

WWDACT NDIS Review

Key themes from consultations and interviews

Being believed

- Recommendation of physicians and specialists is often ignored
- Barriers in accessing the NDIS to begin with – participant told that ‘everyone gets rejected the first time’ – 15 documents provided but were not enough
- Emotional exhaustion and distress of struggling through paperwork and appeal processes- motivation to ‘stay off the system’
- Women are systemically not believed, even those that do have a diagnosis
- Not being seen as experts in your own life
- Spending stupid amounts of money on getting reports only not to be believed
- NDIS don’t read reports from specialists and are defined by their own agenda

Access issues

- People who sit at the intersection of marginalized groups have far less ability to access the NDIS
- Refugee families where children are refused citizenship because they start applying to the NDIS for their kids
- Funding and funding gaps depend on level of being able to communicate with the organisers of the funds – if you are able to self-advocate or have advocacy support, more likely to get the funds you need
- The onus is on the person with disability to prove that they have a disability
- Didn’t occur to participant that they could apply for the NDIS until their psychiatrist mentioned it

- Documents and administration so overwhelming, especially for neurodivergent or psychosocial disabilities – NDIS supposed to increase function but these people are already struggling to juggle many aspects and find administration overwhelming
- Women are systemically not believed, even those that do have a diagnosis
- Men being approved with a single medical document, women have to fight
- A lot of the criteria to be diagnosed is based on a white male – NDIS criteria based on already heavily biased and dysfunctional criteria
- People have to know the exact specialized terminology in order to get approved – engaging advocates who know how to write applications and know the ‘secret code’ - accessibility issues
- Having to jump through multiple hoops to get through
- Lack of Autistic adults on the scheme, women are more high masking and might find it harder to get a diagnosis
- One participant took 2 years to get on the NDIS after 2 rejection letters and help from an advocate
- Burden of administration lies on the person with disabilities, who often has limited capacity to do so
- Multiple participants mentioned being highly tertiary educated (PhD level) and struggling immensely with the bureaucracy – extremely inaccessible for those without that background
- Ability for conditions to be recognised and allocated supports on the NDIS depends on the visibility of the condition and the advocacy of those who have the condition – MS is much better supported than Parkinson’s even though Parkinson’s is more prevalent

Invalidation of disability

- Told ‘not disabled enough’ to receive support coordination, reserved for people who are ‘highly disabled and non-verbal’, even though everyone should be eligible

- Young people feel they are 'not disabled enough' and so not looking into it
- The onus is on the person with disability to prove that they have a disability
- Have to produce 15 documents each planning and assessment period proving how disabled participant actually is
- Being told you are not disabled enough, autism, invisible disabilities
- Government pretends to care about lived experience, but then don't speak the language
- People are over-consulted, consultations are underattended but many people are struggling to get through the day

Choice and control

- No choice in NDIA providers, everyone in the ACT is with Feros Care
- People feel safer in vulnerable situations with other women – but provision of services and planning through NDIS and NDIA are not nuanced, specialised, or culturally appropriate
- Unable to contribute to households
- Participants don't know where information is going – NDIS seems to get linked data from other places (e.g. Centrelink payments) but data sharing is outside of participants control and is often incorrect. E.g. participant whose son had epilepsy got epilepsy recorded in their NDIS paperwork instead
- Participants denied choice to be self-managed rather than agency-managed after interactions with the tribunal – agency-managed meant the loss of a lot of supports
- NDIS conducts internal review processes which are not transparent and do not allow the right of reply or just outcomes for participants
- Participants feel as though they are being made dependent on the NDIS, which removes their choice and control – comparison to domestic violence
- Emphasis on using support workers – NDIS will pay for services and events and will only pay for a support worker to attend as well,

regardless of whether the participant wants or needs this to participate

- E.g. participant paid a dog kennel to walk and socialise their dog through the NDIS. When they became agency-managed, only way they could access dog-walking services was to pay a support worker 3 times as much for a minimum call-out, and without the benefit of the dog being socialised with other dogs
- The only way to get the services you want is to self-manage, but that involves a massive time burden. There is a trade-off between quality of services/choice/control and responsibility/time pressure/auditing requirements

Service quality

- No regulation for NDIS workers, many workers are unfamiliar with procedures on how to take care of disabled people
- Mental health communities in Canberra – a lot of people feel that when the NDIS came in a lot of their grassroots community supports got defunded, rolled into the NDIS and support communities were lost
- Providing more funding for allied health rather than support workers, e.g. OTs and psychologists to give preventative care and increase functionality long term (might also reduce costs)
- No nuanced care is going to be commercially viable – there needs to be other funding models to support this
- Therapeutic supports that participants build rapport with can be taken away without warning, and access to therapeutic supports can be cut if they are deemed by the NDIS as unnecessary
- NDIS support workers/drivers not covered by car insurance that allows other people to travel in the car – can't be active community participants if they can't e.g. take other people to the movies, take grandchildren home from school – had to look for private hire car company to meet needs

Support coordination and interactions with NDIA

- Case workers in different states unable to give recommendations of services and organisations
- NDIS doesn't take necessary efforts to ensure participants understand their packages
- NDIS is viewed as a cash cow, easy money without a lot of work
- Very few direct answers- there is no black and white
- Having a centralized in-person location rather than everything being over phone calls, having people available to walk through application process
- Support coordination severely lacking – there should be support coordination from the day you make an inquiry, getting a dedicated support worker or caseworker working with you through application process
- Support coordinators left early from a planning meeting, and Feros Care staff told participant when alone that they would not get any extra funding
- NDIS supposed to supply funding to maintain wheelchair, but they did not provide that funding
- Women find it hard to talk to planning coordinators who are not women about reproductive health, periods, menopause
- NDIS never makes participants aware of services they might be eligible for
- Disability gateway and list of service providers are impossible to navigate and not kept up to date
- Person who is planning and having a conversation with is not the person who approves the plan – communication is poor e.g. person who is a permanent wheelchair user being questioned by plan approver if they could use a walker instead, although this was clearly inappropriate
- Having to tell your story over and over again
- No decisions are transparent, threat of supports being taken away

- Participant safety is strongly tied to security in knowing funding will not be taken away – hard to feel in a climate where ‘cuts’ and ‘rorts’ are being bandied around in the media
- So much is on the participant to organise their own plan managers and support coordinators, and support can be withheld or delayed if organisations aren’t holding up their side of the bargain
- Difficult to change plan managers, remote plan managers don’t have information about local services
- Difficult to communicate what is allowed to be spent from the budgets – not always clear, and risk that participant won’t be compensated when they expect to be
- The plan that is received is different from the plan that is expected
- NDIS plan review meetings are a cause of stress, NDIA staff found to be judgemental. Participants feel they have to practice what they want to say, have notes
- NDIA recording incorrect disability information, participant doesn't qualify for supports because the NDIA ‘made up’ their disability
- NDIS takes up majority of time and thoughts for participants who have to fight the system to get supports and recognition
- If you try to talk to the NDIA too much you get flagged as a troublemaker and blocked from talking to them
- Recommendation – competency standards for support coordinators
<https://www.intermediaries.org.au/wp-content/uploads/2021/12/Support-Coordination-Standards-of-Practice-v1.0-Dec-2021.pdf>

Waitlists and availability

- Waitlists for OT in the ACT blow out to 18 months
- NDIS doesn’t take anything on board until you’ve had an OT assessment, and there is a shortage of OTs in the ACT. Why isn’t functionality assessment done during the application process, why can’t a psychiatrist or pediatrician do it?

Goals and achievements

- Emphasis on goals and achievements is hard to grasp – participant finds it far too broad
- Don't recognise domestic duty gap – partners expected to bear domestic duties such as house and garden, no NDIS support to share that burden
- Don't listen to goals and dreams unless they align with their own expectations of what those should be
- Don't accommodate travel or creative goals
- Payment for craft classes and creativity has been steadily cut from plans and seen as unimportant and unnecessary – although important for social inclusion

Fluctuating disabilities

- In mental health community – a lot of disabilities are fluctuating and episodic, so supports requiring a permanent functional impairment are at risk, people are vulnerable to funding being taken away
- NDIS asks what supports you need on your worst day, but only funds 75% of the stuff you actually need during that time
- Aimed at the lowest common denominator of support – funding for the bare minimum of existing and barely surviving
- Neurodevelopmental disabilities are questioned and harder for the NDIS to understand fluctuations e.g. not being able to work

False medical/disability dichotomy

- NDIS trying to cut psychology out of funding, which doesn't work for a lot of neurodivergent people who need psychology services
- Grey area between medical health (not funded) and disability (funded) when this dichotomy is false
- No intersection of NDIS and women's health

- Link between neurodivergence and mental health issues such as eating disorders – but this is seen as a health issue and falls outside NDIS, although health system considers a disability
- Menopause, perimenopause, PMDD are all difficult to manage with a disability and not considered by NDIS
- Managing your period when disabled, especially when you struggle with personal hygiene, is not easy but not recognised

Young people and NDIS

- Young people struggle to get the information they need to navigate or be aware of NDIS
- Young people feel they are 'not disabled enough' and so not looking into it
- You can access funding for an OT to come into the school, but teachers don't know this is an option. Shortage of psychologists in primary schools, whichever school advocates the loudest gets psychology and screening assessments on a case-by-case basis. System disjointed from the beginning for young people
- NDIS should be aware of life stages and make recommendations accordingly – as kids leave school, be flagged for driving support or voting support or job search support – awareness of reproductive health and menopause and supports that fluctuate at different stages of people's lives

NDIS and parents

- Women who have had postnatal depression or postpartum psychosis unable to get supports through the NDIS, or concerns about how this interacts with the child protection system
- Infertility and post secondary infertility is not on radar of the NDIS
- No extra support for pregnancy and post-partum
- Don't acknowledge the need for support around being a parent

- Goals around parenting, wanting to be a mother again are not acknowledged as legitimate goals by the NDIS

Violence

- Huge room for women to be abused within the system, safeguards for financial abuse and coercive control not built in
- Expectation from housemates or family that support workers and carers provide support to family members as well as person with disability – if women is in a household, care responsibilities distributed to other people because it is expected
- Quality and safeguards commission operating in a vacuum, not addressing vulnerable intersections who experience violence at higher rates or linking in with Royal Commission findings
- So easy for system to be exploited – partners of people on NDIS can be placed as primary contact and plan manager for complete control. If partner leaves, support is withheld, and very difficult to transfer control back to the participant
- Delay in change of circumstances after leaving abusive relationship meant that plan was unable to be used for 18 months