



Submission on Psychosocial Disability
to the
Joint Standing Committee on the NDIS
inquiry into
the provision of services under the NDIS for people with
psychosocial disabilities related to a mental health condition

Autism Aspergers Advocacy Australia (A4) does not know whether or not *autism spectrum disorder (ASD)* is *psychosocial disability (PSD)*. A4 has not found a clear definition of psychosocial disability (PSD). PSD is not a term defined in the DSM-5 or the ICD-10 which are usually recognised as *the* authoritative sources of definitions of mental disorders.

Matters relating to *restraint* and *deprivation of liberty*, in the context of the United Nations *Convention of the Rights of Persons with Disability (CRPD)*, may have brought the term, psychosocial disability, to prominence. Concerns over treatment, services and supports for people with mental illness and/or intellectual disability have been raised/discussed¹.

8.6 The Australian Civil Society Parallel Report Group Response to the List of Issues as part of Australia's appearance before the UNCRPD in 2013 expressed concern that people with disability, especially cognitive impairment and psychosocial disability, are 'routinely subjected to unregulated and under-regulated behaviour modification or restrictive practices such as chemical, mechanical and physical restraint and seclusion'.
from <https://www.alrc.gov.au/publications/8-restrictive-practices/restrictive-practices-australia>

A [description/definition of PSD given online](#) indicates PSD includes "disorders usually first diagnosed in infancy childhood, or adolescence." This definition clearly includes autism/ASD² in PSD.

While parts of the ASD community have varied views about the medical vs social model of disability, ASD is usually described as a *neurodevelopmental* or *neurological* disorder even though the specific nature of ASD neurology is unknown.

¹ Szmukler, G., Daw, R., & Callard, F. (2014). Mental health law and the UN Convention on the rights of persons with disabilities. *International Journal of Law and Psychiatry*, 37(3), 245–252.
<http://doi.org/10.1016/j.ijlp.2013.11.024>

² Pervasive Developmental Disorders, including Autistic Disorder, Asperger's Disorder and PDD-NOS, were defined/described in the DSM-IV (1994) in the section headed *Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence*. In the DSM-5 (2013), ASD is defined/described in a section headed *Neurodevelopmental Disorders*.

Officials in Australia have a contrary view. The Commonwealth Health Department says ASD is not a mental condition/disorder/illness; it [wrote](#) (2011) “Autism is generally considered as a pervasive developmental disability and as such is the remit of the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).” A4 is interested to know, since Health officials claim autism is not a mental condition; they do not say which part of the body they believe ASD affects.

In its reporting ([here](#), for example), the NDIA distinguishes between “psychosocial disability” and “autism and related disorders”.

A4 has not found the NDIA’s definition of psychosocial disability (PSD). The ABC reports that NDIS applicants are confused (see [Psychosocial disability definition causes confusion among NDIS applicants](#)). It is likely that other people are also confused.

The NDIA does not report how many NDIS participants say they have both “psychosocial disability” and “autism and related disorders”.

Even if ASD is not PSD in Australia, services and supports for people with PSD are important to the ASD community because many people with ASD have essential needs for their other PSDs. People with intellectual disability (ID) and autistic people (people diagnosed with ASD) have high rates of comorbid PSD.

Burdekin Report, in 1993, identified a substantial lack of services for people with intellectual disability and mental illness (which presents as psychosocial disability). It recommended a proactive development of services for people with what it called “dual diagnosis”.

By 2006, the Senate Select Committee on Mental Health reported that progress was minimal so funding and services for the sector needed to improve substantially.³

In 2017, there are a few services remaining that provide for patients with what Burdekin called “dual diagnosis”, that is both intellectual disability and mental illness. The RANZCP says “the closures of state-run disability services which currently provide most of the mental health input for people with [intellectual and developmental disabilities] IDD is concerning”⁴. Mental health services for people with IDD usually excluded people with ASD from their services – the mental health needs of autistic people were rarely being met.

When the Burdekin Report was written, autism was considered a rare disorder ... and was usually associated with ID. Since then, the number of Australian people diagnosed with ASD has increased (see [Autism prevalence in Australia 2015](#)) even if the Health Department wrote

The [Health] Department does not collect data on autism prevalence. The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

³ See

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Former_Committees/mentalhealth/report02/index

⁴ <https://www.ranzcp.org/Files/Resources/Submissions/06220-President-to-Committee-Secretary-re-NDIS-sub.aspx>

<http://a4.org.au/node/359>

Although the number of ASD diagnoses has increased enormously, governments have not recognised nor addressed key needs of autistic people. The [behavioural needs of autistic Australians must be met](#).

Supposedly, society has moved on since 1993. [The National Disability Strategy 2010-2020](#) talks lots about Inclusion; an idea/ideology that dreams of people with disability, *possibly* including people with PSD, getting their services and supports from mainstream services, that is in the same setting as other people. Autistic people with PSD should get quality treatment, services and supports from a “mainstream” mental health system whether or not they have ID, ASD or PSD.

Unfortunately, Australia’s Health and Mental Health Systems have made very little progress toward these goals.

Any part of the Australian Health or Mental Health System can exclude a person with disability whose behaviour is unwanted or deemed unacceptable. Australian law fully protects, even condones/promotes, such disability discrimination (see [Purvis vs NSW](#)).

About ASD

It seems that the Productivity Commission, and then the NDIA, underestimated the number of NDIS participants with ASD ... and ignored advice from the ASD community that their estimates were wrong.

During the planning stage (in 2011), people associated with NDIS planning wrote that “every 7 hours, an Australian child is diagnosed with an autism spectrum disorder” (see [Disability report chronically underestimates ASD diagnoses](#)). This estimate was about ¼ of the Australian ASD diagnosis rate at the time: the ASD diagnosis rate was close to one child every 2 hours.

Australian children aged 10-14 years with a formal ASD diagnosis (2.46%, see [Autism diagnoses in Australia continue to grow in 2016](#)) now exceed children diagnosed with Intellectual Disability (max. of 2.28% with IQ that is 2 standard deviations below the mean).

The following mental conditions/disorders and PSDs are some of the conditions described as relatively commonly comorbid with ASD.

- Anxiety
- Attention-deficit hyperactivity disorder
- Bipolar disorder
- Epilepsy
- Intellectual disability
- Tourette syndrome
- Sensory processing disorder
- Obsessive-compulsive disorder
- Psychopathology

Some of these conditions are often associated with PSD.

Too often, once a person is diagnosed with ASD their other symptoms are ignored. They are not diagnosed with their other PSDs and so they miss out on essential treatment, services and supports for those additional conditions.

For those who are diagnosed properly, the combination of ASD and other PSDs can make treatment more challenging. And a lack of improvement in ASD symptoms is often interpreted as general treatment resistance.

There is chronic under-diagnosis of ASD in adults – ASD diagnoses are growing fastest among adults but adults diagnosed with ASD had their ASD since they were very young children. Some adults are misdiagnosed: rather than ASD, a person is diagnosed with intellectual disability, psychosis or some other disorder.

Apparently, autistic people and people with PSD have a higher risk of challenging behaviour. In Australia, government, service provider and community responses to challenging behaviour need to improve substantially.

Restraint and deprivation of liberty

Governments in Australia fail (refuse really) to recognise and address the needs of people with challenging behaviour for professional behaviour services and supports which if often associated with communication disorder/dysfunction, ASD, PSD, etc. (see [Behavioural needs of autistic Australians must be met](#) and [starting 2017 school year again without discernible progress on services for problem behaviour](#)).

Apparently due to unwanted or challenging behaviour, people with PSD – diagnoses or undiagnosed – are ‘routinely subjected to unregulated and under-regulated behaviour modification or restrictive practices such as chemical, mechanical and physical restraint and seclusion’.

Recent reports from the media include:

- [Perth mental health experts call for closure of seclusion rooms](#)
- [Leading autism service to be investigated over restraint policy](#)
- [Premier intervenes after man shackled to hospital bed for two weeks](#)
- [Autism cage details emerge as United Nations investigates abuse of children](#)
- [Submission to the Royal Commission into the Protection and Detention of Children in the Northern Territory](#)
- [Outrage as autistic boy is chained to a chair using a weighted belt and ankle straps during school lessons to 'keep him under control'](#)
- [Boy with autism locked in 'cage', NSW school being investigated](#)

Denial of service and sub-standard service provision

Some services fail or refuse to treat people with PSD. Other services provide sub-standard services for people with PSD.

Sometimes denial of service or deficient services are fatal. People with PSD die.

Here are some recent examples from the media that relate to intellectual disability and ASD.

- [Why people with intellectual disabilities are dying avoidable deaths](#)
- ['We almost lost him!': Canberrans with special needs turned away from hospital](#)

Coroners' reports

Coroners, in the inquests about deaths of autistic people, accept denial or service and deficient services as appropriate. Lost records and missing memories are routine. The absence of safety provisions for autistic patients and service clients is considered normal.

As a result, nothing is learned and autistic people continue to suffer and die. Disability discrimination is further condoned. The goals of having coroners are not realised for autistic people.

Some example follow:

- <http://a4.org.au/node/547> and <http://a4.org.au/node/545>
- <http://a4.org.au/node/557>
- <http://a4.org.au/node/772>

Terms of Reference

Following are comments on the specific items in the inquiry's Terms of Reference.

a. Eligibility

the eligibility criteria for the NDIS for people with a psychosocial disability;

A [media report](#) suggests that people with PSD do not understand the NDIS eligibility.

A4 describes the NDIS eligibility for autistic people (people with ASD) as *gobbledygook* (see [here](#) and [here](#)). The NDIA refuses to discuss this matter with A4 and ignores written comment.

The NDIS is very unwilling to tell A4 what process it uses to decide NDIS eligibility. A4 questions whether NDIS staff with little or no formal training, experience or qualifications can overrule advice from fully qualified clinicians.

A4 expects that the NDIA deals with eligibility criteria for other PSD in a similar manner.

Too often, eligibility decisions are based on primary disability – too many decision makers do not understand ASD or PSD; and they fail to consider adequately the impact of comorbid conditions.

b. Transition – Commonwealth funded services

the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular;

- i. whether these services will continue to be provided for people deemed ineligible for the NDIS;*

Mental Health services usually exclude autistic people, when their ASD diagnosis is known, even when the person has comorbid mental illness.

A4 expects there are many people who are autistic but have not been diagnosed who receive mental health services (if they were diagnosed it is likely that they would be denied any treatment for their mental illness). Often, their mental health treatment is suboptimal because their treatment is not informed about ASD. It is likely that these people are seen/described as unresponsive to treatment.

A4 has little to say about the transitions of hypothetical services, that is services that don't exist. There are few if any services in this category whose transition to the NDIS interests A4.

A4 is looking to the NDIA and the mental health system to recognise the need to support autistic people with comorbid mental illness and to create proactively services that offer treatment, services and support for their mental illness and PSD. A4 is not aware of any recognition of this serious service

deficit/deficiency. A4 is not aware of any progress towards meeting their needs (which are human rights).

Old age care is one service that is very likely to survive the NDIS transition. A number of children and younger adults with challenging behaviour associated with their PSD end up in aged care units, usually with (excessive or inappropriate) chemical restraint.

Younger people in residential aged care seemed to be an issue 10 years ago ... but little was achieved and it has largely dropped off the Government's agenda⁵. A [government webpage](#) indicates that "On 10 February 2006 COAG agreed to a five-year initiative to reduce the number of younger people with disability living in nursing homes throughout Australia." It is deeply disappointing that:

- we find Australian governments' current (2016) *plan for young children with disability who cannot live at home* is to place them in nursing homes or to make them homeless; and
- there are still 6,200 younger people living in aged care facilities.

The available reports suggest that "as at June 2007, nationally, there were 6,613 residents under the age of 65 years in RAC" so a decrease of just 413 (to 6,200) in 9½ years should be considered failure.

The NDIS is a person-centred system. It creates individual plans for 460,000 people with disability mostly under 65 years of age.

People with disability who are not included in the 460,000 do not get funds to access disability specific services. They will have to get their services and supports using their own funds or via charity, or from mainstream services funded by government.

The NDIA is creating its ILC to assist people with disability who are not NDIS eligible to access services. A4 is not aware that the NDIA has any plans to actually replace key services that do not fit its limited model.

The NDIA is too ideologically driven. The NDIA discourages services like [Home in Queanbeyan](#) or [MyHome in Canberra](#), despite being preferred by their clients; the NDIA and vocal parts of the disability sector see such services as "institutions" that they regard as inherently bad.

It is not clear whether a service like *Home in Queanbeyan* would be able to ask a client for a financial contribution from the client's NDIS plan.

The Autism Advisor service (through *Helping Children with Autism* HCWA) is a crucial service: it will still be needed once the NDIS is fully rolled out but the essential Autism Advisor service will not make the transition to the NDIS. Recently, Assistant Minister Prentice announced funding to keep the service going through the transition (see [Support services extended for families of children with disability](#)). A4 is not aware of funding or plans to continue the essential Autism Advisor service once the NDIS is fully underway.

⁵ See <http://www.theaustralian.com.au/national-affairs/health/effort-to-find-2000-ndiseligible-young-people-lost-in-agedcare-limbo-is-faltering/news-story/ea6a8adc4cefc56f70c23b13af60b4a>

c. Transition – state/territory

the transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular;

- i. whether these services will continue to be provided for people deemed ineligible for the NDIS;*

The ACT is the first state/territory with a full NDIS roll-out. Already, the NDIS transition in the ACT shut down *Autism Asperger ACT* which provided some key services for people with PSD, some of whom are not NDIS eligible.

SHOUT, another key service in the ACT, is at risk (see [SHOUT 'likely to close down' without funding pledge](#)).

d. Scope and level of funding for services under ILC

the scope and level of funding for mental health services under the Information, Linkages and Capacity building framework;

Information, Linkages and Capacity building (ILC) funding and the associated processes are still being developed. It is impossible to tell what the scope and funding of ILC services of any kind will be.

If the ACT is any indication, there are currently no ILC services despite the full rollout of the NDIS in that jurisdiction.

There are few services and supports for autistic people with PSD. The Royal Australian and New Zealand College of Psychiatrists wrote “The health system is badly set up for people with IDD and mental health issues”⁶. Note, IDD includes ASD. Actual information about and linkage to services and supports that simply do not exist is impossible. Fabricating information and linkages is dishonest, stressful, frustrating and depressing for people with disability.

A4 and SOfASD are not optimistic that there will be any real capacity building for autistic people with PSD.

e. Planning

the planning process for people with a psychosocial disability, and the role of primary health networks in that process;

A4 is not especially informed about “*the role of primary health networks*” in prevention, treatment, service and supports for PSD (other than ASD). A4 understands that there are various groups/representatives advocating for better services and support for people with PSD (other than ASD).

A4 is concerned that

1. Relatively little is known about optimal treatment, services and supports for autistic people with PSD;

⁶ <https://www.ranzcp.org/Files/Resources/Submissions/06220-President-to-Committee-Secretary-re-NDIS-sub.aspx> (accessed 27/2/2017).

2. Many people with PSD may have undiagnosed ASD and their treatment, services and supports could be substantially improved through better recognition of ASD and its clinical implications; and
3. Many autistic people may have undiagnosed and untreated PSD.

A4 is concerned that there is no discernible plan to address these matters.

Stakeholder engagement is an essential element of effective planning for any program like the NDIS. A4 and the ASD community felt there was very positive and effective stakeholder engagement with the roll out of the *Helping Children with Autism* package in 2008.

A4 finds it very difficult to engage the NDIA in any form of planning. Recently, A4 has its first direct engagement in years with the NDIA. It was specifically about Early Intervention for autistic children. Afterwards, the NDIA wrote to A4 documenting its position. A4 wrote back to point out key differences in understanding. The NDIA wrote back (5/2/2017) saying:

Dear Mr Buckley

Thank you for your email and letter of reply to my letter sent to you on 17 January 2017.

I wish to acknowledge that I have read your correspondence and I am sorry that your views do not align with the views of the Agency on the implementation of ECEI.

...

As we indicated when we met with you just prior to Xmas, we would be very pleased to meet with you again in six months' time so that we can discuss the Agency's progress on rolling out its ECEI approach nationally.

Kind regards

This communicates clearly that the NDIA is disinterested in consultation or discussion with A4 relating to the NDIA's ECEI Approach ... or in discussion of other ASD-related issues. The Agency has a take-it-or-leave-it approach, dismisses the strongest evidence and is not interested in engaging with stakeholders whose views "do not align with the view of the Agency".

It would help A4 in its advocacy efforts if the NDIA were to articulate the lack of mental health services for autistic people. As A4 indicated above, the NDIA has no discernible capacity building plan.

There is no support for systemic advocacy for autistic people and people living with ASD ... a part of the disability sector that includes significant numbers of people with PSD.

Apparently, the NDIA's main plan is to work with DSS to target minuscule prospects for over-diagnosis of ASD (reported as 2.04%) and to ignore the massive amount of delayed and under-diagnosis.

f. Spending vs projections

whether spending on services for people with a psychosocial disability is in line with projections;

A4 is not particularly aware of any projections or actual spending for PSD generally.

First, governments and their agencies in Australia would need to decide whether or not ASD is a PSD or not.

Second, a real effort to find people with PSD and to properly assess their needs and the cost of meeting those needs is required. Otherwise, any projections or measurement of spending is mere speculation.

g. Outreach to identify PSD

the role and extent of outreach services to identify potential NDIS participants with a psychosocial disability; and

At this stage, there is little or no attempt to identify people with PSD. They may discover they have PSD if/when they ask their NDIS planner “why disability type am I?”. But few will ask that.

There is no discernible plan to identify PSD among autistic people ... even autistic NDIS participants.

Critics of mental health services in Australia argue for improving the approach to mental health to increase early intervention and prevention. However, little planning and less progress is discernible.

In relation to ASD, the NDIA with DSS have been trying to characterise ASD as highly “over-diagnosed”.

In February 2014, DSS allocated \$50 000 to investigate autism diagnostic practices in Australia, with the aim of establishing the extent of over-diagnosis nationally. See <http://a4.org.au/node/1213>

The research found

the rate of over-diagnosis, ... is a fraction of cases diagnosed by 2.04% of diagnosing clinicians.

The research did not report on, or even ask about, delayed or under-diagnosis. Current indications are that just 30% of autistic children are diagnosed by 6 years of age, in time to access government funded early intervention.

Note that these Australian autism researchers, who also teach many of Australia’s clinicians, suggest that ASD prevalence is really “at least 1% in the 2010s” (where ‘at least’ means ‘close to’ or ‘around’, see <http://onlinelibrary.wiley.com/doi/10.1002/aur.1740/full>). If this is true, it means that:

1. with ASD diagnoses recently observed for 2.46% of 10-14 year old children (see <http://a4.org.au/node/1340>), almost three of every five children (59%) are over-diagnosed ... and clinicians are getting ASD diagnosis very very wrong – that is clinicians now get ASD diagnosis wrong more often than they get it right.
2. there are around 250,000 autistic adults in Australia ... most of whom are undiagnosed and untreated.

Note that a substantial proportion of autistic adults also have PSD.

h. Services forensic disability services

the provision, and continuation of services for NDIS participants in receipt of forensic disability services;

The number of autistic people, both children and adults, that the legal system has incarcerated is unknown. A4 expects that the figures are quite inaccurate.

A4 expects that provision of and information about non-ASD PSD is particularly unreliable.

i. Any related matters

The level of funding for disability and/or PSD research is utterly inadequate.

There are serious difficulties staffing disability services. The NDIS will make this worse.

Disability services are well known for cherry picking clients – they refuse or are very reluctant to take clients with challenging behaviour(s) ... which affects a higher proportion of people with ASD and /or PSD. A4 expects this practice will continue with the NDIS.

Australian law, particularly the *Disability Discrimination Act 1992*, protects, even promotes, disability discrimination. In particular, the High Court *Purvis vs NSW* decision encourages organisations to exclude people with ASD and/or PSD from services and supports.

Australian health and safety law does not (but should) ensure the safety of clients in disability services.

People with PSD are very poorly treated by Australia's legal system (it would be completely inaccurate to call it a "justice system"). In this regard, Coroners deserve special mention: their handling of matters relating to people with disability, particularly ASD and PSD, are disgraceful.

If you are interested in further information please contact Bob Buckley, A4 Convenor –

Yours sincerely

Bob Buckley
Convenor

27/2/2017