



# The Autistic Realm Australia Inc. (T.A.R.A)

## NDIS Independent Assessments Submission

APRIL 2021

Authors: Anna Colbasso, Kylieanne Derwent, Yolande McNicholl

*Diversity is Autistic Reality.*

# Contents



Executive Summary .....	3
<b>Introduction .....</b>	<b>4</b>
The Autistic Realm Australia Inc. ....	5
Terminology and Capitalisation .....	6
Recommendation.....	6
<b>Autism .....</b>	<b>7</b>
1. The Nature of Autism.....	8
a) Understanding Autism and the Autism Spectrum.....	8
b) The medical model of disability.....	8
c) The social model of disability .....	9
2. Autistic people's experience of Autism.....	13
a) Pathological Demand Avoidance (PDA) .....	14
b) Prevalence of Psychosocial Disability in the Autistic Community .....	15
c) High Incidence of co-morbidity .....	16
<b>Independent Assessments .....</b>	<b>18</b>
Conclusion.....	20
References.....	20



---

## Executive Summary

---

We, The Autistic Realm Australia (TARA), on behalf of our members make the following submission, with reference to Term of Reference (k):

- The appropriateness of Independent Assessments for people with particular disability types, including psychosocial disability

As an Autistic-led organisation, our position is that the proposed Independent Assessments are discriminatory, and inaccessible to Autistic people.

The proposal lacks an accurate or up-to-date understanding of Autism and the reality of Autistic lives. It makes no accommodation for the high prevalence of psychosocial disability among Autistic people, nor for the impact of this burden of disease. Further, the Independent Assessment will not accurately or fairly capture the multiple comorbidities frequent among Autistic children and adults.

It is inaccessible to us because its design is incompatible with our disability. As a result, Independent Assessments will deny us access to the support we need, and likely, to the NDIS scheme as a whole.

The proposal to introduce Independent Assessment is characterised by manifest inadequacies of the NDIS process, assessment instruments, Independence Assessment staff experience, qualifications or training, and an absence of insight into the Autistic community or an Autism-positive attitude. It is beyond the capacity of the staff it will employ to capture the complexity of disability as it affects Autistic people, let alone to meet our needs.

The Autistic Realm Australia offers a single recommendation in response to Term of Reference (k), ***regarding the appropriateness of Independent Assessments for people with particular disability types, including psychosocial disability:***

### ► Recommendation:

That Autistic clients of the NDIS be excluded from the requirement to complete Independent Assessments at any stage of any process the NDIS directs, e.g., eligibility, access to services, interactions with NDIS employees and subcontractors, coordinators, etc, etc.

This recommendation is made on the ground of the fundamental misunderstanding that the NDIS displays of the nature of Autism and how Autistic lives are experienced. Autism is not a behavioural disorder that can be cured, go into remission, or that reduces over the lifespan.

This submission is arranged in the following sections:

# Introduction

1. The Autistic Realm Australia Inc (TARA)
2. Terminology and capitalisation
3. Recommendation

## ► Autism

### 1. The Nature of Autism

- a) Understanding Autism and the Autism Spectrum
- b) The medical model
- c) The social model
- d) Common misunderstandings

### 2. Autistic people's experience of Autism

- a) Pathological Demand Avoidance (PDA)
- b) Autism and Psychosocial disability
- c) Autism and other comorbid conditions

## ► Independent Assessments - Introduction

The submission argues that Independent Assessments as currently described are NOT appropriate to meet the needs of Autistic people.

► **Independent Assessments are not appropriate for use with Autistic people for three key reasons:**

- An accurate understanding of the nature of Autism is not demonstrated
- The high prevalence of psychosocial disability among Autistic people is not accommodated.
- The multiple comorbidities frequent among Autistic children and adults will not be captured accurately or fairly

For these reasons, the proposed Independent Assessment is discriminatory against Autistic people. It is inaccessible to us because its design is incompatible with our disability. As a result, Independent Assessments will deny us access to the support we need and likely, to the NDIS scheme as a whole.

---

## **The Autistic Realm Australia Inc.**

---

The Autistic Realm Australia Inc (TARA) is a not-for-profit incorporated association providing support, education and advocacy for Autistic people and the parents and carers of Autistic people. Our online communities are very active and have approximately seven thousand members. As a completely Autistic organisation, we put Autistic people at the centre of our work. We honour diversity as Autistic reality, acknowledging and supporting all our members, whatever their history, expression of identity or support needs.

TARA is founded on the core position that Autism is a form of neurodiversity, a natural part of the diversity of human neurology.<sup>1</sup> As such we repudiate all therapies aimed at compliance and the suppression of Autistic behaviours, reject stigmatising and victimising language of any sort, and strongly reject attempts to “cure” Autism or make Autistic people indistinguishable from our peers.

TARA works within the social model of disability,<sup>2</sup> which recognises the impact that structural and environmental conditions have on a person's ability to function and live a meaningful life. As such we challenge preconceived ideas about the capacity of Autistic people and reject simplistic labels that seek to categorise our abilities and challenges. We practice the principle that all behaviour is communication, and challenge the primacy given to verbal speech as an indicator of a person's intellectual capacity or ability to live a meaningful life.

---

<sup>1</sup> Autism Spectrum Disorders 7.1: 49–55.

Dekker, M. (1999). 'On our own terms: Emerging autistic culture', Autism 99.

[https://timelinely-space-001.myc3.digitaloceanspaces.com/files/5/5\\_USUGEY6NNLCQN9QXB1K3C30N6LR2TWVB.pdf](https://timelinely-space-001.myc3.digitaloceanspaces.com/files/5/5_USUGEY6NNLCQN9QXB1K3C30N6LR2TWVB.pdf)

<sup>2</sup> Oliver, M. (2018). 'Disabled students campaign - social model of disability with Mike Oliver', National Union of Students UK, University of Greenwich, <https://www.youtube.com/watch?v=gDO6U0-uo0M>



---

## Terminology and Capitalisation

---

Like many other members of the Autistic community, Tara's members strongly prefer identity-first language when referring to ourselves. This means we are "Autistic people", rather than "people with autism". This is a consistent and growing preference, and is also building momentum among family and carers, although not as rapidly among professionals.<sup>3</sup> <sup>4</sup>The primary reason for this shift in terminology across the Autistic community is that it expresses our acceptance of our Autism as being an integral part of our lives and a filter through which we process the world, rather than it being something separate from us as people.

We also choose to capitalise Autism because we consider "Autistic" to be a cultural identity, rather than an individual difference. The Autistic community is a subculture: we have our own expectations, understandings, humour, and ways of communicating. There is also an element of very Autistic humour in our reclaiming as a name for our community and cultural identity, a word that was originally intended to define Autistic people (from an external (non-Autistic) perspective) as being 'self-centred' and 'isolated from others'.

---

## Recommendation

---

***That Autistic clients of the NDIS be excluded from the requirement to complete Independent Assessments at any stage of any process the NDIS directs, e.g., eligibility, access to services, interactions with NDIS employees and subcontractors, coordinators, etc, etc.***

This recommendation is made on the grounds of the fundamental misunderstanding that the NDIS displays of the nature of Autism and how Autistic lives are experienced. Autism is not a behavioural disorder that can be cured, go into remission, or that reduces over the lifespan.

The remainder of this report provides further context and explanation for this recommendation.

---

<sup>3</sup> Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., and Pellicano, E. (2016). 'Which terms should be used to describe autism? Perspectives from the UK autism community', *Autism* 20.4: 442–462.

<sup>4</sup> Bonello, C. (2018). '11,521 people answered this autism survey. Warning: the results may challenge you', <https://autisticnotweird.com/2018survey/> 1 October 2018 Autistic not weird.

# Autism<sup>5</sup>

The NDIS displays a fundamental misunderstanding of the nature of Autism and how Autistic lives are experienced. Autism is not a behavioural disorder that can be cured, go into remission, or that reduces over the lifespan. This section addresses these misapprehensions to illustrate the fundamental mismatch between the assumptions and design of the Independent Assessment regime and the reality of Autism and Autistic needs that make Independent Assessments inappropriate for Autistic people. Discussion of the different models for understanding disability is also necessary for context, as independent assessments are based on the medical, not social model.<sup>6</sup>

The section covers:

## ► The Nature of Autism

- a) Understanding Autism and the Autism Spectrum
- b) The medical model
- c) The social model
- d) Common misunderstandings

## ► Autistic people's experience of Autism

- a) Pathological Demand Avoidance (PDA)
- b) Autism and Psychosocial disability
- c) Autism and other co-morbid conditions

---

<sup>5</sup> American Psychiatric Association (1980). *Diagnostic and statistical manual of mental disorders* 3rd edition.

— (2013). *Diagnostic and statistical manual of mental disorders* 5th edition.

<sup>6</sup> Deborah Marks (1997) Models of disability, *Disability and Rehabilitation*, 19:3, 85-91, DOI: 10.3109/09638289709166831

---

# 1. The Nature of Autism

---

## a) Understanding Autism and the Autism Spectrum

Autism Spectrum Disorder is defined as a developmental – not a behavioural - disability. As such, it is one of many “mental disorders” included in the current edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, published 2013). Until 1987, “gross deficits in language development” was a core component for diagnosing Autism (DSM-III-R).<sup>7</sup> It was widely believed at this time that intellectual disability was far more commonly present in Autistic people than it was absent. More recent broadening of the concept of “Autism”, along with better case identification, have reduced these estimates to around 25% of Autistic people having limited or no speech beyond the age of 6, and between 30-40% of Autistics having an intellectual disability.<sup>8</sup>

## b) The medical model of disability

Although it is historically and currently classified (by its inclusion in the DSM) as a “mental disorder”, Autism is not a disease. It is a neurological and developmental condition. This means that a person is born Autistic and will die Autistic.

The equation of Autism with mental illness means that Autism and Autistic people are most often positioned within the medical model of disability, which presents disability as an attribute of an individual, and frames the disabled individual as deficient or impaired as compared to an individual without disability. This model, which often stigmatises disabled people, focuses interventions on removing these impairments or deficits from the disabled individual or otherwise rendering them undetectable.

The medical model also leads to a fundamental misunderstanding of the nature of Autism, and what it is to be Autistic. The medical model presumes that treatment will alter the progression of a condition, and cause either a cure or remission.

Autistic people need life-long support. The need tends to be greatest at life transition points: - starting primary school, starting secondary school, puberty, leaving school, getting a job, and so on, through retirement and moving into frail old age. Each stage requires specific support. In an Autistic person, the skills needed are not scaffolded to the next level. They need to begin anew at each stage by learning the skills required in the new context. For example, early intervention pre-primary school does not lead to an Autistic child having no need for further invention at other stages of life.

---

<sup>7</sup> Norrelgen, F., Fernell, E., Eriksson, M., Hedvall, A., Persson, C., Sjölin, M., Gillberg, C., and Kjellmer, L. (2015). 'Children with autism spectrum disorders who do not develop phrase speech in the preschool years', *Autism* 19(8): 934–943.

<sup>8</sup> Australian Institute of Health and Welfare 2017, Autism in Australia. Cat. no. WEB 187. Canberra: AIHW. Viewed 21 August 2020, <https://www.aihw.gov.au/reports/disability/autism-in-australia>



## c) The social model of disability

In contrast to the medical model, the social model of disability facilitates a far more accurate understanding of Autism and Autistic people. It recognises natural diversity in people's physical, intellectual, and neurological capacities and abilities. Rather than being a deficit located within the person, the social model understands disability as the barriers that prevent engagement and participation and seeks to develop environments which facilitate the individual's ability. As Mike Oliver, who originated the social model concept explains: "The problem isn't that I can't get into a lecture theatre, the problem is that the lecture theatre isn't accessible to me".<sup>9</sup>

### ► Environmental barriers for Autistic people may include:

- barriers of attitude, leading to discrimination or bullying,
- barriers of communication, which may involve refusing to communicate in a medium that is accessible for the disabled person (e.g., requiring telephone communication for people with auditory processing delays), or providing necessary information in a format that is inaccessible to those with disabilities affecting hearing, vision, or cognition,
- systematic barriers, such as organisation's which deny individuals the reasonable adjustments, they require to be able to participate in work or community roles – including the Independent Assessment model as described by the NDIS to date.
- Reasonable adjustment is implicit in the requirement to avoid indirect discrimination under the Disability Discrimination Act 1992, section 6. Indirect discrimination occurs where a person with disability is required to comply with a condition or requirement which they cannot comply with and which a greater proportion of people without the disability are able to comply with.<sup>10 11</sup>

Many Autistic people identify as disabled. However, we are not disabled by anything being inherently wrong with us, but because we live in a society that does not understand or accommodate our differences in processing and perception.

This disabling social environment means that we are more impacted by our differences and less able to function effectively in our lives. It also means that we are far more vulnerable to other disabilities and chronic illness,<sup>12</sup> particularly mental illness, and more likely to die earlier of preventable causes than the general population. These outcomes are in part associated with aspects of disability such as poverty caused by un- and under-employment,<sup>13</sup> and more broadly due to the trauma we experience from being Autistic in a society that does not value or support us. Additionally, our marginalised social position makes us vulnerable to exploitation and abuse, which only compounds our trauma. As just one example, Autistic women experience higher rates of sexual harassment, sexual assault, and intimate partner assault than non-Autistic women<sup>14</sup> and are ten times more likely than the general population to die by suicide.<sup>15</sup>

9 Oliver, M. (2018). 'Disabled students campaign - social model of disability with Mike Oliver', National Union of Students UK, University of Greenwich, <https://www.youtube.com/watch?v=pDO6U0-ua0M>

10 Reasonable adjustment| Australian Human Rights Commission. (n.d.). Retrieved from humanrights.gov.au website: <https://humanrights.gov.au/about/news/speeches/reasonable-adjustment>

11 Australian Government. (2012). Disability Discrimination Act 1992. Retrieved from Legislation.gov.au website: <https://www.legislation.gov.au/Details/C2018C00125>

12 Cashin, A., Buckley, T., Trollor, J.N., and Lennox, N. (2018). 'A scoping review of what is known of the physical health of adults with autism spectrum disorder', *Journal of Intellectual Disabilities* 22.1: 96–108.

13 Scott, M., Milbourn, B., Falkner, M., Black, M., Bólte, S., Halladay, A., Lerner, M., Taylor, J.L., and Girdler, S. (2019). 'Factors impacting employment for people with autism spectrum disorder: A scoping review', *Autism* 23.4: 869–901.

14 Brown-Lavoie SM, Viecili MA, Weiss JA. Sexual knowledge and victimization in adults with autism spectrum disorders. *J Autism Dev Disord*. 2014 Sep;44(9):2185-96. doi: 10.1007/s10803-014-2093-y. PMID: 24664634; PMCID: PMC4131130.

15 Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S., and Trollor, J.N. (2019). 'Mortality and cause of death of Australians on the autism spectrum', *Autism research* 12.5: 806–815.

## ► Common misunderstandings

Despite growing understanding of Autism as an example of neurological difference (rather than as deficits in behaviour, social interactions, or communication), both health professionals and the general public often still understand Autism exclusively as a set of perceived deficits and conflate it erroneously with both intellectual disability and lack of speech. This popular belief limits understanding and stigmatises Autistic people.

*"I love being autistic. I love that I now know what makes me tick and what I need to thrive. But I don't like sharing my diagnosis with most people because they lack the understanding and look at me and my family through the lens of stigma and deficit"*  
- KL, 42 Kenny et al. 2016<sup>16</sup>

## ► The DSM-5 currently lists three 'levels' of Autism, reflecting different levels of support needs: -

- Level 1 indicates *some support* required,
- Level 2 indicates *substantial support required*, while
- Level 3 indicates *very substantial support required*.

It is important to note that the three levels indicate that all Autistic people require support, no matter what level they may be diagnosed at.<sup>17</sup>

---

<sup>16</sup> Quotes provided in this submission are sourced from a survey of our members conducted in 2019, about their attitudes towards being Autistic and their lived experience – including their experience of the NDIS.

<sup>17</sup> American Psychiatric Association (1980). *Diagnostic and statistical manual of mental disorders* 3rd edition.

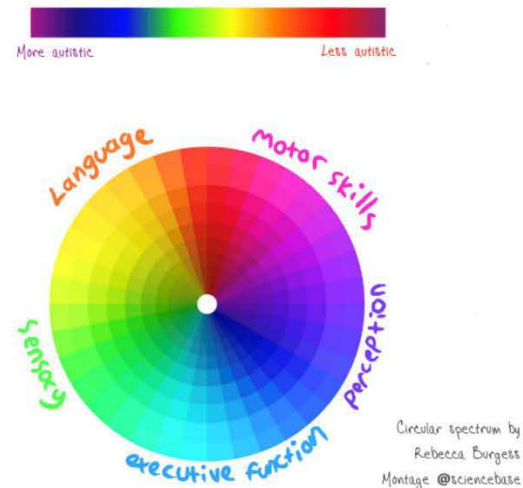
— (2013). *Diagnostic and statistical manual of mental disorders* 5th edition.



The levels are not intended to reflect part of the diagnosis, but to indicate the support needs of the individual at the time of assessment. However, these levels are frequently used as part of the description of the person's 'Autism severity'.

This impetus to rank or grade Autistic people is also reflected in common phrases like 'high functioning' or 'mild' Autism, as contrasted with 'low-functioning' or 'severe' Autism. These terms may be misleadingly used as a euphemism for Autism without intellectual disability versus Autism with intellectual disability, just as the obsolete term "Asperger's Syndrome" is sometimes used to claim status for Autistics who do not have an intellectual disability over those who do. TARA rejects the implication that some Autistics are more valuable as human beings than others. These usages misrepresent and dehumanise Autistic people, with deeply detrimental consequences.

Misuse of labels and misapprehensions based on the terminology used to describe Autism invalidate the experience of Autistic people and minimise our needs. When someone is labelled as 'high-functioning', 'level 1' or 'mildly' Autistic (or as having 'Asperger's Syndrome'), the very real struggles that Autistic people experience at different milestones in life or at times of increased stress or burnout are often dismissed, and they may be blamed for "not coping" or "not trying hard enough". Conversely, when someone is labelled as 'low functioning', 'level 3' or 'severely' Autistic, the assessment made at the time that the label was applied to them may not reflect their capacity for development over their lifespan. As a result, these Autistics are frequently denied opportunities to learn, to develop independence to learn, develop independence, advance, and achieve.



Another example of terminological confusion that serves Autistic people very poorly is the widespread misuse of the term "Autism spectrum". The misleading phrase, 'on the spectrum' leads to the perception that the spectrum is a linear scale from A Little Bit Autistic at one end to Extremely Autistic at the other, or even a line on which the entire human population has a position. Neither of these assumptions is correct. The term "spectrum" arises from the fact that Autism is a spectrum condition.

Rather than a two-dimensional line, the Autism spectrum is better illustrated<sup>18</sup> as a variety of traits. These traits include language facility, sensory sensitivity, executive function capacity, perceptual experience, motor skills, and more. There is no typical pattern to the skill levels exhibited. The common feature is a 'spiky' profile, characterised by unusually wide variation between our ability in one skill versus another.

<sup>18</sup> In The Loop About Neurodiversity - <https://intheaboutneurodiversity.wordpress.com/2019/03/06/the-autism-spectrum-is-not-binary/>



Each Autistic person will have a different presentation in each area of skill, e.g., one Autistic may have a lot of sensory sensitivities and require ear defenders every day to deal with sound, but also be a great conversationalist. Another may be highly successful in a professional role that requires analytical thinking and attention to detail, but struggle to drive a car or do day-to-day tasks in a timely way.

It is important to note that these profiles, like the various categories (mis)used to rank Autistic people (discussed above) represent a snapshot of the Autistic person at one point in time. A key overlooked feature of Autism is that our functional abilities vary under different levels of stress or sensory input and fluctuate significantly from day to day and across our lifetime.

► **In summary, an accurate understanding of Autism recognises that:**

All Autistic people have the potential to live meaningful lives, regardless of speech or intellectual ability.

- All Autistic people require some level of support to thrive in a non-Autistic world.
- Ranking Autistic people prevents us reaching our potential to live meaningful lives, through denial of support and/or opportunity.
- Only Autistic people are 'on the spectrum.'
- The spectrum visually describes the skill profile of one Autistic individual.
- No two Autistics have the same skill profile.
- Autistic people's skill profiles combine unusually high with unusually low skills.
- An Autistic person's skill profile is not static.<sup>19</sup>

As we have seen in this section, the nature of Autism makes Independent Assessment inappropriate for a range of significant reasons:

► **Autism is a lifelong condition that cannot be cured or mitigated by medication.**

- Behavioural interventions (i.e., ABA) do not remit or resolve Autistic needs for support. They only aim to make the Autistic individual indistinguishable from their peers.
- Autistic people ALL require some level of support as per the diagnostic criteria of the DSM- 5.

---

<sup>19</sup> American Psychiatric Association (1980). *Diagnostic and statistical manual of mental disorders* 3rd edition. — (2013). *Diagnostic and statistical manual of mental disorders* 5th edition.

- ▶ **Autism is a spectrum disorder: i.e., no two Autistic people are the same, therefore:**
  - a crude question and answer format cannot capture support needs adequately or lead to consistent decision-making. Any such guide must not be applied to Autistic people.
  - because one Autistic person can function better or worse from day to day and week to week, fair assessment is the province of highly skilled specialists.
  
- ▶ **Autism professionals struggle to understand and meet the needs of their Autistic clients, even if they have known them for a long time. This includes those with up to thirteen years of education required, as per psychiatric practice or six years for clinical psychology.**
  - The NDIS has stated that Independent assessors may be graduates of allied professions. The studies completed by these practitioners only include a few days discussion of Autism.
  - It is IMPOSSIBLE for Independent Assessors to have the necessary high-level knowledge and training AND insight into Autistic needs. These practitioners are not appropriate judges of the needs of Autistic people.

---

## 2. Autistic people's experience of Autism

---

In this section we present information about Pathological Demand avoidance, as a sub-type of Autism particularly ill-suited to the proposed Independent Assessment model, as well as providing insights into the complexity of Autistic experience and presentation. This complexity makes accommodating the needs and working positively with Autistic people a task requiring high levels of skill and adaptability. Key issues are the frequent presence of psychosocial and other comorbid conditions which arise from the stress and trauma of being Autistic in non-Autistic world. The section is structured as follows:

- a. Pathological Demand Avoidance (PDA)
- b. Autism and Psychosocial disability
- c. Autism and other comorbid conditions

## a) Pathological Demand Avoidance (PDA)<sup>20</sup>

The NDIS appears to be unaware of the growing recognition of Pathological Demand Avoidance as a diagnostic category increasingly applied to Autistics. We discuss it here in some detail as it has a direct bearing on the inadequacy of the Independent Assessment model to support these Autistic people. Please note that Autistic people are receiving formal diagnoses of this condition, even if the NDIS is unaware of it.

Pathological Demand Avoidance (PDA) is becoming understood to be part of the autism spectrum. Individuals who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This is rooted in an anxiety-based need to be in control. While it is unknown how common PDA is among Autistic people, it is important to recognise and understand this distinct profile because it has implications for the way Autistic individuals are best supported and managed. PDA is dimensional and affects individuals to a varying extent. This has direct relevance to the introduction of Independent assessments by the NDIS.

Individuals with PDA have all the same challenges of other Autistic people, in terms of social aspects of interaction and communication, together with some repetitive patterns of behaviour. Autistics with PDA may appear to have better social understanding than other Autistic, but this is at the surface level only and makes them particularly vulnerable to the deficiencies of the Independent Assessment as currently described by the NDIS which means some of their difficulties may at first appear to be less obvious.

### ► Features of PDA include:

- Resistance and avoidance of ordinary demands of life, which may include getting up, attending school, joining a family activity or other day to day suggestions. This may be the case even when the person seems to want to do what has been suggested.
- Using social strategies as part of the avoidance. e.g., distracting, giving excuses
- Excessive mood swings and impulsivity.
- Being comfortable in role play and pretend, sometimes to an extreme extent.
- Obsessive' behaviour that is often focused on other people.
- Appearing sociable on the surface, but lacking depth in their understanding.

These characteristics make the question-and-answer format of Independent Assessment the worst possible method with which to engage with Autistic people with PDA. The format of the interaction in the proposed Independent Assessment interview is in essence, discriminatory.

It is often the case that some strategies that are typically effective for people with Autism (such as the use of routine, predictability, and structure) need considerable adaptation. Individuals with PDA respond better to less direct and more negotiated approaches, which means that Independent Assessments will not be effective and will actively exclude some Autistic people from even gaining access to the NDIS, let alone being supported by it.

---

<sup>20</sup> Newson, E, Le Maréchal, K, David, C (2003) Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood* 88: 595-600.



► **The following strategies are imperative for any interaction with Autistic people with PDA.**

- Choosing priorities, e.g., which demands are necessary and which can be avoided for now?
- Reduction of demands, where possible, e.g., certain requests and expectations.
- Being very flexible and creative.
- Giving choice and using negotiation.
- De-personalising of requests. e.g., using written suggestions, attributing reasons for a request to other factors, such as health and safety
- Using indirect language, humour, and games to obscure demands.
- Use of indirect praise and affirmation.<sup>21</sup>

This list demonstrates how ineffective the Independent Assessment approach is for the PDA sub cohort of Autistic people. Pathological Demand Avoidance negates any expected utility of the Independent Assessment as a tool to measure support needs.

## **b) Prevalence of Psychosocial Disability in the Autistic Community**

There is a high prevalence of psychosocial disability in Autistic people, which stems from the constant stress of living in an unaccommodating and even hostile world.<sup>22</sup> Many Autistic people are late diagnosed, making us vulnerable to psychosocial disability, including trauma. Adverse life outcomes are linked to late diagnosis and to a lack of appropriate support. These adverse social, economic, health, legal, educational, etc. outcomes include, but are not limited to Autistic individuals experiencing one or more of:<sup>23</sup>

- Abuse (physical, sexual, emotional, etc.)
- Family violence
- Family breakdown, traumatic separation, and divorce
- Loss of child custody/access
- Unemployment and underemployment
- Poverty
- Exploitation: being scammed, manipulated by others
- Misdiagnoses and inappropriate medical treatments
- Self-harm and suicide
- Psychiatric admissions
- Criminalisation and incarceration

<sup>21</sup> Pathological Demand Avoidance Australia & New Zealand  
<http://www.pdaanz.com/>

<sup>22</sup> Lai MC, Kassee C, Besney R, Bonato S, Hull L, Mandy W, Szatmari P, Ameis SH. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *Lancet Psychiatry*. 2019 Oct;6(10):819-829. doi: 10.1016/S2215-0366(19)30289-5. Epub 2019 Aug 22. PMID: 31447415.

<sup>23</sup> Rumball, F., Happé, F., and Grey, N. (2020). 'Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events', *Autism Research*

- Leaving formal education without completing any award or 'piece of paper'
- Homelessness

For these reasons, the premise underlying Independent Assessments, which has been revealed as cutting costs, would be better served, not by seeking to deny Autistic people the support every one of us needs, but by supporting Autistic people as early as possible and consistently, to meet their ongoing needs, with increased support around transition points across the lifespan. This approach is necessary to prevent these harms identified above. Scaffolding us through the NDIS to move through less traumatically through our lives would save the enormous social and economic cost to the individual and the nation represented by multiple, repeated, and compounding experiences of this kind. It would also enable more of us to work, produce, and pay tax. Considering the number of Autistic Australians, how can we as a nation afford to do anything else?

## c) High Incidence of co-morbidity

- **The third important element of Autistic experience of Autism is the incidence of other co-morbid conditions. Autistic people frequently experience multiple comorbidities<sup>24 25</sup> that:**

- impinge upon our wellbeing.
- render our personal circumstances particularly complex.
- are not amenable to capture in the proposed structure of Independent Assessment interviews of only one to three hours duration.
- cannot adequately be assessed by an assessor who has minimal education or experience in any of the conditions with which a client has been diagnosed, let alone familiarity with all their conditions.

A typical response to our survey was, "I have multiple comorbidities including physical disability and have been rejected by the NDIS. I am in the process of having the decision reviewed. "This situation can only worsen under the proposed Independent Assessment model, which discriminates against people with multiple conditions.

- **The experience of Autistic people makes Independent Assessments inappropriate**

We have outlined the ways in which Independent Assessments are inappropriate for Autistic people due to our high rates of psychosocial disability and prevalence of multi-comorbidities. In this

<sup>24</sup> Hossain MM, Khan N, Sultana A, Ma P, McKyer ELJ, Ahmed HU, Purohit N. Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatry Res.* 2020 May;287:112922. doi: 10.1016/j.psychres.2020.112922. Epub 2020 Mar 18. PMID: 32203749.

<sup>25</sup> Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. *Autism*, 24(4), 884–898. <https://doi.org/10.1177/1362361320912143>



section we highlight the impact of these factors, alongside the consequences we experience from living in an intolerant world.

It is inappropriate to subject Autistic people to the proposed Independent Assessment, as follows.

► **The format is unsuitable to our needs. We commonly:**

- Have a fear or strong discomfort with meeting and interacting with strangers: allowing a stranger in our homes asking questions can be a trigger for trauma responses.
- Have higher generalised anxiety than the mainstream population, which may be worsened by performance pressure and high stakes situations, e.g., assessment or exams.
- Have specific trauma around similar situations, e.g., related to appointments and interviews, particularly where their Autism is a focus of attention or conflict, or a perceived disadvantage. This includes trauma induced by an extended wait to access diagnostic services, and by the difficulty of accessing and interacting with an understaffed and incompletely realised NDIS Scheme.
- Have a history of misdiagnosis and inappropriate medical treatment (including psychiatric admission), invalidation of our experience and having our concerns ignored, that makes us fear and mistrust similar situations.<sup>26</sup>

► **The NDIS independent assessor interview is at odds with the features of our disability because:**

- It requires high order cognitive skills, high order ability to self-regulate,
- It is high order anxiety inducing, because NO supporting evidence from known and familiar clinicians is allowed to help the person in explaining their condition and its impact on their life without starting from scratch. Three hours is not enough for an Autistic person to explain from scratch.
- It does not accommodate differences in communication styles that are common among the Autistic community. There is the necessity of accommodating non-traditional communication techniques, i.e., AAC, PECS, Auslan, typing, etc., however, very few people have these skills outside specialised environments.

► **Not all Autistic individuals have access to support during an interview, but many:**

- Have difficulty comprehending and responding to questions without notice, and
- require significant extra time (and sometimes the opportunity to discuss with a trusted person) in order to digest information and formulate an answer that reflects them accurately - time limits are not suited to Autistic people.

<sup>26</sup> Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, 23(6), 1508–1518. <https://doi.org/10.1177/1362361318818167> <https://pubmed.ncbi.nlm.nih.gov/32203749/>



- struggle to self-advocate, based on comorbid conditions e.g., PTSD, situational mutism, etc.,
- Have generalised trauma (due to exploitation or abuse) from the travails of living for years without diagnosis or support. This experience is often due to the under-diagnosis of girls and women.

# Independent Assessments

The Autistic Realm Australia believes that Autistic people should not be subject to independent Assessment because the process of their development has not included meaningful input from the Autistic community. Nor does it draw upon the expertise and experience of Autistic people to implement or operationalise an Autism-informed and Autism-positive process.

Specifically,

- **There has been no consultation with Autistic-led organisation's that included co-design of assessment tools or training for staff (assessors, supervisors) who will use them.**
- To produce valid instruments and training, Autistic people must be involved in the design, delivery, and evaluation of tools and staff training.
- Assessors who complete the assessment tool and more senior staff who interpret the completed assessments are not Autism-informed and Autism-positive. This could have been achieved by employing people who have lived experience of Autism, and by supporting them with appropriate training.
- **However, given that the contracts for Independent Assessors have already been awarded, no attention has been paid to assessors' knowledge and experience, or to their ability to:**

- demonstrate understanding of Autism that is accurate, up to date, deep and informed by lived experience.
- be able to practice in a trauma-informed and Autism-positive way.
- understand and apply the social model of disability OR
- determine accurately and fairly what supports the client needs.

► **Assessors must have appropriate skills and attitudes, to be able to work effectively and fairly with the diversity of sub-populations in the Autistic community, including:**

- across the life course
- Intersectionality and compounded disadvantage
- Different manifestations, profiles, and presentations of Autism as a spectrum, e.g., PDA

► **For staff to acquire these capabilities requires experience, qualifications, and training. At present, adequate knowledge, experience, skills, and attitudes to identify Autism Spectrum Disorder and different neurotypes are not universalised.**

- To date the professions of practitioners who are licensed in Australia to diagnose and support Autistic people i.e., the professions of psychiatry, clinical psychology, and general practice have been unable to ensure that all their practitioners can accurately identify or support Autistic citizens.
- Allied health - practitioners, e.g., speech pathology, occupational therapy, and other may have only the barest exposure to Autism while gaining their qualification.
- In these circumstances, an assessor without specific qualifications and experience and detailed training cannot be expected to do their job effectively and fairly in relation to Autistic people.

► **To expect inadequately prepared assessors to assess Autistic people is to lay the NDIS scheme open to:**

- an increase in requests for plan reviews
- legal challenge to the NDIS scheme
- responsibility for the death or total incapacitation of an NDIS applicant or participant (e.g., Annemarie Smith)
- litigation for damages
- 

Given these manifest inadequacies of NDIS process, assessment instruments, Independent Assessment staff experience, qualifications or training, and the absence of insight into the Autistic community or an Autism-positive attitude, we reiterate: The Autistic Realm Australia believes that Autistic people should not be subject to independent Assessment.

Finally, a more general but important point. The proposed Independent Assessment is not truly independent. It is inevitable that contractors paid by the government will act not for the interests of PWD, but to cut costs. Independent Assessment introduces a rehabilitation model. NDIS is not a rehabilitation system, or a welfare payment designed to restore a quantum of function or provide subsistence in the short-term and then eject the participant. The purpose of the NDIS is to support people with a disability to live meaning and fulfilling lives of our choice and under our control.

---

## Conclusion

---

People with a disability should not have to fight for entry, or to retain access to supports that we need. The proposed Independent Assessment is not appropriate to the needs of Autistic people, nor to the purpose of the NDIS, nor for any of the other participants of the Scheme.

Our recommendation is that Autistic people should be excluded from Independent in any interaction with the NDIS>

---

## References

---

American Psychiatric Association (1980). Diagnostic and statistical manual of mental disorders 3rd edition. — (2013). Diagnostic and statistical manual of mental disorders 5th edition.

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2018). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, 136236131881816. <https://doi.org/10.1177/1362361318818167>

Australian Institute of Health and Welfare 2017. Autism in Australia. Cat. no. WEB 187. Canberra: AIHW. Viewed 21 August 2020, <https://www.aihw.gov.au/reports/disability/autism-in-australia>

Brown-Lavoie, S.M., Viecili, M.A. & Weiss, J.A. Sexual Knowledge and Victimization in Adults with Autism Spectrum Disorders. *J Autism Dev Disord* **44**, 2185–2196 (2014). <https://doi.org/10.1007/s10803-014-2093-y>

Bonello, C. (2018). '11,521 people answered this autism survey. Warning: the results may challenge you', <https://autisticnotweird.com/2018survey/> 1 October 2018 Autistic not weird.

Cashin, A., Buckley, T., Trollor, J.N., and Lennox, N. (2018). 'A scoping review of what is known of the physical health of adults with autism spectrum disorder', *Journal of Intellectual Disabilities* 22.1: 96–108.



- Crossman, C. (2019, March 6). The Autism Spectrum is Not Binary [Review of The Autism Spectrum is Not Binary]. In the Loop about Neurodiversity.  
<https://intheloopaboutneurodiversity.wordpress.com/2019/03/06/the-autism-spectrum-is-not-binary/>
- Dekker, M. (1999). 'On our own terms: Emerging autistic culture', Autism99, [https://timelinefy-space-01.nyc3.digitaloceanspaces.com/files/5/5\\_USUGEY6NNLCQN9QXB1K3C30N6LR2TWVB.pdf](https://timelinefy-space-01.nyc3.digitaloceanspaces.com/files/5/5_USUGEY6NNLCQN9QXB1K3C30N6LR2TWVB.pdf)
- Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. Autism, 24(4), 884–898. <https://doi.org/10.1177/1362361320912143>
- Hossain MM, Khan N, Sultana A, Ma P, McKyer ELJ, Ahmed HU, Purohit N. Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. Psychiatry Res. 2020 May;287:112922. doi: 10.1016/j.psychres.2020.112922. Epub 2020 Mar 18. PMID: 32203749.
- Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S., and Trollor, J.N. (2019). 'Mortality and cause of death of Australians on the autism spectrum', Autism research 12.5: 806–815.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., and Pellicano, E. (2016). 'Which terms should be used to describe autism? Perspectives from the UK autism community', Autism 20.4: 442–462.
- Lai MC, Kassee C, Besney R, Bonato S, Hull L, Mandy W, Szatmari P, Ameis SH. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. Lancet Psychiatry. 2019 Oct;6(10):819-829. doi: 10.1016/S2215-0366(19)30289-5. Epub 2019 Aug 22. PMID: 31447415.
- Marks, D. (1997). Models of disability. Disability and Rehabilitation, 19(3), 85–91.  
<https://doi.org/10.3109/09638289709166831>
- Newson, E, Le Marechal, K, David, C, (2003) Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. Archives of Disease in Childhood 88:595-600
- Norrelgen, F., Fernell, E., Eriksson, M., Hedvall, Å., Persson, C., Sjölin, M., Gillberg, C., and Kjellmer, L. (2015). 'Children with autism spectrum disorders who do not develop phrase speech in the preschool years', Autism 19.8: 934–943.
- Oliver, M. (2018). 'Disabled students' campaign - social model of disability with Mike Oliver', National Union of Students UK, University of Greenwich,  
<https://www.youtube.com/watch?v=gDO6U0-uaoM>

Pathological Demand Avoidance Australia & New Zealand. (n.d.). Retrieved April 25, 2021, from pdaanz.com website: <http://pdaanz.com>

Rumball, F., Happé, F., & Grey, N. (2020). Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM -5 and Non-DSM -5 Traumatic Life Events. *Autism Research*. <https://doi.org/10.1002/aur.2306>

Scott, M., Milbourn, B., Falkmer, M., Black, M., Bölte, S., Halladay, A., Lerner, M., Taylor, J.L., and Girdler, S. (2019). 'Factors impacting employment for people with autism spectrum disorder: A scoping review', *Autism* 23.4: 869–901.