

Many small steps

A submission to the Select Committee on Autism

“The first step in solving any problem is recognising there is one.”
Jeff Daniels as Will McEvoy in *The Newsroom*.

“We always hope for the easy fix: the one simple change that will erase a problem in a stroke. But few things in life work this way. Instead, success requires making a hundred small steps ..., [and] everyone pitching in.”
— Atul Gawande, *Better: A Surgeon's Notes on Performance*

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1. Introduction

Autism Aspergers Advocacy Australia, known as A4, values the opportunity to give evidence to the [Senate Select Committee on Autism inquiry](#) in 2020. We appreciate the Senate recognising that Autism Spectrum Disorder (ASD), sometime called “autism”, is a distinct disability with an increasing impact on our community.

There are voices in the community complaining that this inquiry is specific to autism; saying that autism should not be singled out.

In response, A4 notes that autism was previously regarded as a “rare disorder” but diagnosis rates have risen and the current rate of autism diagnoses for Australian children is 2.5-3.2%, which is now above the rate of intellectual disability (a max. of 2.2%). No other major disability type is increasing like this.

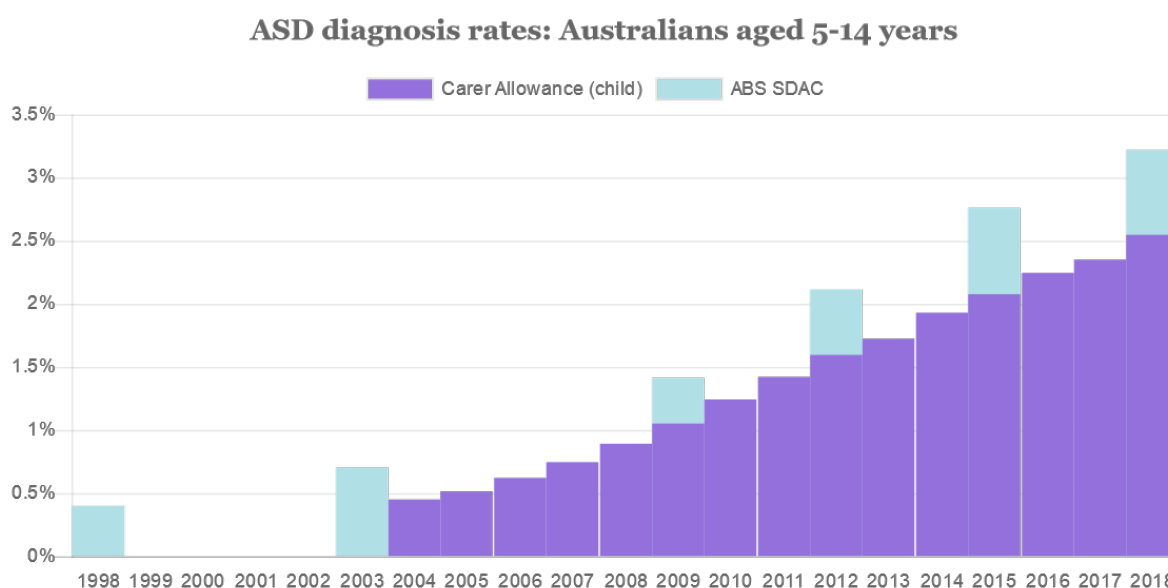


Figure 1. ASD diagnosis rate in children from independent sources.

Autism, formally called Autism Spectrum Disorder, has now emerged as the biggest distinct disability in the NDIS. Currently, 31% of NDIS participants are autistic. Many more than the anticipated 20% of NDIS participants. The ASD community warned the NDIA from the outset that its estimates were wrong but the NDIA rejected our advice. Other essential services and supports have also failed or refused to recognise increasing service and support needs arising from increasing numbers of autistic Australians.

A4 recognises that there are other emerging disability types that also need better attention than our governments in Australia give them. A4 hopes that other distinct disability types will benefit in the wake of any progress achieved for autistic Australians.

A4 observes that reviews, policy, planning and service provision for people with disability generally ignore or exclude recognition or consideration of the needs of autistic Australians. The consequences are clear: evidence show abysmal outcomes in education and employment, outcomes that are substantially worse than they should be and substantially worse for autistic Australians than they are for Australians with disability

more generally. Outcome for autistic Australians simply will not improve while governments continue to ignore the specific needs of autistic Australians.

The age profile of autistic Australians (Figure 1 above) is substantially different from most other types of disability. Most known autistic Australians are under 25 or 30 years of age.

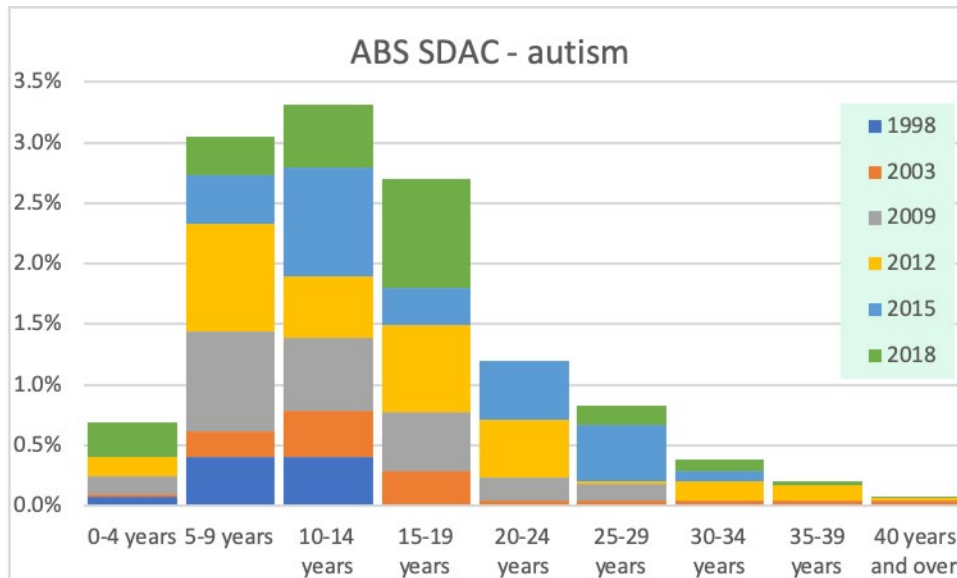


Figure 2. Age profile for autistic Australians

The age profile for autistics is different from that of people with disability generally. Figure 3 below shows disability rates are low in earlier years and increase with age.

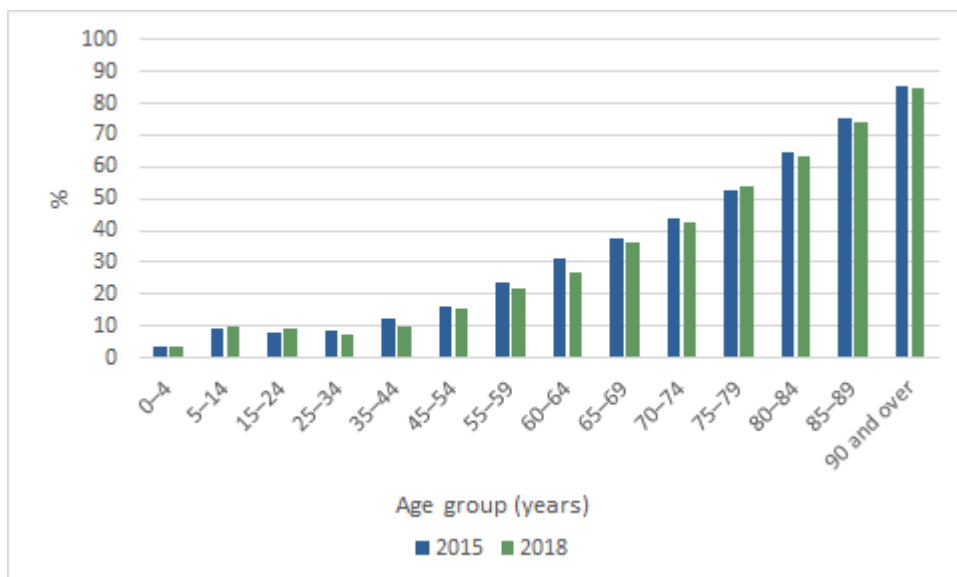


Figure 3. SDAC - disability rates generally increase with age-group

Disability rates for other major disability types are relatively stable, or even decreasing, over time. The Australian Bureau of Statistics (ABS) [reported](#) that general disability rates in 2018 were “16.1%, down from 17.0% in 2015 and 17.4% in 2012” while the number of autistic Australians rose 25.1% from 2015 to 2018.

About Autism Spectrum Disorder

Current criteria for diagnosing Autism Spectrum Disorder (ASD) are given in the DSM-5 and the ICD-11. These documents are manuals of “disorder” that unsurprisingly focus of negative aspects of autism.

The number of Australians diagnosed with ASD has increased substantially in the last few decades. Autism was described as rare up to the 1980s; at most 1 per 1,000 people. The diagnosis rate has increased more than 30 times since then. Currently, over 3% of Australian children are autistic. Diagnosis rates for adults are much lower 0.1-0.3% of Australia’s adult population.

Currently, ASD is listed in the DSM-5 as a neurological disorder but ASD diagnoses are based entirely on behaviour: there are no recognised biological (genetic, neurological, physical or chemical) markers for ASD. There is a degree of interpretation (clinical judgement) in an ASD diagnosis. The Australian Government’s [attempt to identify over-diagnosis of autism](#) failed; instead, it gave evidence that few clinicians give questionable ASD diagnoses.

It is likely that the different diagnosis rates for children and adults result from chronic under-diagnosis of adults rather than substantial increases in underlying ASD prevalence.

People must appreciate the distinction between ASD diagnosis rates and actual prevalence.

The key problem with under-diagnosis of ASD in adults is that undiagnosed autistic adults do not get the services and supports that they need for their ASD. Providing ineffective or inappropriate supports delivers poor outcomes and is expensive.

Terms like Asperger’s Disorder/syndrome and PDD-NOS were described in previous version of the manuals, the DSM-IV and the ICD-10.

The previous DSM-IV and ICD-10 classified autism as “developmental disorder”. The change to a neurological classification recognises that as a neurological disorder, autism cannot be cured. We simply cannot change their neurology.

Effective strategies for improving the lives of autistic people involve structuring environments to avoid or decrease their opportunities and need for dysfunctional behaviour balanced with learning beneficial/functional (albeit often divergent) behaviour in a community that accepts and respects difference increasingly.

Our community must promote autistic people being exceptional rather than wanting them to be “normal”.

Autistic people have many positive traits, but beneficial features associated with “autism” are not normally a focus of clinical attention. Increasingly, some of people’s beneficial autistic traits are being recognised and even valued in employment.

Unfortunately, [ABS reports](#) show that most autistic Australians are under-educated and unemployed.

Some people say that they have “autism”, but that they need *acceptance* and maybe some accommodation; they do not need support. If so, they do not meet diagnostic

criteria for ASD – it is unclear what criteria they base their claim to be “autistic” on. Perhaps, the less-rigorously described term, “neurodivergent”, better describes their condition.

Autism myths and misconceptions

Few autistic people have savant skills ... besides, “savant” is not clearly defined. It is probably more common in non-autistics.

A long time ago, Rimland showed that autism was not due to “refrigerator mothers”. Nor is it due to bad or inadequate parenting. Research indicates that blame for autism is mostly genetic – and we are not really ready to blame people for their DNA. People in the NDIS ECEI pathway need to realise that pushing parents of autistic children into better parenting programs does not cure their child’s autism (anticipating that most autistic children will not become NDIS participants at age 7 years). Parents, especially mothers, of autistic children will ask for the support and advice they need; they do not need denigration from bureaucrats who think their child’s autism is due to their parenting.

ASD is not contagious.

Children do not “grow out of autism” if “autism” means their neurology. There may be developmental delay, although it’s more developmental divergence, associated with ASD. Autistic children progress so they develop skills, often functional and perhaps unusual skills. Some of them learn to live quite independently. They may do especially well if they learn functional skills and their “differences” are tolerated or celebrated (even better). Research suggests that some autistic children learn functional skills sufficiently that they lose the “autism” label if the term “autism” means dysfunctional behaviour as in the diagnostic criteria (more on this below).

Autism is not a result of socio-economic status. Some research shows higher rates of autism in higher socio-economic groups, presumably because people higher up the socio-economic scale can afford services that recognise/diagnose autism. Having an autistic child usually diminishes family income, so a family’s lower socio-economics performance is more an effect than a cause.

Some people say “we are all a little bit autistic”. This is ignorant and offensive: it aims to diminish the significance of an autism diagnosis. It dismisses/denies the pervasive nature of autism: an autistic person is fully autistic 24/7. Autism is not being a little finicky or occasionally miscommunicative or tongue-tied. The following submission shows that, For most autistics, their autism is a pervasively challenging and they need substantial support. Autism is not something we all experience a little of

2. Addressing the Inquiry's Terms of Reference

Following are sections addressing the Inquiry's Terms of Reference. These Terms of Reference are enormous. We apologise that we have not done them justice.

In the following subsections, we identify problems or issues relating to an item in the Inquiry's Terms of Reference. The challenge for Government is to recognise the problems we raise. A4 has raised most of the problems before and government agencies have simply ignored the issues.

Paraphrasing Duke Ellington:
every problem is an opportunity to do your best.

After we identify problems related to an item, we provide background information and suggestions relating to the item.

We try to address all the items in the Terms of Reference in what follows.

a. current approaches and barriers to consistent, timely and best practice autism diagnosis

The key problems relating to diagnosing autistic Australians are:

- 1) underdiagnosis and misdiagnosis of autistic women and girls
- 2) timely diagnosis for young Australians
- 3) inadequately trained clinicians diagnosing autistic Australians.
- 4) underdiagnosis and misdiagnosis of autistic adults

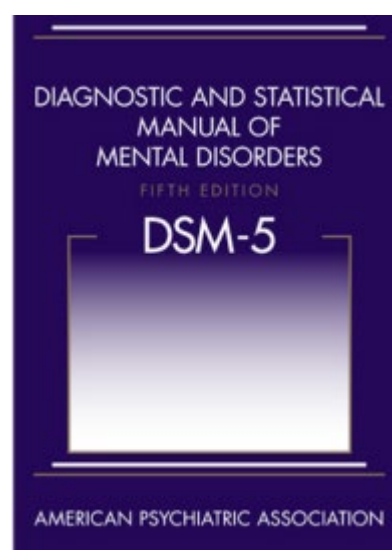
Problems relating to ASD diagnoses for women and girls are discussed in detail in Item c below.

Internationally recognised diagnostic criteria for Autism Spectrum Disorder are given in

- a) the American Psychiatric Association (APA) *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* (2013) — known as [the DSM-5](#), and
- b) World Health Organization's *International Statistical Classification of Diseases and Related Health Problems, tenth revision* (ICD-10) or the newer 11th edition known as [the ICD-11](#).

A comparison between the DSMs and the ICD-10 for autism/ASD is available at <https://a4.org.au/ASDformal>

These are clinical manuals; they focus on disorder or dysfunction. Their purpose is primarily clinical, bringing a perspective that is criticised reasonably for emphasising the negative aspects of people's autism.



The criteria are also criticised for focusing on children, especially young male children. Some people argue that criteria describing autism in adults are needed or could at least help improve diagnosis of autistic adults.

ASD is diagnosed based purely on behaviour. There is no physical test for autism. An ASD diagnosis relies on subjective interpretation of a person's behaviour being seen as "deficits in social-emotional reciprocity", "highly restricted, fixated interests", and "needs support". According to the DSM-5 criteria, diagnosing clinicians need to distinguish "highly restricted" from "moderately restricted", etc. without guidance from any object measures.

The criteria for a diagnosis given in these manuals relate to people who need support: the diagnostic criteria for ASD do not describe people who need only awareness and acceptance. A4 is not aware of a recognised criterion for "autism" that describes a condition whose needs are met fully through awareness and acceptance.

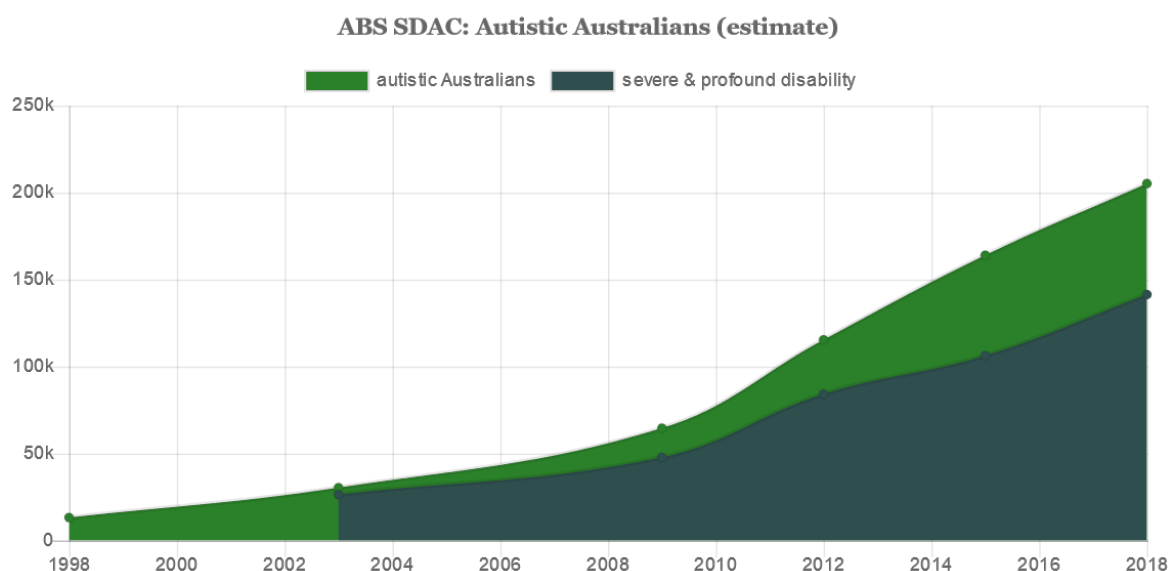


Figure 4. Proportion of autistic Australians with severe & profound disability.

Apparently, interpretation of diagnostic criteria for autism has shifted over time. In the past, a person generally needed intellectual disability and quite severe "autism", as well as probably being male, as prerequisites before they were considered for an "autism" diagnosis. These prerequisites never were part of autism diagnosis.

Some people believe that much of the increase is due to most new diagnoses being for mild, moderate or borderline ASD. Data from the ABS SDAC says their belief is wrong: as recently as 2018 over 2 in 3 (68.9%) autistic Australians had severe or profound core limitations. Apart from the period from 2012 to 2015, increased ASD diagnoses were mainly for people with severe or profound disability.

[Government officials sought evidence of overdiagnosis of autism but failed to find it:](#) they found that just over 2% of clinicians *might sometimes* over-diagnose autism. A4 believes that a substantially higher rate of under-diagnosis also exists especially for adults, women and girls and in some states/territories (see below), but government has little or no interest in tackling under-diagnosis of ASD.

Diagnostic practice has changed. Many more of the people who meet the criteria are now assessed then diagnosed with ASD. Increasingly, ASD is considered distinctly from intellectual disability, as it should always have been.

Australia's diagnosis rates are pretty much in line with diagnosis rates overseas. Whatever is happening in Australia seems to resemble what is happening with ASD diagnosis overseas.

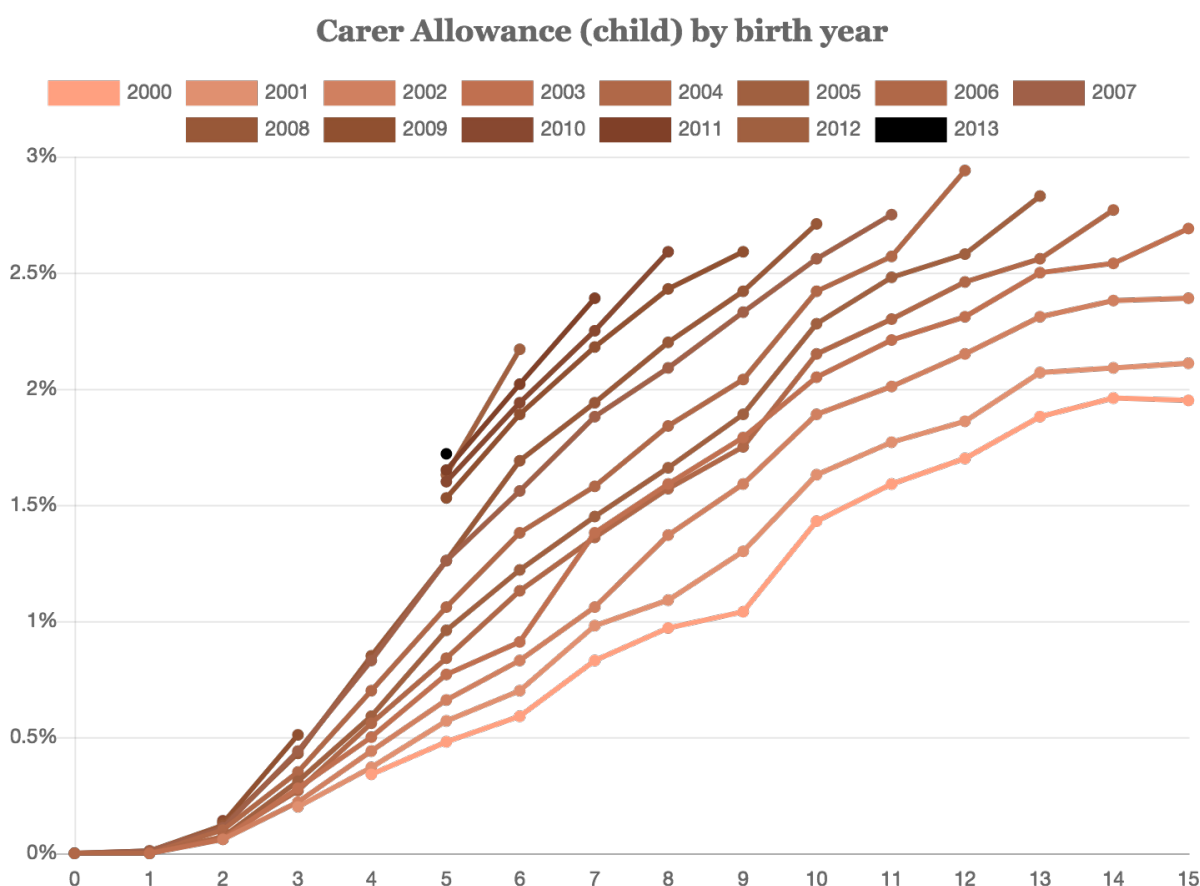


Figure 5. Age of diagnosis by year of birth

Autism diagnoses are often delayed. Figure 5 above shows that the median age of diagnosis for Australian children is about 7 years of age: at least 2.69% of children born in the 2002-3 financial year were diagnosed by age 15 years but just 1.38% were diagnosed by age 7 years – most autistic children are diagnosed too late to access ASD-specific early intervention funded by Australian governments.

Key barriers to timely ASD diagnoses include:

- Inadequate awareness of autism among early childhood, health and medical practitioners who miss early signs of autism in many children.
- Clinicians and health workers who advise families to “wait and see” hoping the child will “just grow out of it [their neurological disorder]”.
- Long delays, early age cut offs and unreliable performance from ASD diagnostic services in the public health system (see <http://a4.org.au/node/2169>).

- High cost of diagnosis (without insurance cover¹) in the private sector.

ASD diagnosis in Australia lacks consistency. For example, Figure 6 below shows substantial variation between states and territories in apparent ASD diagnosis rates for children. ASD diagnosis rates vary by up to a factor of 2: diagnosis rates in Victoria, South Australia and Queensland are double those in Western Australia, Northern Territory and the ACT.

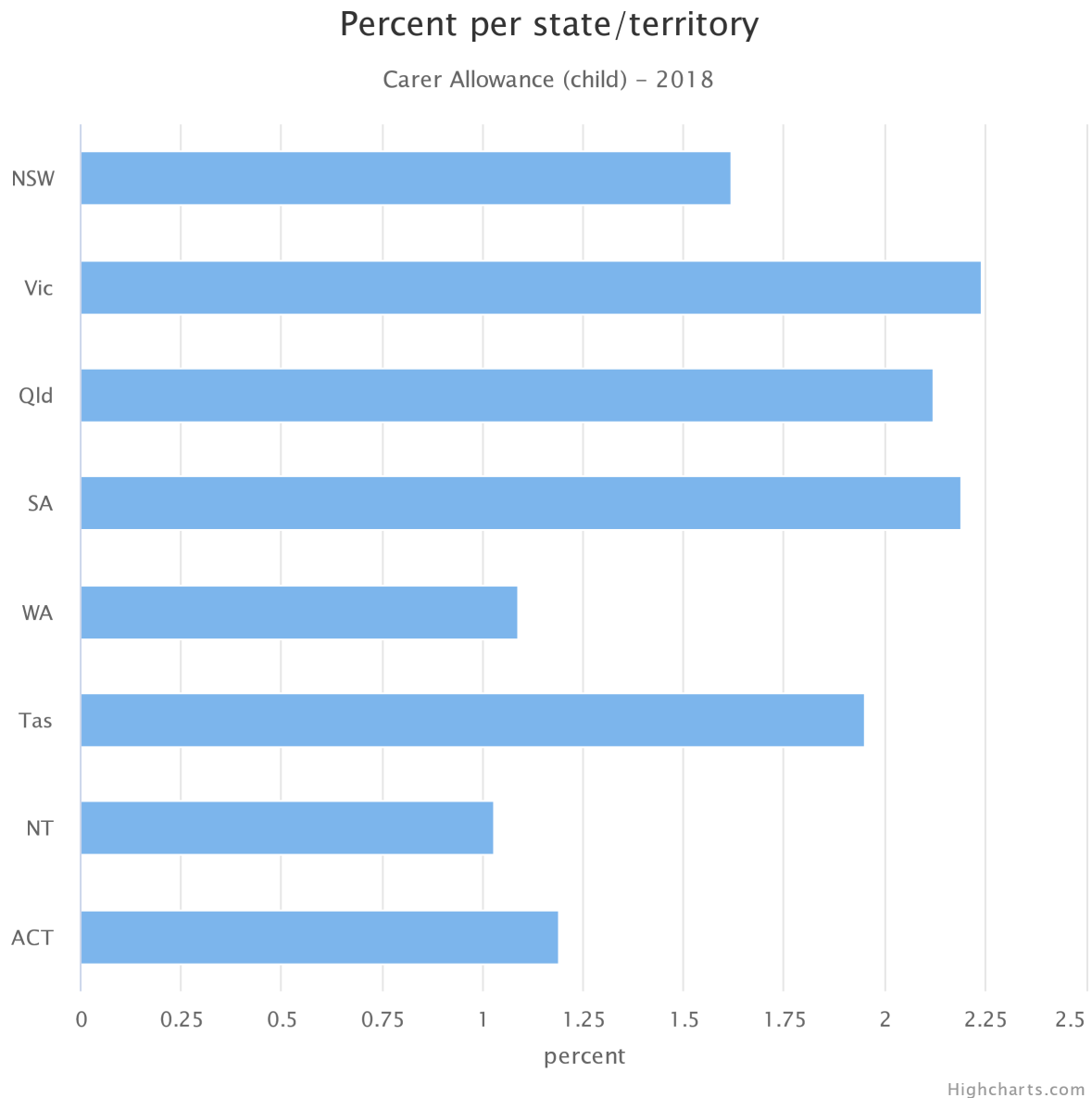


Figure 6. Carer Allowance (child) for ASD by state/territory in Australia

A4 would also like to bring the issues of “postcode discrimination” to the Committee’s attention: see <https://a4.org.au/node/2169>

¹ A4 understands that a) all states in the USA now require private health insurance to cover the cost of diagnosis and early intervention for ASD, and b), no private health insurance fund in Australia covers autism diagnosis or early intervention.

The primary supports for diagnosing Autism Spectrum Disorder (ASD) are [MBS Item 135](#) and [MBS Item 137](#). The Health Department devised these items in 2007 or 2008 without any community consultation. A further description, from 2016, is available [here](#) on the Victorian health website. A4 is not aware of any review or assessment of the operation of these items.

These items are for children under 13 years of age. The items are meant to fund diagnostic “assessment, diagnosis and the preparation of a treatment and management plan for a child aged under 13 years” for “at least 45 minutes”. Very few clinicians diagnose Autism Spectrum Disorder with a 45-60-minute assessment; usually, assessments take longer, and families pay for the extra time it takes.

Families report that these MBS Items do not cover much of the diagnostic assessment cost.

In recent times, Australia saw the completion of a much publicised PhD project proposing [a National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia](#). The project sought to describe consistent diagnostic standards for ASD. In A4’s view, it omits several essential elements.

- 1) Standardised format for diagnostic reports ... preferably providing a standardised diagnosis report template.
- 2) Objective measures of behavioural elements of ASD diagnosis.

The guidelines ask that diagnosing clinicians advise about or prescribe treatment. This is not appropriate. It is like asking pathologists to prescribe treatment.

The DSM-5 describes a diagnostic report that documents:

- Two severity ratings for parts A & B of the ASD diagnostic criteria
- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
- Associated with another neurodevelopmental, mental, or behavioral disorder
- With catatonia

A4 has never seen a diagnostic report that contains all these items.

One wonders whether the APA really knew what it meant when it asked for reporting of genetic conditions in the context of rapidly advancing genetic sciences. And it is remarkable vague about “environmental factors”.

Commentary on the DSM-5 suggests that children who do not meet diagnostic criteria for ASD may have Specific Learning Disorder or ADHD. A4 is not aware that much data about these diagnoses are available in Australia.

A4 is extremely disappointed when it still hears of clinicians who regard autism as a form of “attachment disorder” or associated with “refrigerator mothers”. A4 believes this hypothesis was thoroughly discredited decades ago. We are very concerned that this disparaging view of women persists in some clinical settings in Australia.

Diagnostic criteria and manuals, DSM-5 and ICD-11, do not describe “high functioning autism”; there are no criteria and no one is ever diagnosed with “low functioning autism”. Use of the term says more about the clinician than the person being diagnosed.

Too many paediatricians and GPs are barriers to ASD diagnosis when they advise families to “wait and see” rather than seek a proper assessment. Apparently, these health workers expect children to grow out of their autistic traits—which very rarely happens. Too many clinicians are uncomfortable “labelling” a young child with ASD; they prefer to label them with “developmental delay” or “global developmental delay” without appreciating that these are temporary or inconclusive diagnoses that are themselves barriers to good or best practice early intervention, services and supports for specific disability types.

Medicare funding for ASD diagnosis cuts off at age 13 years.

Autistic adults have difficulty getting their ASD diagnosed because there are few clinicians willing or able to diagnose ASD in adults, even for people who can afford it. Australian law does not protect autistic adults from this very clear example of age and disability discrimination.

The NDIS promotes poor and non-standard diagnostic practice for autism though its [eligibility gobbledygook](#). For example, NDIS intake officials often complain if they are given a properly documented ASD diagnosis with two severity ratings: they want just one severity rating. The sections on autism in NDIS [List A](#) and [List B](#) are confusing at best. These issues are discussed further in e. and f. below.

The NDIS’s eligibility criteria have been an issue for the ASD community for a long time. After the much-publicised [autism eligibility debacle](#), the NDIS CEO, Board Chair and senior officials promised A4 that the NDIS would draft new eligibility criteria. This has not happened. A4 understands that the issue was raised in [the NDIA’s Autism Advisory Group \(AAG\)](#) but the NDIA is blocking progress.

Rather than getting advocacy and advice from existing groups like A4 and its AAG, the NDIS is constantly starting up new consultations like [Participant First: Help shape the NDIS](#) that is can also ignore.

Since the NDIS rejects proper ASD diagnosis reports, it applies other ways to assess autistic applicants. One of its favourites is the PEDI-CAT. The NDIS has been told repeatedly that the PEDI-CAT is inappropriate for assessing autistic children, but they persist. Numerous clinicians assessing autistic children for the NDIS have been asked “does your PEDI-CAT result reflect the child in front of you?”. When they answer “No”, the NDIS still requires the clinician to enter the misleading PEDI-CAT result into the NDIS system without noting its incorrect result.

An ASD diagnosis often acts as a barrier other diagnoses. Too many clinicians cannot see beyond a person’s autism, attributing everything to autism and ignores other ailments. Too many autistic people have undiagnosed chronic health conditions. Autistic people experiencing trauma or mental illness are denied services and supports for other illnesses because they are excluded from services or their needs are not recognised.

The DSM-5 and ICD-11 regard ASD as a primary diagnosis. An autistic person with an intellectual disability is usually give a diagnosis of ASD with intellectual disability. But

the NDIS has 10,000 NDIS participants that they say have Intellectual Disability listed as their primary disability and autism/ASD as secondary. Apparently, many people including NDIS staff believe this disability listing gets a person a “better NDIS plan”. The NDIS is meant to be based on disability, not on a person’s diagnosis.

Academics and clinicians apparently agree that good practice in ASD diagnosis starts with an evaluation to answer the fundamental question: *Does the person being evaluated meet criteria for a clinician diagnosis of ASD?*

A4 feels that best practice in diagnosis goes beyond this. It should also ask: *Does an ASD diagnosis explain all the clinical issues? What other diagnoses, if any, are needed to explain the full presentation?*

Suggestions

- 1) ASD diagnosis for women and girls needs specific attention aimed at improving awareness of autistic women and reliability in diagnosing women of all ages.
- 2) ASD diagnosis in Australia need improvement through:
 - a. Properly training graduates in education, health, allied health, etc.
 - b. Retraining relevant parts of the workforce, especially health, mental health, education and early childhood.
- 3) Long waiting times, delays and unreliability of diagnostic services are tolerated because governments maintain their plausible deniability on these issues. Attending to diagnostic service especially for children. The performance of early childhood diagnostic services needs to be monitored and reported on officially. It should not be left to volunteers like A4 to scabble about finding data on ASD diagnoses and reporting on it.
- 4) Australia needs to improve its support for autistic adults, especially as yet undiagnosed adults. This must start with radical reeducation of the mental health sector.
- 5) Fix the NDIA’s eligibility and intake process to accept (preferably, to actually require) properly presented ASD diagnoses ... and the attitude of the whole organization to autistic participants.

b. the prevalence of autism in Australia

Problems relating to ASD prevalence in Australia are mostly that:

- 1) the physical nature of ASD, its etiology, is unknown so diagnosis is subjective and variable;
- 2) people confuse diagnosis rates with prevalence; and
- 3) the quality of ASD diagnosis data in Australia is limited.

Since the physical presence of ASD cannot be tested, the prevalence of ASD is also unknown. We do not have a definitive test for autism; instead, we ask “do clinicians regard various aspects of a person’s behaviour to warrant clinical attention?”

Subjective assessment means that different clinicians interpret the boundaries for their answer, yes or no, differently. We already saw in Figure 6 above that diagnosis rates vary between states even though we expect that the underlying prevalence is the same.

The rapid growth in the number of ASD diagnoses (see Figure 1. above) indicates that clinicians collectively have answered the ASD diagnosis question differently over time.

Clearly, previous figures show we can observe diagnosis rates and their change over time. Until we understand clearly the physical nature of ASD, we simply will not know its prevalence.

The main issue with using diagnosis rate as a prevalence estimate is that in most places there are autistic people who never get a diagnostic assessment. It seems that epidemiological studies mostly, possibly always, give higher prevalence rates than the previously known diagnosis rates because a) they find people who were not previously assessed, and b) over-diagnosis is very rare (or mis-counted in these studies).

Professor [Whitehouse claimed that autism/ASD prevalence is stable around 1.1% of the population](#). This would mean that Australia has massive over-diagnosis of children and severe underdiagnosis of adults. This view does not fit A4's understanding of the available data.

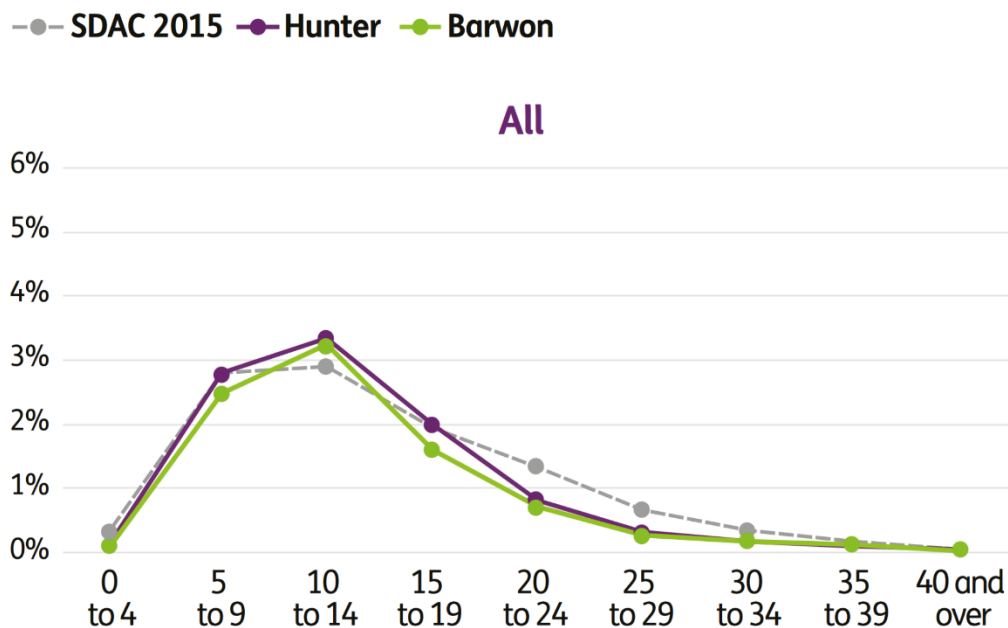


Figure 7. ASD diagnosis data from ABS SDAC and two mature NDIS regions

Australian data for ASD diagnoses is challenging to explain or justify.

Data from the ABS SDAC 2015 and a couple of NDIS regions in June 2018 show a similar pattern. Note that while the NDIS rejected A4's concern that NDIS 2018 data should be compared with 2018 SDAC data, not 2015 SDAC data as above; the NDIS said they did not expect SDAC 2018 data would be much different from 2015 data. All the ABS previous releases of SDAC data had shown substantial increases so the NDIS

expected an unusual result. A4 expected an increase. The ABS subsequently reported autism numbers rose by 25.1% from 2015 to 2018 (see Figure 2 above) – A4 feels that 25% increase over 3 years is quite a significant increase.

Also note that Figure 2 and Figure 7 above cut off at age 40 years so much of the adult section of these charts is not shown; the region of under-diagnosis is under-represented in these charts.

The main point here is that diagnosis rates varies enormously with age. This is a consistent pattern from two distinct data sources. These data are also consistent with data A4 obtained about Carer Allowance (child) over a much smaller age range.

We cannot discern how Australian diagnosis rate data relate to ASD prevalence.

We expect that the low level of diagnosis in 0 to 4 year-olds is because young children are not yet diagnosed. This pattern is quite evident in Figure 5 above.

The drop off with age past 25 years is a more challenging issue. It is not known whether the under-lying prevalence varies in the same way. We are not aware of profoundly reduced life-expectancy for autistic adults. Nor can we be sure that it is entirely due to chronic under-diagnosis; there is no clear evidence of massively increased ASD prevalence in recent years.

The data we have does indicate there was, and probably still is, chronic underdiagnosis of autistic adults in Australia.

So diagnosis rates may not be a good approximation for ASD prevalence.

ASD is often reported as having a 4:1 male:female ratio. This ratio has been dropping in Australia; it is approaching 3:1. We do not know what the ratio is in actual prevalence.

Suggestions

- 1) Australia should contribute more to the worldwide efforts to better understand autism etiology.
- 2) Do not use ASD diagnosis rates as a proxy for autism prevalence and ensure people understand the difference between diagnosis rates and prevalence.
- 3) Better diagnosis (see a. above and c. below) especial for women and adults help better understand autism prevalence.

c. misdiagnosis and under-representation of females in autism data, and gender bias in autism assessment and support services

Many women report being misdiagnosed or missing out on an ASD diagnosis.

Many researchers report 4:1 ratio for male to female diagnosis rates.

Many women report not being diagnosed until they understand their child's diagnosis. They report not being diagnosed as children. Many women report that their ASD was previously misdiagnosed as some other mental illness.

Figure 7 below shows that with improving awareness, ASD diagnosis rates for Australian women and girls are increasing.

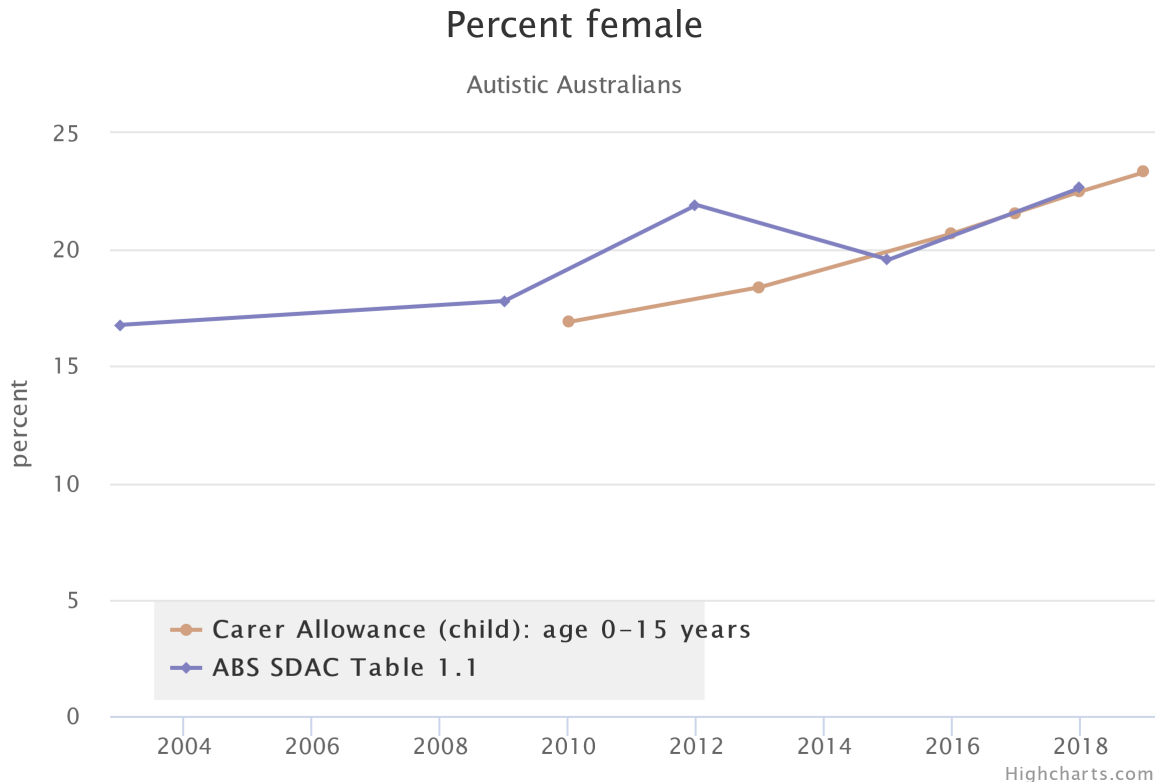


Figure 8. Changing diagnosis rates for Australian women and girls

Sex Education and Screenings.

A myth is that Autistic people do not seek relationships. Autistic people do not differ in the desire to be in a relationship to non-autistic people though may worry about their ability to develop and maintain good relationships.

Sex education is often limited and not designed for an Autistic communication style. Social isolation and negative peer experiences (bullying, mate crime and abuse) reduces opportunities for incidental learning through peer engagement.

For Autistic women and girls, who are under diagnosed or mis diagnosed, they are isolated from their Autistic peer group and are often in male dominated learning support units or schools. From research we know:

- 59% of Autistic women had unwanted sexual advances
- 35% of Autistic women experienced sexual behaviours with others that they either did not want or regretted doing so following the event
- 48% of Autistic people have never been tested for STI due to anxiety or simple lack of knowledge.
- American research shows that Autistic women have lower (-19%) rate of Autistic women having had a PAP smear in the last 3 years to non autistic women
- Autistic women have higher rates of Polycystic ovaries and lower diagnostic rates to non Autistic women

Autistic people having less social peer engagement, along with receiving less sex education, leaves individuals at a double disadvantage from non autistic peers. Autistic women, who may also be victims of sexual assault, may require adaptations for both their autism and trauma to enable reproductive health screening. Our community requires:

- 1) Sex education targeted at the communication style of autistic people
- 2) Facilitated peer group engagement to support sex education learning and information sharing
- 3) Education of parents on the reproductive rights and needs of their autistic daughters
- 4) PAP smear screening clinic days for Autistic people and those that are abuse survivors

Maternal Healthcare

Motherhood is an important transitional stage for women. For Autistic women, who are often undiagnosed and therefore unable to express the accommodations they require, or afraid to disclose their autism to professionals, it can be detrimental to their mental health and wellbeing. From research we know:

- Alarming, 60% of Autistic women experience postpartum depression and 40% antenatal depression that would be a health crisis if within the non autistic population.
- Concerning is recent research of higher rates of elective C-sections of Autistic women
- 34% said the process of birth not explained well to them
- 64% had difficulties breastfeeding their 1st child 51% has difficulties breastfeeding their 2nd child
- 61% of mothers said they need additional support from service providers but only 14% received the support they required when they asked for it
- 60% of mothers had anxiety speaking to professionals with 44% of Autistic women experiencing selective mutism due to anxiety of speaking with professionals
- 80% of mothers worried that the attitude of professionals would change towards them after disclosure of their autism.

Our community requires:

- 1) Development of post natal depression screening tools and intervention targeted at Autistic mothers
- 2) Lactation consultants to have training to support Autistic women
- 3) Autistic women urgently require antenatal interventions targeted to them and practitioners to be trained.
- 4) Autism specific parenting groups aimed at Autistic people opposed to mothers with an autistic child

d. international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity

Items a) and b) above discuss diagnostic practice and outcomes.

Regrettably, the notion of “international best practice” in support services and education is a problem. The term “support service” may mean services and supports outside education. Education is discussed in Item f. below.

The Australian Bureau of Statistic has [been reporting abysmal education outcomes](#) and employment for autistic Australians [since 2009](#). There is not really an agreed or advised “international best practice” for autistic students in education or subsequently for autistic people in employment.

Autism is often seen as a childhood disorder so there is more consensus of early childhood and education. Sometimes, early childhood and primary education are bundled together since early childhood transitions to primary education.

As [advised by the Australian Government](#), expert clinicians both in Australia and internationally advise that, based on evidence, autistic children need intensive individualised ASD-specific early intervention.

A4 acknowledges and respects that some autistic disagree.

A4’s view is that families need to make informed decisions about their child’s early intervention. The NDIS needs to ensure families have full access to impartial information and advice about interventions for autism. And the NDIS needs to respect the family’s decisions – the NDIS is legislated to provide choice and control, not misinformation and barriers.

Unfortunately, few autistic children in Australia are diagnosed in time to access good or best practice early intervention before the NDIS’s premature cut-off at school entry of age 7 years. Since the NDIS caused the demise of the national Autism Advisor Scheme that was part of the *Helping Children with Autism* package, few parents are informed about good practice for autistic children so they are unable to make an informed choice for their autistic child. And the NDIS often resists requests for evidence-based supports for young autistic children: families may have to take their service request to the Administrative Appeals Tribunal to get their child’s needs met.

Regrettably, Australia’s autism “experts” omit a key source and major reference, the National Research Council (2001) “*Educating children with autism*”, National Academy Press, Washington from their [various reviews](#) of “good practice” provided to the Australian Government. Maybe Australian experts do not regard early intervention as an essential prerequisite for, or just part of, education. The National Research Council committee (in the USA) clearly regards early intervention as key to effective education for autistic children.

Generally, the focus for autistic children is early intervention rather than education. This is problematic because fewer than 50% of autistic children are diagnosed under 7 years of age which is the Australian Governments arbitrary and ill-advised cut-off for early intervention for their autism.

In its 2012 review, ASfAR’s authors rated intervention methods for autistic children (the Government published [the result](#) on the DSS website). Only one approach was rated eligible for HCWA funding based in “established research evidence”. However, the NDIS and its representatives tell many NDIS participants that “the NDIS does not fund ABA”. The NDIA’s response is unacceptable: see <https://a4.org.au/node/1588>

The NDIS and many Australian academics and clinicians espouse eclectic, multi- or trans-disciplinary approaches that they regard as “good” or “best” practice. ASfAR’s authors did not rank this approach in the table -- either because this popular approach is ill-defined (too vague) or lacks real research evidence. Little progress towards clarifying the term or measuring its efficacy has been made since the 2011 report.

Another problem is that Australia does not register behavioural clinicians and an insufficient number are being trained locally. Currently, there are a small number (about 100) of internationally registered² behavioural clinicians practicing in Australia (see <https://bacb.com/services/o.php?page=101135> and choose “Australia” for “Country”).

The challenge in relation to “effectiveness” is that opinions vary substantially about goals. The lack of consistent research goals makes measuring effectiveness in achieving goals difficult or impossible to report.

The cost of autism is poorly understood. Suffice it to say that effective early intervention reduces support overall/life-long costs substantially. Currently, the cost of NDIS support for autistic NDIS participants is shown in Figure 9 below.

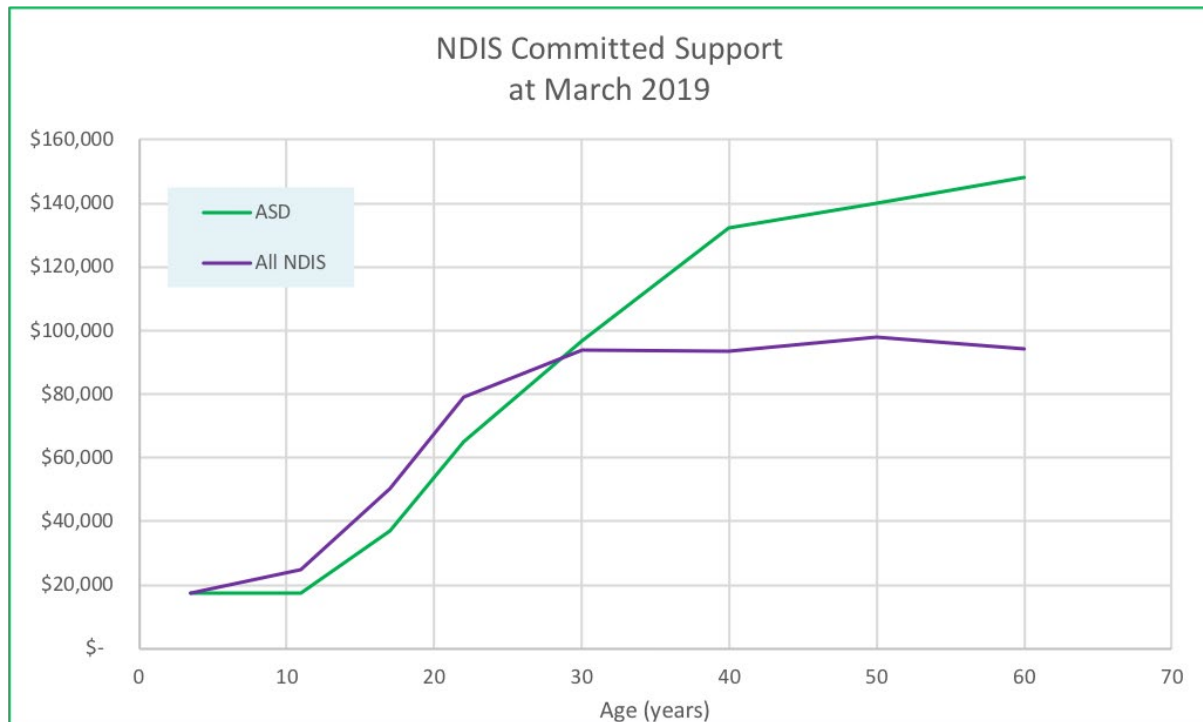


Figure 9. NDIS funding per participant.

The estimated lifetime NDIS support cost for an autistic person is \$6.7 million per NDIS participant to age 70 years. This does not include Disability Support Pension, Carer Allowance, etc. nor the financial impact on parents, siblings, etc.

[An Australian report](#) described costs and recommended earlier diagnosis and investment in strategies to improve life outcomes. [Research from WA](#) reported that having an autistic child had a financial impact of \$35,000 per year on the family.

² International registration is due to cease in the relatively near future. Australia needs to ensure it creates a register of professional behavioural clinicians as soon as possible.

Many research reviews have concluded that best outcomes for early intervention requires a minimum of 20-25 hours per week of targeted fun and learning for an autistic child. Less than this rarely achieves “best outcomes”, where “best outcomes” means substantial inclusion, often with adjustments but with fewer supports, in mainstream settings (education, employment, etc.). The ABS reports that currently, “two in five (40.8%) of the children attended a special class in a mainstream school or a special school”.

Suggestions

- 1) Reinstate the independent national Autism Advisor scheme
- 2) Ensure the NDIS respects expert advice in relation to ASD, and ensures its staff are trained for autistic participants.
- 3) Measure and reports the delivery of evidence-based practice.
- 4) Ensure Australia has a register of professional behavioural clinicians as soon as possible.

e. the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;

There seems to be very little measurement and reporting of service demand and satisfaction (adequacy) for autistic Australians at any level of government.

According to their diagnosis, autistic people need supports. The main sources of supports for autistic people are:

- Family and friends – called “informal supports” in the context of the NDIS
- Disability Support Pension (DSP)
- The NDIS now provides support for most autistic Australians.
- Employment supports

This inquiry does not seem to be about informal supports. Suffice it to say that governments have an over-reliance on informal supports for autistic citizens.

At this stage, A4 has not accessed data relating to autistic people who receive a DSP. A4 has a small number of volunteers who have limited capacity for this type of work.

A4 has focused on the NDIS during its roll-out. A4 is not aware that the NDIA attempted to be or become aware of demand for services from autistic. Quite the opposite, A4 observes that the NDIA regards autistic NDIS participants as making excessive demands thereby presenting a threat to NDIS long-term viability.

The NDIA largely dismissed [advice it obtained about early intervention for autistic children](#), preferring to base its ECEI Approach on advice that specifically stated it was not relevant for autistic children. It turns out that over 50% of NDIS participants in early childhood are autistic so its ECEI Approach was not designed for the majority of its participants.

The ABS reports that education outcomes for autistic children are abysmal, substantially worse than they should be.

The NDIS takes the view that school-age children get their disability support from the state/territory or private education systems. School-age children are meant to attend school for 30 hours per week which is less than 18% of their time (some autistic children are not allowed to attend school full-time, so they have less attendance). Apparently, the NDIS feels autistic children should be dormant or non-autistic the rest of the time. Issues with and concerns over education of autistic children are discussed in Item f below.

Services and supports for autistic people were never properly developed. Provision of services and supports at all levels of Government have not kept pace with the substantial growth in the number of people diagnosed with ASD. Most government agencies reject, ignore or refuse to recognise the growth in numbers and its associated growth in demand for ASD-specific disability services.

Figure 7 shows that a high proportion of autistic Australians are NDIS participants. The level of demand for services for autistic non-participants is not known to A4. What we do observe is that governments expect autistic people to rely on the scraps left over from generic disability services designed to meet the needs of people with other types of disability.

The ILC, previously a responsibility of the NDIS, has few supports for autistic citizens.

The NDIA insists that the number of autistic NDIS participants should be 20%, not the current 31%, of participants (see [the latest NDIS Quarterly Report](#)). Clearly, the NDIS does not have a handle of demand for services and supports from autistic Australians. Many (around 10,000) NDIS participants list Intellectual Disability as their primary disability and autism as a secondary disability so they get a better NDIS plan.

The NDIS regards autistic participants as a major problem.

- a. There is at least 50% more of them than the NDIS expected, and most of autistic NDIS applicants turn out to be eligible despite various strategies³ trying to exclude as many of them as possible.
- b. The number of autistic Australian keeps growing which means the number of autistic NDIS applicants keeps growing. Such growth was not planned for (they ignore advice from the ASD community on this issue).
- c. The NDIS, like much of the disability service sector, has inadequate understanding of autistic people and their support needs.

The lack of appropriate services and supports is particularly acute for autistic adults. Even getting a diagnosis is often a major challenge, hence the diagnosis rate for adults is at best 1/10th of that for children; we expect the real prevalence of autistic adults is similar to children so there is still massive underdiagnosis of autistic adults. Those adults who are diagnosed cannot get many of the services and supports that they need because these services do not yet exist. There are neither plans nor policies to create essential services that autistic adults need.

³ [NDIS eligibility List A](#) remains gobbledygook presumably to discourage as many applicants as possible; [NDIS List B](#), item 1 contains a confusing list of autism-related labels and omits ASD levels 1; the [NDIS tried to remove "autism Level 2"](#) from List A.

Note that [NDIS data](#) (Figure 10 below) shows participants spend under 80% of their NDIS plan allocation on average. This means that people with disability generally cannot access all the services that the NDIS deems “reasonable and necessary” for their disability.

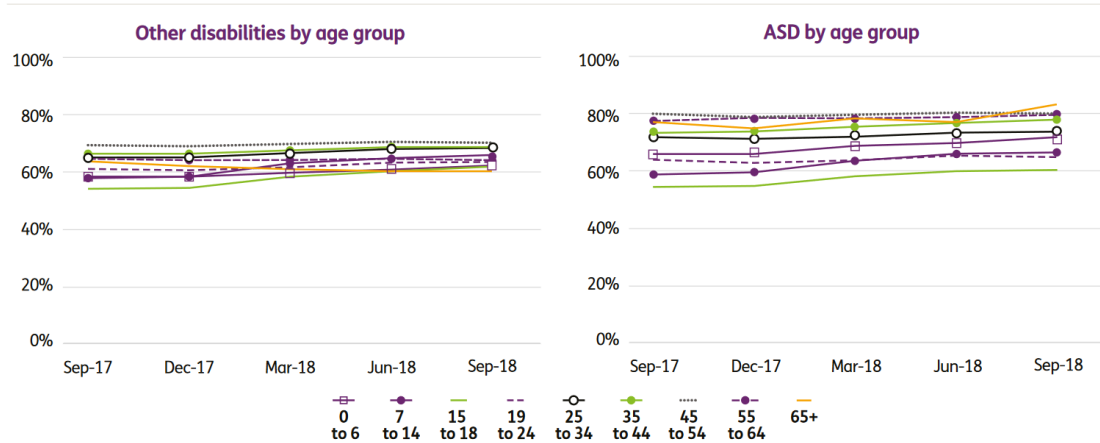


Figure 10. NDIS utilisation of plan funding.

Beyond the NDIS, at the Commonwealth level:

- The Department of Health professes ignorance of increasing ASD diagnoses – see <http://a4.org.au/node/359> – it does not seem to monitor or report the number of MBS Items 135 and 137.
- Employment outcomes for autistic Australians are abysmal, far worse than they should be.

State/territory governments now expect that the NDIS provides most disability services and supports, except for in primary and secondary education. They dropped most or all support for people with disability, especially their autistic citizens.

State Mental Health services largely ignore the needs of autistic citizens – see <https://a4.org.au/node/2114>, <https://a4.org.au/node/2192>, <https://a4.org.au/node/439> and <https://a4.org.au/node/420>.

There are many complaints and reports of failures in state/territory health systems over issues from the autism diagnostic services to how hospitals treat (or don't treat) autistic patients; for example, <https://a4.org.au/node/1949> and <https://a4.org.au/node/1410>.

Australian state and territory governments abandoned as much of their support for autistic people as they could when the NDIS started. Their education support has always been inadequate. Their health support for autistic citizens is sporadic and unreliable at best.

Governments encouraged charities and volunteer groups to be “more business-like”, to be commercially viable. It cut funding for specialist disability groups, focusing on generic disability groups who have never understood or represented autistic Australians. This resulted in the demise of state territory autism groups like *Autism Asperger ACT* or the transition of other to service providers.

Suggestions

As always, Government agencies operate in bureaucratic silos – they need to improve their policy and program development to address the needs of individuals with disabilities and those associated with them.

Government at all levels needs to recognise and respect the distinct needs of autistic individuals, and that autistic people have a spectrum of needs. There are no single solutions in the autism service space.

Governments need to engage with their autistic citizens to co-design supports – most governments and their agencies make massive efforts to avoid their autistic communities.

- f. the interaction between services provided by the Commonwealth, state and local governments, including:
 - i. health and mental health,
 - ii. education,
 - iii. employment,
 - iv. justice, and
 - v. housing;

Relatively few services are designed or even intended to meet the needs of autistic Australians. Government and its agents simply do not recognise the distinct needs of autistic Australians; the design and delivery of services and supports rarely meet autistic needs.

Notably, the federal Health Department, in 2011, used a tactic of *implausible deniability* with [its advice to Senate Estimates](#) that “the Department is not aware of any evidence of any major shifts in prevalence of autism in Australia”. Apparently, it prefers to remain ignorant and inactive in relation to autistic Australians.

A4 made numerous submissions about services and supports offered by the Commonwealth Government over the years.

A4 has written on all these subjects.

- i. A4 and other autism organisations have written extensively on the need to improve health and mental health services and supports for autistic Australians. The inadequacy of mental health services and supports for autistic citizens needs serious attention.
 - [Submission/comment to Productivity Commission Mental Health inquiry](#)
 - [A4 sent a report on Australia and the UN CRPD](#)
 - [Submission on autism/ASD and the NDIS in the ACT](#)
 - [Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition](#)

- [Senate Select Committee on Mental Health](#)
 - [Inquiry into mental health](#)
 - [DRC-CognitiveDisability-final.pdf](#)
 - SOfASD [Submission to ACT inquiry into youth mental health](#)
- ii. In February, A4 made a major submission on education to the Disability Royal Commission (see <https://a4.org.au/node/2173>). See also: [A4's submission to Senate Standing Committee on Education and Employment](#), [submission to Victorian Education Inquiry](#), [Inquiry into Teacher Education](#)
- iii. Employment: A4 already made submissions [to the Senate Standing Committee on Education and Employment](#) and [on National Disability Employment Framework](#)
- iv. Australia does not have a justice system. Australia has a legal & penal system. Australians do not have rights. This is especially true for autistic Australians: see A4's [report on Australia and the UN CRPD](#)
- v. Housing: many autistic Australians live their life with their parents until their parents die. A4 made a brief submission to the DRC on group housing, see <https://a4.org.au/sites/default/files/DRC-GroupHomesSubmission-final.pdf>

g. the social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people;

Not enough is known about existing costs and benefits associated with autistic people, let alone the cost of not meeting service needs.

Figure 9 above shows the NDIS costs on a per person basis. These might be combined with diagnosis rates to see some of the costs.

A4 does not have current DSP numbers – current data collection and management may not deliver especially accurate indications.

In terms of key life stages, poor education outcome result in poor employment rates. Apparently, employment rates are unacceptably low, but we do not have estimates of what that costs the country financially.

A4's impression is that parts of Government do not really want this issue answered because the answers will likely indicate that their policy and program development relating to autistic Australians is inadequate.

h. the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:

- i. autism understanding within the NDIS,

- ii. the utility of the Early Childhood Early Intervention Pathway for autistic children,
- iii. the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings, and
- iv. the adequacy and appropriateness of supports to empower autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services;

The NDIS has numerous problems with its approach to supporting autistic Australians.

- i. From the outset, NDIS officials refused to recognise that they underestimated the number of autistic Australians who need support. From the outset, NDIS officials expected just 20% of participants would be autistic. As recently as [1 June 2018, the NDIS CEO told the Senate Community Affairs Legislation Committee](#) that being around 50% over was “broadly in line” with estimated numbers. They were wrong. As full roll-out approached, over 30% of NDIS participants have autism as their primary disability. Senior NDIA officials do not understand the basic numbers let alone more subtle issues like the types of services and supports that autistic people need. The NDIS has not shown A4 any evidence that the NDIS tries to ensure its staff at any level have a sufficient understanding of ASD to perform their roles.
- ii. NDIA staff do not understand the nature of best practice early intervention for autistic people. They did not like [advice the government got prior to the NDIS](#) so commissioned another (a 3rd) review of early intervention for autistic children (see [here](#)) hoping to get a different conclusion. They did not like the answer so the document merely “informed the ECEI approach” rather than being regarded as one of the “key research pieces [that] form the basis of the ECEI approach”⁴. They keep trying to get the report they want rather than understanding what services and supports autistic people need: see [here](#) and [here](#). We understand that the NDIA has recently contracted [the Autism CRC](#) and [The Nous Group](#) to write [yet more reviews](#). The NDIA cannot be allowed to persist with this charade—they need to understand autism rather than keep searching for scraps of evidence to justify their anti-autism prejudice.
- iii. The NDIS often does not recognise autistic people as having complex needs; for example, the NDIS did not use its “complex needs pathway” for an autistic man with a plan costing over \$300,000 per annum and needing two support workers whenever he is not in the care of his parents (informal carers). A4 does not know how many cases there are like this.
Too often, prison systems in Australia simply do not recognise inmates as autistic. It is unlikely that transition of autistic prisoners from prison to the NDIS will be well managed.
- iv. National data indicates that 68.9% of autistic people have severe or profound disability involving disordered or dysfunctional communication. Most autistics are children or young people. Some also have intellectual and cognitive disability. They find NDIS planning a difficult process. The government does not fund advocacy for autistic individuals. Typically, generic disability advocates or advocates that specialise in other disability types are quite poor in their advocacy for autistic clients. Autistic people have very little experience of

⁴ See <https://www.ndis.gov.au/media/862/download>

appropriate supports and few good models to emulate so their self-advocacy is often limited by their lack of experience of appropriate services and service models.

As a result of their “different” communication, NDIS planners often fail to recognise and respect the goals and aspirations of autistic NDIS participants.

i. the development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy;

Parts of the autism community, especially the Australian Autism Alliance, are keen on having a National Autism Strategy. The National Disability Strategy is regarded as irrelevant to autistic Australians.

Proponents of a separate strategy for ASD seem unconcerned that [Victoria's Autism Plan](#) has yet to show actual outcomes.

Autism is largely ignored or misrepresented in generic disability strategies. For example, the [National Disability Strategy 2010-2020](#) says:

- Commonwealth, State and Territory governments are committed to improving early intervention and support for children with autism. The Commonwealth Helping Children with Autism initiative (\$190 million) includes:
 - establishing eight Autism Specific Early Learning Centres across Australia
 - funding for early intervention therapies
 - PlayConnect Playgroups (autism-specific playgroups)
 - Early Days family workshops
 - professional development for teachers, school leaders and other school staff
 - workshops and information sessions for parents and carers.

New Medicare items are also available for children aged under 13 years (for diagnosis and treatment planning) and under 15 years (for treatment).

This is wrong: there are six (6), not eight (8), Autism Specific Early Learning Centres. The autistic community cannot have any faith in a process where a simple single-digit number is out by 33%.

The *Helping Children with Autism* package was already at least 1.5 years into its 5-year term by the start of the NDS 2010-20. The “Early Days ...” and “workshops and information sessions for parents and carers” are the same thing, so that is double counting. The “professional development for teachers, ...” was largely over by the 2010 start of this strategy. The Medicare items are inadequate and have an unreasonable age cut-off. The PlayConnect service is not evidence-based.

ABS data for 2018 indicates that the generic National Disability Strategy 2010-20 did not deliver for autistic Australians; there is no reason to do more of the same. The autism community expects that a general disability strategy will again fail to recognise

the distinct nature of ASD. And it will be another ten years before there is any chance the distinct issues relating to autistic Australian will be addressed.

So far, there is no sign that a new NDS will recognise the distinct needs of autistic Australians.

A4 wants solutions. We do not care how they are achieved; we just want improved outcomes and goals to be achieved. The NDS 2010-20 did not work for autistic Australians. We need Government to do significantly better.

j. the adequacy of funding for research into autism;

In previous Items, we show that far too many key questions relating to ASD remain unanswered. Many of the questions need answers to inform policy and service development needed by autistic Australians.

There are major issues relating to poor understanding of autism aetiology and prevalence. These areas of research do not get the funding they need.

A high percentage of autistic Australians are NDIS participants so the NDIA could easily collect much better information about the service and support needs and outcomes of autistic Australians. Knowledge of service demand and outcomes is unsatisfactory.

The Government recently announced research funding of \$2.5m See <https://ministers.dss.gov.au/media-releases/5916>. This appears to be one-off funding. Relative to a \$22 billion annual NDIS budget, this is grossly inadequate.

Even the Autism CRC funding is inadequate relative to the cost-benefit achieved through funding an effective level of autism research.

A recent report <https://www.cadr.org.au/images/ch/1792/audit-update-2017-final.pdf> indicates that insufficient research is being done across the whole disability sector. Australia need a disability research scheme to compliment the NHMRC and ARC, and to support the NDIS, the DSP, etc.

Suggestions

Legislate a clearer role for the NDIS is disability research.

Create a national disability research scheme complimenting the NHMRC and ARC.

k. the social inclusion and participation of autistic people within the economy and community;

Social inclusion for autistic people is a complex issue. Autistic people often want social inclusion but they usually want it on their own terms: they may need to withdraw quickly and feel safe doing so. They may need tailored settings for their social inclusion. Their needs are rarely recognised and addressed.

Social inclusion for a person with communication difficulties and different behaviour is hard to sustain for all parties. And many Australians are less tolerant than is ideal.

Many autistic people function better in group activities rather than social inclusion. Scouts and guides are examples of structured activities that suit some autistic youth. Activities that suit autistic adults are often harder to find.

Some autistics prefer to socialise in their own autistic community/culture but this type of social/community participation is frowned on and rarely supported by government at any level. Autistics call people “neurotypical” when they cannot communicate and socialise with them.

Participation in the economy is about moving money. Employment is discussed elsewhere. The NDIS provides funds that allow autistic Australians to participate much more in our economy. In this respect, the NDIS can be considered relatively successful.

Social trauma is a barrier to autistic participation. A high proportion of autistic Australians are bullied at school. Mostly, the bullying reporting process further victimises and traumatises students; they are taught to distrust authority and their community. Their natural response is withdrawal. Some are left severely traumatised but their trauma is not recognised nor addressed.

For some, their trauma is exacerbated through their treatment by police.

There are very few services providing safe and effective environments for autistic people to increase participation.

Suggestions

The Government will measure and report on autistic participation if it is serious about improving social inclusion and participation for autistic Australians.

Action is needed to recognise and address trauma in Australia’s autistic citizens.

Recognise, respect and actively support autistic culture in the same way as (or better than) we support other sub-cultures.

1. the capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities;

Advocacy funding and supports for autistic Australians are inadequate; one might say absent.

The NDIS CEO’s Forum is a significant platform for disability advocacy. The NDIS does not include A4, a recognised Disability Representative Organisation, in its process.

The National Disability Advocacy Program (NDAP) does not fund any ASD-specific advocacy⁵. The NDAP funds generic advocacy and others specialist advocacy groups. Often, advocacy via the NDAP does not meet or address the needs of autistic clients.

In 2010, [the Government's review of disability advocacy](#) said:

There was support for the continued availability of specialist advocacy services, for example, those with specific expertise in multicultural or Indigenous issues, or a specific disability type, such as mental health or acquired brain injury.

Notice that the report fails to even mention the absence of advocacy funding for autism, which is the biggest distinct disability type in the NDIS. Despite “support” which is really “a need”, there has been no discernible effort from the Government towards advocacy for autism as a “specific disability type” in the decade since the report.

DSS collects data for the NDAP but ensures that clients of advocacy services are not recognised as autistic in the data collection systems. A4 understands data about autistic clients are used instead to inflate apparent need for and provision of advocacy support for other disability types. This means that data that DSS collects about disability advocacy is incorrect and misleading.

Advocacy for autistic people is complex. The autism community is polarised on several key issues. Non-autistic advocates often do not respect the views and experience of autistic people; they often have their own ideology and agendas that are contrary to the needs and preferences of autistic people, their families and associates. And some autistic advocates do not respect other autistics with views that vary from their own. Autistic people need compatible and effective advocates who respect their clients' expectations and preferences.

Currently, funded organisations and service providers refer autistic clients in (unsustainably) growing numbers to charities and volunteer organisations like A4 and the [Autism Advisory and Support Service](#) that provides an unfunded national 24-hour advocacy hotline. These organisations, and others like them, provide individual advocacy for autistic Australians from their unfunded capacity.

There is enormous scope to develop autistic self-advocacy and self-determination. In addition to increasing efforts to support individuals to make and express their own decisions, services and communities need to be much more receptive and responsive to autistic people when they communicate their needs and desires. Autistic people will improve their independence as they succeed in their attempts.

The issue of what autism actually *is*, in the eyes of the autism community, is a primary issue. Autism is defined in manuals of “disorder”, the DSM-5 and ICD-11. However, many articulate autistics say autism is not a “disorder”, instead they describe it as a “condition” or “difference”. Some use the term “neuro-divergent”.

The autism community is polarised over what is good practice for autistic people, especially in relation to early intervention for young children and behavioural intervention for all ages. There are some (especially vocal) autistics and parents who

⁵ see <https://www.aihw.gov.au/getmedia/a77135a0-927a-43ac-b5c0-445bf2e7f577/aihw-dis-75.pdf.aspx>

oppose all intervention. Many others, both autistics and the families of severely or profoundly affected autistics, strongly support evidence-based clinical practices.

Government refuses to fund systemic advocacy for autistic people and their associates; while there is a history of funding for other disability peak bodies, the collection of funded and recognised peak bodies for disability has never included an adequately-funded peak body for autistic Australians.

Issues relating to self-advocacy and self-determination can be complex. Some autistic people are very capable of self-advocacy and self-determination. Many autistic people are not good at self-advocacy for a range of (relatively obvious) reasons.

Most (68.9% in 2018) autistic Australians are severely or profoundly affected by their autism. They are not good communicators. They do not articulate clearly their long-term goals. They need support with strategy, communication, organisation, activation and with achieving their goals and aspirations.

Unfortunately, the Government's funded National Disability Advocacy Program (NDAP) does not fund anyone to deliver individual advocacy for autistic Australian. Funded advocates are generic or historically supported other disability types. NDAP services providers assume autism is not distinct, that supports designed for other disabilities will suit autistic people. There would be no point to diagnosing autism if the needs were met with other diagnostic labels; then clinicians would just diagnose the other disabilities instead.

Clearly, the National Disability Advocacy Program has failed to properly ensure advocacy support for the 31% of NDIS participants with autism as their primary disability. Autistic participants seeking advocacy support find that the advocacy services they can access are ideologically driven to promote *inclusion* rather than accessing behaviour support to prepare an autistic person for a transition to increasing social inclusion. The advocates simply do not recognise and understand – they have no experience with – the risks due to unsupported social submersion and how social skills might or might not emerge for an autistic person.

In too many instances, advocacy services are driven by their performance measures and case closure rates rather than the needs of their clients. They want to close cases, especially difficult cases which is where their autistic clients are usually categorised. Their advice to clients is about getting their clients to accept what the NDIS offers them rather than getting the needs of autistic clients met, or helping autistics exercise choice and control in their lives.

The review process for NDIS issues, via the AAT, is poorly designed. The legislation is about having the AAT review NDIS planning decisions; but the system works by first trying to get the NDIS to develop a new plan through the conciliation process. The NDIS draws this out for as long as it can knowing that most people with disability cannot survive extended periods on their existing inadequate plan, intimidation and predatory scrutiny from NDIS lawyers. The process tests the endurance of people with disability and their informal supports (that is, their families). It is a test of how long people with disability can last and whether they can push towards getting a hearing date from the AAT.

The NDIS and its lawyers do not act as a model litigant. And no one holds them to account in this regard.

The process is a test of attrition. People who can get their review to the steps of a hearing get most of what they want on the steps of a hearing ... so the NDIS avoids having a precedent set. Few people with disability can hold out to the end so there are few actual hearings. Very few NDIS plans are subject to actual external review.

Sometimes autistic people, especially less verbal autistics, express their needs and preferences through their behaviour. Their communication is different and usually described as dysfunctional. People do not recognise their communication until the autistic person ramps up their communication to a level where others cannot continue to ignore it. People call this style of communication “unwanted” or “challenging” behaviour. People rarely recognise and respect expression-through-behaviours as “self-advocacy” or “self-determination”.

Autistic people are excluded from considerations and reporting associated with the United Nations Convention on the Rights of Persons with Disabilities, see <http://a4.org.au/node/2124>

If the government decides to develop advocacy supports for autistic people, then it must be developed in collaborations with autistic people and their associates. It is likely that more than one service will be needed to ensure the full range of the spectrum of needs is properly addressed.

Autistic people are often omitted or excluded from advocacy ... for example, autistic communities cannot provide direct input into reports such <http://www.internationaldisabilityalliance.org/news-inclusive-education-2020>. While reports like this claim to represent all people with disability, they do not include or represent the voice of autistic people.

m. any bill that relates to matters within the scope of this inquiry that is referred to this committee

A4 is not aware of any legislation having been referred to this Committee.

Australia does not have any legislation relating to autistic people. Some other countries including the USA, UK and Ireland do.

There are some serious problems for autistic people in Australia’s legislation and legal systems. Australia does not have a justice system; its legal system does not ensure justice for autistic people.

Australia’s [*Disability Discrimination Act 1992*](#) protects government institutions and others from complaints about most disability discrimination against autistic people. This is the opposite of what people and international law expects such legislation should

do. The precedent set in *Purvis vs NSW*⁶ is wide ranging, as was demonstrated in *Walker vs Vic*.

It is simply inconceivable that an historically prejudiced and relatively litigious country like Australia has no instances of successful prosecution for disability discrimination targeting autistic people in its legal record, unless legal systems in Australia protect perpetrators of disability discrimination against complaints from autistic Australians.

The Disability Royal Commission is revealing significant issues around the education of autistic students. These students have no protection. There is no watchdog or safety net.

The HREOC has not addressed concerns raised with it about disability discrimination against autistic Australians.

The new NDIS Quality and Safeguards Commission does not investigate adequately complaints about the treatment of autistic NDIS participants and has an unacceptably limited jurisdiction.

n. any other related matters.

Some of us in the ASD community have difficulty getting good information from the NDIA. The NDIA is a very secretive agency.

The NDIA maintains eligibility criteria for autistic NDIS participants that are confusing (at best). They should promote properly formulated diagnostic reports according to either the DSM-5 or the ICD-11.

The process for reviewing NDIS plans can be substantially improved.

3. Discussion and Conclusion

The number of autistic Australians has increased substantially in recent decade. Autism diagnoses went from rare to more frequent than intellectual disability.

The number of autistic women & girls and adults is unclear.

Many autistic people are benefiting from the NDIS but the NDIS still needs major improvement. The ILC need to recognise autistic NDIS non-participants and to meet their needs.

Outcomes for autistic Australians in education, employment and health, especially mental health, need substantial improvement.

Autism Aspergers Advocacy Australia (A4) is optimistic for the future of autistic Australians. We hope this Committee can promote many of the improved outcomes that autistic Australians need.

⁶ See also <http://classic.austlii.edu.au/au/journals/FedLawRw/2007/4.html>