

# NDIS Consultation Submission

NDIS Consultation  
not that Labor or Liberals want it  
They would rather closed door deals  
For List of NDIS supports  
[NDISConsultaion@dss.gov.au](mailto:NDISConsultaion@dss.gov.au)

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23 August 2024

## **Re: Submission regarding proposed changes to list of NDIS supports**

Dear Department of Social Services (DSS)

I am writing to you to express my deep concerns regarding the proposed (now rammed through) changes to NDIS supports listed in the consultation document provided on the DSS Engage website:

<https://engage.dss.gov.au/consultation-on-draft-lists-of-ndis-supports/draft-list-of-ndis-support/>

The consultation process has been inherently flawed, there has been limited time dedicated to allowing individuals with disabilities, organisations, and peak bodies representing people with disabilities, to inform their members, discuss content and formulate an informed response.

Frankly, as Senator Jordon Steele-John has publicly stated: "We ALL have milk in our fridge with a longer expiry date than the initial time for "consultation".

Given only a short extension time of one week, there is still not enough time nor space for any of the advocacy groups and peak bodies to enact appropriate and accessible procedures to ensure their members voices are heard, so its left to individuals like me to express our concern and objection to the proposed 'draft list of NDIS supports'. Now laws.

Apart from choice and control, or rather alongside it, I particularly object to the new proposed changes around Assistance Animals. This is a highly misunderstood and underfunded area within the NDIS to begin with, the future changes will restrict nearly all participants the access to use an Assistance Animal as a reasonable and necessary medical aid/disability support.

### **1. Assistance Animals**

#### **Description**

An animal specially trained by an accredited assistance animal provider to help a participant with tasks. These are things the animal wouldn't naturally do otherwise, like guiding a

participant through crowded places. Includes ongoing maintenance costs such as vet fees, transport and special diets for the assistance animal.

**Carve outs that are not 'NDIS supports'**

N/A

Please be advised there are NO "accredited assistance animal providers" in relation to nation-wide based training and assessment. Most teams (a team being a person with a disability and an assistance animal) work under the Disability Discrimination Act 1992 (DDA) which is a Federal law and not internal based policy, it's clear this is why it's been added to the list. There are however individual state by state laws in some, but not all states and territories.

There are NO accredited assistance animal training, each company devise their own, no standard or program exists.

For example, Tasmania has no state-based laws and so teams mainly use the DDA to legally work, train and move freely within our community.

Via Freedom of Information (FOI) I obtained the amount of AA's in May 2013, it consisted of 409 plans for AA's, of these AA's 82% were for visual impairment, 9% Autism, 2% psychosocial disability. Between 1 January 2022 and 31 March 2024, 205 AA's were approved for vision impairment, 12 for Autism and all psychosocial disability, all other groups 21 AA's were approved.

163 AA's during this brief period were denied to participants with Autism and psychosocial disabilities.

205 were approved for vision impairment.

In December 2022 there were 498 AA's funded by the NDIS. Clearly demonstrating a gap in need and access for participants.

It is clear there is systemic basis against participants with non-vision impairment when accessing the medical / disability aid an AA provides participants. NDIS's own operating guidelines specifically state they do not fund AA's for Autism; this is blatant discrimination based on disability. Someone needs to take their case to the human rights commission.

In relation to AA's, the NDIS reflects an outdated model of support that is nothing short of a return to a medicalised model of service, ignoring and neglecting to reflect Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), or the once human right based model of practice as stated in the objects of the NDIS Act 2013 (may it rest in abject horror) or even Australia's National Disability Strategy.

They go even further, due to lack of knowledge, firmly imprinted systems that define individuals to squarely place themselves in a neat NDIS service box, in particular when it comes to **owner training** an AA. Most teams operate under the DDA, which is Federal law and not a NDIS internal policy, (god rest the 2013 NDIS ACT), choice and control of how your supports are provided were once the corner stone building blocks of the NDIS (RIP NDIS 2013).

These owner-trainer teams have as much right to training and maintenance funding as that afforded to participants with vision impairments. Training bodies that support a fully trained AA are incapable of keeping up with demand, they also all have their own narrow interest areas with which some people with disabilities don't comply.

The individual owner trained handler's will not be able to comply with outdated newly introduced changes to the NDIS ACT, slammed through parliament with back yard deals and no consultation with disability groups, advocates and participants. They cannot become registered providers, nor can they complete accredited training THAT DOES NOT EXIST. It's clear that only the vision impaired and a small select few will be able to access an AA via the three main training bodies, with waiting lists that have been shut for years. Even those bodies operate under a state by state law. Effectivity denying NDIS participants, choice and control in their choice of support.

The fact is most AA's are approved via AAT mandates after a long and expensive process that is also mentally and physically exhausting for participants. I lodged an FOI requesting cost of lawyers' fees paid by the NDIS out of their magic pudding endless bucket of money for fighting participants seeking funded AA's. That FOI, including multiple other FOI's lodged in June, have not all been provided to me, despite the legal time frame to do so.

During the NDIS review in 2023, I had the pleasure of interviewing multiple participants that were owner training their own AA's, doing so at great financial impact to limited incomes, for the process of "co-design" .... I wonder did Bill kick back and smoke a big fat cigar prior to announcing the NDIS review, lets waste taxpayers money and totally ignore all recommendations, a review which made 26 recommendations and 139 supporting actions. Multiple people I interviewed spoke about the inflexibility of the NDIS to listen, you cannot create an accreditation or law that does not exist in your state, you can't access Occupational therapists to support your claim because there are very few trained in this area of AA's. And if you are in a state without a registered provided or state laws then things become impossible. Several participants withdrew from the process to access funding due to suicidal ideation, caused by the constant hounding of the NDIS. (Senator Jordan Steele-John as always is correct, people will die).

A participant can spend a year at the AAT to gain funding for an AA, only to have the NDIS remove it from the participant's next plan. Again an FOI specific to my daughters case where 5 lawyers were involved, has not been provided to me, so I can estimate the figures the NDIS are currently paying in relation to funding the service in the first place against fighting it at the AAT.

My daughter had an AAT mandate, funding for AA owner training was gained, plus maintenance costs - only for it to be removed in the following plan review. Even though all allied health professionals agreed and supported an AA as the best means of support for her. We are now once again going through yet another AAT case, and despite telling the NDIA multiple times that we are owner training with an organisation, that my daughter owns the dog - they still repeatedly ask for things like 'can the training company provide a vet check, quotes for insurance etc'. The training company PROVIDES TRAINING, NOT AN AA. My daughter owns the AA and as such these questions should be directed to her or to her nominee.

My daughter cannot leave her accommodation without psychical support. She is an Honors student of Psychology, has a grade average of 89%, she will one day work in the field of neurodivergent neurological research, but she is currently viewed as a drain on our society. She is denied the individual support (an AA) that allows her to integrate into mainstream society, so once again we are at the AAT. The NDIA can not get through their own bias and simplistic views - they hammer an 'either-or approach'; eg: either my daughter has support workers, psychology, OT and Speech Therapy, **OR** 'maybe' an AA. They fail to recognise the transition period of capacity building requires **both** to begin with.

Currently her main level of support is provided by her dorm mate, a 19 year old girl with her own disabilities, and the risk of carer burn out is already extremely high. That risk could be lowered significantly by the use of an AA, With an AA my daughter can move more freely without paid or informal supports for a lot of her daily activities, but not all. Her roommate is not coping well with the demands of university and being a 24/7 unpaid carer. My daughter is two states away from her home state - her future is determined by the request of \$9,000 further in training for her AA and \$3,500 a year in maintenance. Do the math, the dog is far cheaper for the NDIS in the long run.

The very system set up to support her rights to education (under article 24 of the United Nations CRPD), the NDIS will be the reason she fails to achieve her goals, now isn't that irony. Simply because the NDIS can't think outside of the box, can't set aside its own constraints, can't see past pre-determined algorithms, can't see value in a support they know little about - let alone understand the daily positive impact an AA has on the lives of participants.

My daughter is inherently, academically smart. One day she could potentially unlock the gene of Autism and develop a way to cover it, effectively turning it off.... And yet the NDIS fails to see beyond their own bias, their own ingrained ableism. My daughter has multi-deficits in executive functioning, multiple intersecting impairments, therefore the very system set up to supposedly enable her to live a full and inclusive life on an equal basis with others (the NDIS) – is instead, setting her up for a future working in a sheltered workshop under slave wages.

Whilst federal Labor, specifically Bill Shorten used the slogan of reforming the NDIS **FOR** participants prior to the election, with the promise of co-design, it is clear that post-election both Labor and Shorten have one and one aim only; to reduce the NDIS budget by 14 billion dollars.

It's also blatantly obvious these cuts are coming from restricting access to the scheme and reducing participants plans, restricting access to those with psychosocial disabilities proves this beyond a shadow of doubt, so too does the constant mention of Autism, clearly next on the NDIS chopping block (or the "Autisms" as Pauline Hanson likes to call them).

Given the railroaded deal with states and territories, the erosion of the NDIS and participants rights to a quality of life within a human-rights framework, their fate is sealed.

<https://jec.org.au/disability-rights/a-fairer-ndis/explainer-understanding-the-ndis-review/>

Justice and Equality Centre released a paper on the NDIS reviews final report, ironically the government called it "working together to deliver the NDIS"....sorry but no one invited me to these behind closed doors deals made this week , so clearly working together is no longer on the table.

#### **4. Supports for specific cohorts of people with disability** **Children with disability**

The NDIS Review recommends more support be available to children and families through mainstream services and 'foundational supports', rather than individualised NDIS budgets. This shift would particularly apply to children with developmental concerns.

The Review proposes increasing supports available outside the NDIS for two main reasons:

1. to enable supports to be delivered in natural settings (where children live, play and learn), reflecting best practice and leading to better outcomes for children; and
2. to better maintain the sustainability of the NDIS.

I live in Tasmania. There is a statewide crisis for allied health professionals. An Occupational Therapist will have a 12 month waiting list now, we can't even get access to general practitioners (GP's,) and yet you sign a dodgy agreement to push through changes that will further restrict access for Tasmanian's to a standard of living, in line with bigger, better equipped states.

Our incomes are significantly lower than our interstate counterparts and yet we pay the highest rent, leaving home ownership for future generations impossible. People simply can't afford the out of pocket cost of these non-existing "foundational" supports. Early intervention works, which is why it was one area where the NDIS did support funding in a manner that reflected need.

We lack the essential services required for children even with the support of the NDIS, people wait two years plus for a state funded diagnosis, these two years could be critical in the development of the kids waiting, two years that cannot be gotten back.

I know my son has Autism, the school psychologist has done all the necessary testing but for some reason that can't be used for access to the NDIS, I need \$2200 to pay privately, which I simply can not afford. So, he suffers. He is suicidal and the CAMHS refuse to provide services. He was able to access services for 12 months with Life Without Barriers, but due to their funding model after the 12 months we were left with nothing.

The NDIS is already means tested covertly, because low socioeconomic demographic can't afford the FCA's and assessments required to access the scheme.

### **People with psychosocial disability**

The NDIS Review proposes a new approach to NDIS supports for people with psychosocial disability, focused on personal recovery and increasing independence. As this relies on increasing psychosocial supports outside the NDIS, the Review recommends governments prioritise investing in foundational supports and improving access to mental health services for people with severe mental illness.

As you would be aware, despite the use of the word 'disability' in reference to psychosocial disability, these participants were first to face the chopping block, proving that there is indeed a hierarchy of disability within the NDIS, this can quickly be pointed out by looking at the current consumables page which lays strictly in a medical model of practice and denies the needs of those with "invisible disabilities".

Under a mental health plan you can receive the maximum of 10 visits to a psychologist, these require an out of pocket payment, (I paid \$84 a fortnight for my child, \$210 after the mental health plan was used, and it crippled our ability to provide basic household items, such as food) which is utterly inefficient and will increase the mortality rate of those living here with psychosocial disabilities, luckily we have convenient access to the Tasman Bridge. That will help reduce the numbers waiting for services the state of Tasmania doesn't have.

There is currently no assistance to access psychiatrists.

Paediatricians in the state have closed books, my son has been waiting to see one at the Royal Hobart Hospital for 18 months despite suicidal ideation due to Autism.

Autism, psychosocial disabilities, non-visible disabilities are in fact every bit as disabling as having to use a wheelchair. Given they are non-visible that should help Bill's cut, slash and burn, if we don't see them, they simply don't exist, and numbers of jumpers from the Tasman Bridge are not reported – how very handy. My daughter is on both hit lists....do I push her or do I jump myself so I don't need to watch her erosion of services and her decrease in value and worth in our society, to watch her wither away without the required funding, to stay only in one room and never have a life outside of it...because no one sees her, those that supported removal of these participants hold the internalised ableist notion that invisible disabilities are not real and Bill Shorten just gave every Australian a loaded gun yesterday, maybe its his way of being kind?

My daughter daily expresses she wished she had been born with physical disabilities rather than invisible so she could access supports she requires.

These rammed through list and changes, rules based approach to supports is not in line with choice and control nor was it the first step recommended by the NDIS Review. Just some key issues with the proposed lists include:

1. They reflect an outdated model of disability supports that is 'othering' and medicalised. The lists would force people to use expensive specialist providers for items that could be purchased more cheaply and effectively from mainstream sources.
2. Excluding everyday items like household appliances, batteries, and recreation equipment will make it harder for people with disabilities to live independently in the community. These items are often crucial disability supports when used creatively. Excluding other items, like menstrual products ignores the real need and additional costs faced by people with disability as well as the complexity of disability. Removing these options also reduces amenity and dignity especially for personal items.
3. The lists are overly restrictive and will stifle innovation in how people use their NDIS funding to meet their needs.
4. Flexibility and choice are core principles of the NDIS. These changes remove choice from individuals and hand control over support selection to Governments who do not understand our needs or our rights.
5. Even with a one week extension, there has not been enough time for genuine consultation with the disability community on these major changes including very little time with plain English and/or Easy Read materials for people with intellectual and cognitive disability.
6. Real co-design is needed in conjunction with the disability community before developing any Rules, as well as considering passing legislation.
7. The proposed approach contradicts recommendations from the recent NDIS Review for more flexible budgets with minimal restrictions.
8. Forcing people to use more expensive specialist disability products and services will likely increase costs for the NDIS overall.
9. The consultation period and arrangements are completely inadequate given how big these changes are and how many supports are being removed. We need more time to properly review and respond to these proposals.

10. Removing and restricting support items like these risks forcing people to rely on state and territory systems that either don't exist or won't be ready in time. This could leave many people without the supports they need.

Some of the supports I'm particularly concerned about include:

- Access to menstrual products because they enable my daughter to live with dignity with complex, multiple and intersecting impairments ( I guess this is null and void given you realised more than half Australians bleed)
- smart household product which has features which enable participants to operate it but is not a specialised product
- Visiting a hairdresser to wash participants hair as this prevents the need for more support workers and saves her dignity
- Use of a smartwatch which reduces worker costs, health costs and gives participants greater independence
- Trampolines or games because these are great for therapy and exercise
- Gaming therapy or yoga as this is an effective evidence based form of physical therapy for participants
- Access to Assistance Animals without the need to go to the AAT
- Consumables budget that allows items for individuals with invisible disabilities to support their needs
- Sensory products that can be life altering in the moment and provide immediate assistance
- Google hubs to prompt life reminders daily (dawn clocks are restricted to four reminders)
- Tables and laptops to allow people with extreme social anxiety to connect with allied health providers
- Immediate recognition of psychosocial disabilities
- Continued access for those with Autism
- The removal of the ability to raise internal reviews
- Reassessments and the lack of information provided around these
- Lack of support in relation to educational opportunities, the States are failing miserably
- Animal based therapies such as horse riding to increase social participation, capacity building and lived experience

I urge you to abandon these flawed and prescriptive lists and instead work closely with people with disability to develop a more flexible, person-centred approach to defining reasonable and necessary supports, before making any further changes to the NDIS.

Any future guidance should empower participants to make choices that work for them, and not restrict their options. There is still time to get this right, but it requires slowing down and truly listening to the disability community.

### **Choice and control, reasonable and necessary**

I also urge you to seek greater community consultation in any changes “nothing about us without us”, there are no greater experts on disability than those with disabilities.

I worked for 25 years within the disability sector prior to the NDIS. I worked in both day support and residential settings where individuals rarely left the house due to inadequate staffing, or had to accommodate staffing changes ie; going to bed prior to when they wanted because they required two staff to use lifting gear and at 10pm only one staff was rostered on.

There was no choice in relation to staffing, you could be a victim of sexual assault and still have male staff rostered to work with you, there was absolutely no control of your own life. The industry was so bad I knew multiple parents when aging who had suicide plans for themselves, taking their adult children with them because they couldn't trust their child would be cared for. Your current rammed through changes will see a swift change back to those dark ages.

When the NDIS was introduced service providers amalgamated to retain viability of their operations. When I was working I was a whistle blower on clear breeches of duty of care and the CEO told me *"lower you standards, we need bums on seats"*. With NDIS smaller models of practice popped up which were client centred and focused, who provided quality care. Participants should retain their ability to have smaller providers, exercise their choice and control, not have it forced upon them by a bureaucratic system with a sole focus on a budget, pushing them into large corporations where the model of practice is merely "bums on seats".

I have registered providers that rip my family off, I am the nominee for two participants and oversee two siblings. I've lodged several complaints to NDIS Quality and Safeguards Commission - resulting in...NOTHING, no action. The registration system does not protect participants, my daughter currently is seeing a new occupational therapist who has charged more in non-face to face fees than the ONE face to face session she has actually had with my daughter. She sent an email suggesting an appointment time which my daughter did not respond to, (be clear it was a suggested time not an appointment) charged for the email, then charged for ringing me the day prior to see if my daughter was attending an appointment no one had agreed too. Since when do providers get to charge to set up an appointment anyway? When I questioned the registered provider, they sent me back the price list the NDIS themselves set which allows for this gouging of funds. If this had be a private arrangement and not the NDIS it would never have happened. The very first question in Tasmania when you ring allied health professionals will be "are they on the NDIS", some services restrict themselves to only NDIS clients. The next question will be "can you send us their plan" it's so they can see how much money they can gouge.

When you get a plan you immediately bank 12 hours of each therapy because you know the NDIS will insist on FCA's and reports in two years' time. The NDIS wastes vast amounts of money in their requirements for continued access, they then ignore the FCA's and reports and type one diagnosis into an algorithm, why bother spending \$5000 in funding? Smart participants then lodge a review, others go through the unfair process of the AAT where the NDIA is spending god knows how much money on lawyers. Why do we not know how much taxpayers are proving the NDIA to waste on lawyers, because no one with in the NDIA will provide the figures. And yet you launch a smear campaign on "sex workers" and "sex aids" to distract the Australian public from the real issues.

The Justice and Equality Centre writes:

##### **5. Transparency and accountability of NDIA decision-making**

*"PIAC has consistently raised concerns about the lack of transparency in the NDIA's decision-making, particularly in its approach to planning decisions. For example, we have recommended the NDIA provide detailed reasons for its decisions, and ensure its operational guidelines are updated to be consistent with court and tribunal outcomes.*

*The Review has heard the complaints from the disability community about these issues. The Review recommends codifying NDIA operational guidelines and policies in legislation and the NDIS Rules. The Review adds that where operational guidelines continue to be used, they must be*



*consistent with the law. PIAC welcomes this recommendation to support transparency and consistency in decision-making, and improve the accountability of the NDIA.”*

They do so with good reason, because since his election Bill Shorten has launched a smear campaign against all NDIS participants rather than look inwards at the endless internal waste they have created within the beast called the NDIS. Examples:

- Requesting FCA's for every review
- Considering any report or FCA over 12 months invalid
- One year plans, yet still requiring full FCA's prior to review
- Two year plans when there is clearly going to be no substantial change within that time frame
- NDIS failure to provide FOI's in time frames
- NDIS time frames being “desired times frames” rather than legal time frames
- Lack of any contingency for immediate change in circumstances (my friend was murdered by her ex husband, her son spent weeks in hospital whilst his plan was reviewed)
- Planning meetings that last only 20 minutes
- LAC's that do nothing more than hit KPI's
- Lack of meaningful funding for Coordinators of supports, or are they navigators now? No one knows!
- The use of algorithms which force reviews because needs are not met (think you covered that by removing the right to a review)
- Untrained call centre staff that have no ability to directly link to other areas within the system
- The use of multiple law firms at the AAT, if participants must represent themselves then so should the NDIA
- NOT Standing by AAT mandates further than one plan
- NOT Actually, standing by and supporting the NDIS Reviews 26 recommendations and 139 actions
- NOT allowing co-design
- NOT allowing a time frame for meaningful consultation process

In conclusion, well played Minister Shorten, you managed in your term so far to alienate a minority group from society even further, to show them to all Australians as taxpayer rorters, people who are living large on misappropriated funding, individuals draining our society merely to live, individuals unable or unworthy of trust or the ability to make informed decision about their own lives. Minister Shorten actively set out to degrade an already marginalised group, dismissed their basic human rights, (one he was entrusted to care for) ignored the recommendations of a lengthy and costly review. Hammered through legislation opposite to his parties election platform and managed to focus a nation on “sex workers and sex toys”...well played Shorten, did you smoke a cigar and sing to “this is the best day of my life”, heaven help the \$5000 coffee tables in parliament house, because nothing will save our disabled community. Only conceding to period products because frankly half his voters bleed, self-protection at its finest.

I have one final question on just about every disabled persons lips; what the hell are “carve outs”?

But what would I know, I'm just a mother with a daughter who has;

- Autism level 2
- CPTSD
- Social anxiety

- Agoraphobic panic disorder
- OCD
- hEDS
- narcolepsy
- ADHD
- Sensory processing disorder
- Auditory processing disorder
- Dyslexia
- Dyscalculia
- Synaesthesia

A son with;

- Undiagnosed Autism because I can't afford the \$2200 for assessment
- ODD
- Communication disorder
- Depression
- Social anxiety
- Suicidal ideation
- Dyslexia

Grandmother of children with;

- Autism level 2
- ADHD
- Extreme social anxiety
- Tourette's
- Depression
- ODD
- Suicidal ideation
- Dyslexia
- Delayed Global development


A sister of two siblings with:

- Delayed Global development
- Autism
- Social anxiety
- ODD

I am utterly terrified for the future of my daughters, my son and my grandchildren, all of whom are in Shortens sights for the "hit list", the expulsion of people with invisible disabilities from the NDIS and from the minds of the Australian public as being worthy of supports, thanks to the endless campaign against them so the average Australian would applaud a government protecting the bottom line, rather than ensuring basic human rights. I wept openly when watching Senator Jordan Steele-John using his last 9 minutes, in particular "if I could sit down I would", even at the highest level of government we fail to see the needs of people with disabilities, a simple "Senator, are you finished", simple respect not given to a man who works tirelessly for his community.

I have voted Labor all my life, both state and federal, my senate was always Greens, Shorten has ensured myself and all my family will now vote Greens across the board, including my parents who have voted labor for 66 years.

Thank you for the opportunity to provide this Submission, and I hope that someone will read it, and take note of what I have said, but I doubt it.

  
Dated 23/8/2024