in the treatment of ASD,
- a service model with the flexibility to meet the needs of people with ASD, and

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[3] For details contact Professor Bruce Tonge, Head of Department, Developmental Psychiatry & Psychology, School of Psychology, Psychiatry and Psychological Medicine, Faculty of Medicine, Nursing and Health Sciences, Phone: +61 3 9594 1354

- a means of coordinate services for an individual.

d. the appropriate role of the private and non-government sectors;

People who need services for their ASD have very little discretionary spending. The profit motive that drives the private sector is absent as there is little prospect of profiting commercially from ASD services.

In this context, the profit motive invites a cherry picking approach to services. Such a service model leaves large service gaps and the most vulnerable and the most needy miss out.

Currently, government policy dogma means existing services are largely contracted to non-government non-profit organisations. The contracting process adds the cost of contracting and regulation to the cost of the services. And it compartmentalises services making it difficult if not impossible to coordinate services for people with diverse and/or complex needs.

Implementation of the purchaser/provider model expanded some existing services. But it has been less successful where services providers did not already exist … for example, few new ASD services have been created and existing services have not increased inline with rising diagnosis levels.

The non-government sector tends to focus on specific services or specific client groups. The result is service compartments and gaps. So some essential services for people with ASD, especially those requiring expertise specific to ASD, simply do not exist … or are only available to the few people who can pay for them from private providers.

Private and non-government providers have limited relevance in the treatment of ASD.

e. the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes;

Government and its agencies take significant care to ensure unmet is not measured directly and reported.

One indication of levels of unmet need comes from the ACT. People who need supported accommodation first need to be given an Individual Support Package (ISP). The latest round of ISP applications in the ACT identified 94 people needing this type of support … yet just 15 of them were awarded an ISP.

In the ACT, 84% of adults identified with complex needs, many with mental illness or high risk of developing them, continue to have enormous levels of unmet need.

People with ASD rarely succeed in competitions for jobs. For example, see the letter to A4 in Annex A. In this case, the existing provision deny a person with ASD, who is keen to work and appears quite capable of working, the services needed to get into a job and to stay there.

Most people with ASD need substantial support to get into a job and to stay there. Throughout most of the country, the services they need simply do not exist.

Many families fear emerging government policy and existing opposition policy deny people with ASD access to either employment or welfare. The negative attitudes, continuous attacks and the ongoing uncertainty over employment and welfare issues increase stress on some of the nations most vulnerable citizens and are likely to exacerbate mental health problems.

f. the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence;

Children who are diagnosed with ASD need treatment for their ASD. Currently they do not get the treatment they need.

The most conservative overseas experts tell us best practice provides a minimum of 20 hours per week of ASD-specific treatment. But “experts” in Australia describe the NSW Autism Association’s Starting Blocks program as “an excellent program” when Starting Blocks provides just 2 hour per week, just 10% of the minimum. The Starting Blocks program is limited to a small number of children.

The Australian Government signed up to the UN Convention on the Rights of the Child; agreeing in Article 2 (1) that our nation ...

> “shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”

We urge the federal government to address Article 23 (3) [see Annex C]. It says ... recognizing the special needs of a child who is disabled by ASD, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the child who is disabled by ASD has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, ...”

Currently, few children with ASD have access to education that is effective for them. Failure to provide effective treatment for their ASD means they lack the communication and social skills that they need to access education effectively. They miss out on the health care and rehabilitation services that they need. This also means that adolescents with ASD are not effectively prepared for employment, recreation and opportunities to participate in the community.

Information on aged people with ASD is non-existent. There are some indications that people with ASD have reduced life expectancy.

We have no information on ASD among the indigenous population; or about ASD in association with drugs and alcohol dependence.

People with ASD are, by definition, socially isolated. Most of them have complex and comorbid conditions. There is some evidence that their social isolation contributes to higher incidence of other mental illness among these people, their families and their carers.

Any service that exists is located in the metropolitan areas. Access to essential services for Australians with ASD who are geographically isolated requires them to travel. Volunteer services that help people in remote location travel for health reasons rarely extend to people with ASD.

g. the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness;

Of necessity, families caring for people with ASD mostly train themselves in the treatment as well as support of people with ASD. The requirement to be expert in treatment arises from the limitation in the services people with ASD and their carers can access.

In recent times, some services have started offering training. But the training is in lieu of treatment. In some cases, provision of parent training diverts resources from any possibility of providing training.

Families complain that the paid carers in supported accommodated lack the knowledge, skill and experience required to adequately support a person who is severely or profoundly disabled by their ASD.

The combination of people with ASD and other mental illness is even more challenging. Professionals lack the required knowledge so they are not really in a position to train families and carers properly.

The concerns and recommendations of the Burdekin Report, Chapter 21 over people with dual or multiple disabilities (that is, both mental illness and intellectual disability/developmental delay) have not been addressed. There has been no discernible progress for people with ASD in the intervening 12 years.

h. the role of primary health care in promotion, prevention, early detection and chronic care management;

Primary health care services do very little in relation to ASD. Their main focus is on early detection and diagnosis. But there is little point in diagnosing an ASD if the treatment required does not follow.

Currently, there is no service model for treating ASD. Should responsibility for assessment and accessing treatment rest with the GP or a paediatrician? Or would an autism-specific service manage assessment and treatment of this complex condition better? Such a model is closer to specialised treatment regimes like oncology and cardiology.

Prevention is not an option for ASD. The nature and cause of ASD are not known ... so there is no way known to prevent ASD.

Detection of ASD in young children has increased markedly in the last decade. The diagnosis rate in Australian children seems similar to diagnosis rates overseas.

Early detection would improve if waiting lists for diagnostic assessment were reduced.

There are strong indications that adolescents and adults with ASD have significant levels of other mental illnesses that are undiagnosed. The health system lacks adequate services for people with communication or social disability.

i. *opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated;*

As people with ASD do not get treatment, there is little prospect of iatrogenesis.

Parents and families (consumers) are already thoroughly involved. The need is for more professional involvement from the mental health workforce.

As indicated above, consumers already have far too much responsibility for treating ASD.

Government funded service providers dispute the existence of "recovery-focussed care" for people with ASD. For example, Roberts [13] questions the research literature relating to "recovery" through behavioural intervention for Autistic Disorder. The ACT government dragged out a complaint to the ACT Human Rights Office and ACT Discrimination Tribunal about its failure to provide effective early intervention for a child's Autistic Disorder from mid-1997 until now. The ACT government argues against needing to provide the only treatment with evidence that it offered a reasonable prospect of recovery for a child with Autistic Disorder. Almost eight years on[4], an initial decision in the matter has yet to be reached.

j. *the overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people;*

The lack of relevant data prevents us from commenting.

k. *the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimising treatment refusal and coercion;*

The lack of relevant data prevents us from commenting.

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[4] In the meantime, the government has contributed some services that help the parents and the schools in providing treatment in an education setting for a few (initially two, later four) children.

l. the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers;

The lack of relevant data prevents us from commenting.

m. the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness;

Agencies such as housing, employment and law enforcement rarely recognise ASD. Until they recognise people with ASD have distinct needs, they have no reason to account for or develop proficiency in supporting people with ASD.

Increasingly housing in the form of supported accommodation is recognising ASD, especially when they are faced with profoundly challenging behaviour. They have a strong interest in getting effective treatment for challenging behaviour, so it is in their interests to obtain treatment that addresses the person's ASD.

Few people with ASD are employed. Most people with ASD are granted a Disability Support Pension as soon as they reach the eligible age. This shows most people with ASD have little prospect of getting a job.

Even people with ASD who are relatively able have great difficulty getting a job. See Annex A for an example.

People with ASD do not understand their community. Encounters with law enforcement agencies can lead to poor outcomes. When questioned by police, they are likely to give answers they think the police wish to hear. They are likely to confess to crimes they had nothing to do with. Some are prone to becoming agitated, incoherent and possibly violent when stressed.

Corrective Services in NSW could (or would) not tell us how many people with developmental delays it currently holds in its gaols. There may be around 20 that they know of in Goulburn and Long Bay. There are indications there are more elsewhere.

It seems even basic accountability is absent in NSW. Other states appear to be in a similar situation.

The ACT is building a new prison. ACTCOSS and the community expressed concerns about autism, ADHD and other disabilities in the prison system. But the ACT government has not discussed these issues with ASD organisations in the ACT.

We have no access to prison facilities so we cannot comment on their proficiency. Much of the material collect by the NSW Law Reform Commission [14] a decade ago remains relevant.

n. *the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated;*

Funding for ASD research in Australia is minimal. The government responded to a Question on Notice about research into ASD (Question no. 2559) on 4 December 2003. The questions were:

> (5)How much (a) in total, and (b) as a proportion of the National Health and Medical Research Council funding will be spent on research specifically related to autism/ASD in (i) 2003, and (ii) 2004.
>
> (6)How much (a) in total, and (b) as a proportion of the Australian Research Council funding will be spent on research specifically related to autism/ASD in (i) 2003, and (ii) 2004.
>
> (7)Will he identify any other funding programs or projects being conducted specifically in respect of the treatment for autism/ASD in Australia.
>
> (8)Does the Government direct or intend to direct any funding specifically to autism/ASD research in Australia.
>
> (9)How does the proportion of Government research funding spent on autism/ASD compare to the relative burden autism/ASD imposes on the Australian community.
>
> (10)Is the Government aware of any data on the financial cost to Government when people with autism are not treated appropriately.
>
> (11)What data is available on the long-term cost-benefit resulting from evidence-based treatment of children with autism (eg. as a result of the reduced need for intensive services when the child becomes an adult).
>
> (12)What data is available on the direct cost to Government of caring for Australians with a diagnosis of autism/ASD.

The government's response was …

> (5)(a) and (b), (i) and (ii) National Health and Medical Research Council funding for research related to autism in 2003 will be $717,512. This is approximately 0.3% of the total National Health and Medical Research Council funding for new and continuing grants in 2003.
>
> In addition, the National Health and Medical Research Council will provide approximately $31 million in 2003 for funding of research projects into mental health and neurosciences, which may have the potential to benefit those suffering from a range of conditions including autism.
>
> Information relating to funding in 2004 is not yet available.
>
> (6)(a) and (b), (i) and (ii) The Australian Research Council does not fund research in the area of clinical medical research. However, in its area of responsibility the Australian Research Council has provided $241,360, between 1999-2004, for socially based autism/ASD related projects.
>
> (7)I am unaware of any other funding programs or projects being conducted specifically outside the work of the National Health and Medical Research Council and the Australian Research Council.

(8)The National Health and Medical Research Council funds health and medical research across a wide range of mental health and neuroscience disciplines which may include autism.

I am unable to comment on the funding arrangements of other organisations.

(9)(10), (11) and (12) The comparison cannot be made because there is no national data on the diagnostic profiles of people with autism/ASD.

This provides an optimistic or exaggerated view of the amount of Australian research conducted into ASD.

o. the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards; and

Data collection, outcome measures and quality control relating to ASD are minimal.

p. the potential for new modes of delivery of mental health care, including e-technology.

There is enormous potential for new modes of delivery of treatment and mental health care for people with ASD.

Any introduction of effective treatment for ASD would be a new mode of delivery. Similarly, treatment for other mental illness in people with ASD would be a welcome new mode of delivery.

The health system could improve data collection, outcome monitoring and planning using e-technology.

The health system as a whole shows particularly poor performance in workforce planning and demand prediction. The nation deserves a health system that is much better planned and managed than the current mode of operation provides.

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Annex A. Employment services and ASD

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

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

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

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

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

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

The main points I want to emphasise are:

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

Annex B. National Mental Health Strategy

From
http://www.health.gov.au/internet/wcms/publishing.nsf/Content/mentalhealth-mhinfo-nmhs-index.htm

The National Mental Health Strategy is an agreement between the Commonwealth and all State and Territory governments that aims to improve the lives of people with a mental illness.

In April 1992 Australian Health Ministers endorsed the National Mental Health Strategy as a framework to guide mental health reform over the period 1993 to 1998. The Strategy provides a framework for national reform from an institutionally based mental health system to one that is consumer focused with an emphasis on supporting the individual in their community. The Strategy was reaffirmed in 1998 with the *Second National Mental Health Plan* and again in 2003 with the endorsement by all health ministers of the *National Mental Health Plan 2003-2008*.

The National Mental Health Strategy aims to:

- Promote the mental health of the Australian community;
- To, where possible, prevent the development of mental disorder;
- Reduce the impact of mental disorders on individuals, families and the community; and
- Assure the rights of people with mental illness.

About the Strategy

It is estimated that mental health problems and mental illness will affect more than 20% of the adult population in their lifetime and between 10-15% of young people in any one year.

Many will recover spontaneously and, of the remainder, the vast majority can be treated and will fully recover. However, a smaller number of people will experience longer periods of distress and disability.

Despite the suffering and the great personal and financial costs resulting from mental illness, the community has not always recognised the needs of people with a mental illness, or their right to live independent lives.

People with a physical illness evoke community concern and sympathy, and we readily recognise their needs. People with a mental illness are not usually so fortunate.

In the past, the more severely affected people were isolated and treated in psychiatric institutions, and had little opportunity to participate in the life of the community.

Recently, things have changed and, although some people with severe mental illness will still require hospitalisation, the emphasis is now on treating and supporting people with a mental illness in their own communities.

For community-based treatment of people with an ongoing illness to be effective, they may need access to a range of different services:

- specialised mental health services that recognise their rights and respect their dignity;
- general medical services, housing, accommodation support, social support, community and domiciliary care; and
- income security, employment and training services that can all have a significant impact on the capacity of a person with a mental illness or

> psychiatric disability to live in the community, free from discrimination and stigma.

As a result, all levels of Australian government have recognised that they need to work together to reform services and mental health policy to ensure that, wherever possible, people with a mental illness are able to enjoy the same opportunities as other Australians.

Annex C. Extract from UN Convention on the Rights of the Child

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. States Parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties.
2. For this purpose, States Parties shall provide, as they consider appropriate, co-operation in any efforts by the United Nations and other competent intergovernmental organizations or non-governmental organizations cooperating with the United Nations to protect and assist such a child and to trace the parents or other members of the family of any refugee child in order to obtain information necessary for reunification with his or her family. In cases where no parents or other members of the family can be found, the child shall be accorded the same protection as any other child permanently or temporarily deprived of his or her family environment for any reason, as set forth in the present Convention.

States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;
(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
(c) To combat disease and malnutrition, including within the framework of primary health care, through, iner alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
(d) To ensure appropriate pre-natal and post-natal health care for mothers;
(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breast-feeding, hygiene and environmental sanitation and the prevention of accidents;
(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.