



people with
disabilities
western
australia

Submission

Inquiry into Current Scheme Implementation and Forecasting for the NDIS

Joint Standing Committee on the National Disability Insurance Scheme

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People with disabilities WA (PWdWA)

Since 1981 People with Disabilities (WA) Inc. (PWdWA) has been the lead member-based disability advocacy organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run BY and FOR people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

Introduction

PWdWA would like to thank the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for the opportunity to provide comment on the current implementation of the NDIS.

PWdWA provides individual and systemic advocacy around issues experienced by individuals, families, carers and the community concerning the National Disability Insurance Agency (NDIA) and the NDIS. Our individual advocacy supports people engaging with the NDIS processes at all levels. NDIS continues to be the most common issue PWdWA are contacted for support with. In 2021 PWdWA has supported over 350 people with issues relating to the NDIS. Half of those issues were s100 internal reviews, or Administrative Appeals Tribunal (AAT) reviews, relating to insufficient funding in a participant's plan. We also note there has been a significant increase in requests for support with AAT proceedings in the last 6 months.

The points raised in this submission are informed by trends in our individual advocacy services, in addition to community and sector consultation. Quotes are taken from an online community survey we ran to provide an accessible way for people with disabilities to contribute to the inquiry via our submission. We received 31 responses, 24 of which were people with disabilities, family members or carers. We have also included information from our NDIS Transition and Interfaces project which ran in 2019-2020. This project included a largescale community survey completed by over 300 persons with disabilities, in addition to numerous focus groups and individual meetings.

Response to Terms of Reference

(a) The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:

(i) The availability of support outside the NDIS

NDIS was not designed to support all people with disabilities, being aimed towards those with lifelong disabilities that have a severe impact on a person's functional capacity. This leaves over 80% of Australians with a disability reliant on alternative

forms of support for their disability, including people over the age of 65. Despite this, it is often assumed that because a person has a disability, they will be supported by the NDIS.

PWdWA's experience since the rollout of the NDIS has been that those who are not eligible for the NDIS, or Continuity of Support Programs, are struggling to find the support they need. We note the Western Australia government no longer provides funding for disability related supports outside of those who are on continuity of care arrangements. This of course requires that the person be previously receiving state funded support. Low level support that was previously available through the Commonwealth Home and Community Care program no longer exists. Community mental health support such as the Personal Helpers and Mentors program were discontinued with the rollout of the NDIS. We are also aware of several individuals who have been told they no longer meet eligibility criteria and live with the threat of NDIA revoking access. This trend has been observed nationally by other disability advocacy providers.¹

Many of the people who cannot access the NDIS still need personal support, case management, assistive technology, therapy, and access to transport support. We note that a third of respondents to our survey indicated they had lost access to services since the rollout of the NDIS including transport, Support Coordination, therapy services, respite and community mental health supports. All these respondents indicated the impact on the person with a disability to be moderate to severe. Isolation, mental health issues, increased severity of disability and health conditions, and relationship breakdowns were all mentioned as consequences of not receiving adequate support.

Some of the main community services that survey respondents had accessed included Disability Employment Services, Peer Groups, Community Mental Health Supports and Disability Advocacy. However more than half of those respondents said the support did not meet their needs. In particular, people mentioned long waitlists for non-NDIS

¹ PWdWA attends a national meeting of NDIS Appeals advocates where information about trends is shared between disability advocacy organisations

support as a barrier, and a desire to see more access to transport to promote community inclusion.

Without alternative support available in the community people are reliant on family, friends, and other informal support (if available) to help them, which is not appropriate and often not sustainable. Additionally, many people are forced to choose between privately funding support or basic necessities which drastically impacts on quality of life. This has a disproportionate impact on people with lower incomes, especially those on JobSeeker payments.

We note that these issues also significantly impact people with a psychosocial disability, with approximately one third of people seeking support from PWdWA for accessing the NDIS identifying as having a psychosocial disability. Streamlined pathways were created through funded programs to support people with psychosocial disability to test their eligibility for the NDIS however, funding for many of these programs has ceased.

People who are not eligible for the NDIS on the basis of residency, such as those on bridging visas, have the added barrier of finding alternative supports that do not have residency criteria for eligibility. Many government funded community supports have restrictions based on residency or visa status. PWdWA are aware of some CaLD specific services which rely on community support, volunteering and donations to meet these gaps.

Local Area Coordinators (LACs)

LACs as one of the pillars of Tier 2 supports is clearly failing in its mandate to support the wider disability community to promote inclusion and access to mainstream supports. PWdWA notes the Overview of the NDIS Operational Guidelines provides the following explanation and example of Local Area Coordination pillar of the ILC:

What does it do?

Helps people to plan and access supports in the community, with an emphasis on connecting people with mainstream supports and services.

Example

Taking a person to their local community bowls club and helping them sign up.²

Additionally, the NDIS website also states that LACs will help you:

- *Learn about support available in your local community;*
- *Understand how the NDIS works with other government services – this is supports like education, health, and transport;*
- *Sustain informal supports around you – this is family, friends and local community members.³*

The experience of PWdWA is that LACs do not fulfill these mandates. Focus is on meetings KPI's, including plan reviews. Little, if any individual support is provided around eligibility and NDIS access. Many LACs are unfamiliar with community and local supports, if they exist. People who are seeking to test their eligibility, or access non NDIS supports are regularly referred to advocacy organisations who are already overwhelmed by request for support with NDIS.

For many of the people accessing PWdWA's support we note that NDIS specific functions such as plan implementation and support to connect with service providers or navigate between NDIS and mainstream services are not provided by their LAC. In many cases the individual does not have Support Coordination, or they need help accessing Support Coordination.

Access Issues

PWdWA has been contacted by over 150 people in the last year for help relating to accessing the NDIS. Significantly, 30% of these individuals identified as having a psychosocial disability and 15% are Aboriginal or Torres Strait Islander. We know individuals who are homeless, transient or may never have been to a doctor, those who are trapped in domestic violence, as well as individuals in settings such as prisons and

² Overview of the NDIS Operational Guideline Section 5.1.1, 5.1.2 [Overview of the NDIS Operational Guideline - Support and Assistance | NDIS](#)

³ LAC Partners in the Community: <https://www.ndis.gov.au/understanding/what-ndis/whos-delivering-ndis/lac-partners-community>

hospitals, all face additional barriers accessing the NDIS. If people cannot afford assessments and reports, they are prevented from accessing the NDIS. PWdWA supports many people who rely on the Disability Support Pension (DSP) as their only income. People on the DSP cannot afford the kind of reports the NDIS requires. Furthermore, there is a discrepancy in terms of the quality and detail of reports provided by the public health versus private health sector. PWdWA have seen firsthand the difference in quality of reports provided by the public health system and the private health system. Professionals working in the public health system do not have the resources or time to understand the complex language requirements of the NDIS, resulting in under-reporting and lower quality evidence. People with disabilities can wait up to a year to see a public health professional. If this professional is not proficient in NDIS, the person with disability is further disadvantaged by waiting longer for reports. Thus, the NDIA is perpetuating systematic discrimination, and reinforcing the cycle of disadvantage and poverty for those who experience it whilst accessing the NDIS.

All these individuals require some form of support to live independently in the community. PWdWA has limited capacity to support with NDIS applications. As noted above this was previously envisioned to be the role of LAC. The gap is being filled by advocacy agencies that are already experiencing pressures due to NDIS issues. Many of these individuals are found eligible for the NDIS with the right support to gather and present evidence. However, time taken to gather evidence, and protracted reviews and appeals mean that they can be left without access to any support for more than 12 months. Without access to the NDIS many of these individuals will face declines in health, wellbeing and circumstances, and/or be placed at risk of harm due to the lack of alternative supports.

Case Study 1

Linda contacted PWdWA for advocacy assistance for her son's NDIS Access Request. Her son has neurological and psychosocial disabilities. The first access request included the initial diagnosis evidence and the functional capacity at the time of diagnosis, when her son was nine years old. The access request was rejected, with the NDIS requesting updated diagnosis and functional capacity assessments. Linda and her son spent another nine months attending multidisciplinary appointments to gather this

evidence, all while her son struggled through high school. The evidence used in the second access request included the original evidence, and new evidence from a Neuropsychologist, Psychiatrist, a Social Worker, Paediatrician, Occupational Therapist and Speech Pathologist. All new reports confirmed the original diagnosis as lifelong with no treatment and confirmed a severe impact on his functional capacity. NDIS rejected this second access request again, stating that there still was not sufficient evidence to prove the disability is permanent. There are no mainstream services available to this family to provide the kind of support Linda's son requires.

b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services

PWdWA is aware of ongoing issues between NDIA and mainstream government services at both a systemic and individual level. These issues include confusion and disagreement over who is responsible for funding supports and a lack of coordination between NDIS and other services.

PWdWA has supported individuals facing interface issues in the areas of health, education, aged care, housing and the justice systems.

Health

PWdWA is aware of an increase in the number of social admissions to WA hospitals which has been linked to inadequate funding in NDIS plans. We have supported several individuals throughout the last year who have either been hospitalised or at risk of hospitalisation because of the impact of inadequately funded supports. This includes issues with inappropriate care ratios being funded and inadequate behaviour supports.

When I decline and become symptomatic my only choice is often the ED which is unhelpful⁴

⁴ PWdWA Survey Respondent

Case Study 2

Donna has a spinal cord injury and requires 24/7 support to live independently in her own home. Prior to NDIS, Donna's support workers had worked with her for over 30 years, enabling her to maintain a quality of life, and stay connected to the community. During her transition from State-based supports to the NDIS, Donna's support worker hours were reduced to 8 hours per day, despite numerous reports stating her need for it. She lost access to her long-term support workers and her health and wellbeing quickly deteriorated. Her service provider frequently rang the ambulance and requested for her to go to hospital because of her deteriorating functional capacity and wellbeing. Donna would sometimes spend up to 3 weeks in hospital, saving up support worker hours to come home. An internal review increased her supports to 20 hours per day, but Donna continued to face issues recruiting appropriate support workers and keeping them employed. As a consequence, her service provider still rings the ambulance frequently to ensure that the hospital provides oversight of her functional capacity.

Case Study 3

Danny is a woman in her 30s with an intellectual disability and complex trauma who lives with her mother. Without adequate support to manage her behaviour Danny can engage in violent and abusive behaviour towards her mother, including threats which mean Danny's mother can't sleep. Danny's support team has recommended 1:1 support 24/7 to enable her to live as independent as possible in a way that supports her and her mother's safety. NDIA would not provide 24/7 support and cut all recovery coaching support in favour of inadequate behaviour support funding. This means Danny's mother is unable to sleep and Danny's behaviour keeps escalating. Over a period of 18 months Danny had been hospitalised on numerous occasions. On many of these occasions the police or ambulance were called because of the violence towards Danny's mother. Danny's mother is at breaking point.

We continue to see issues with a lack of timely NDIS plans in place post hospital admission which is delaying discharge. In some cases, health professionals will assume NDIS will provide post-release support even if the increased care needs are not related

to disability. Even if the increased supports needs are related to disability the NDIS will not always fund them, especially if they are considered rehabilitation.

Lack of knowledge from medical staff around what is a "permanent" disability and what the NDIS could actually support the person with. It's a handball to NDIS for everything as soon as the person with disability mentions NDIS, even if the NDIS will not fund a support.

Health are very keen to offload their responsibilities onto the NDIS plan, even though you don't have funding for it⁵

Delays in plan approvals, or the requirement to undertake an s100 plan review to have the issue addressed, mean that people who should be living in the community are tying up hospital beds. This is especially concerning as WA's hospitals have experienced several Code Yellow events in the last 6 months and are now anticipating an increase in the number of hospitalisations due to COVID-19 in the next few months. Additionally, people are being discharged without adequate support which is impacting their recovery or leading to further decline.

A 2020 report on transition to NDIS in WA by PWdWA also found interface issues with health services:

WACHS feedback from Esperance and Kalgoorlie has been that it is an extremely difficult system to engage with for families and that people are now coming back to the health system and being hospitalised because services are not available. Kalparrin peer supports stated that there is an increase in people bringing their children in to the hospital to provide respite to the family because the NDIS plans do not provide respite breaks for families. The family support workers at Kalparrin advised that they spend 90% of their time supporting families with the NDIS plans and accessing services. Other

⁵ PWdWA Survey Respondents

feedback included people losing access to healthcare cards, mobility allowance and respite services. ⁶

Disagreement over nursing support in the community, such as catheter care, administration of medication, and other medical needs which are directly related to disabilities also continues. In many cases the NDIA declines to fund supports they believe are the remit of the health system, but which the health system has no capacity to provide. This leaves the NDIS participant in limbo, without support, and often facing a long-protracted review and appeal process.

*My child has ongoing concerns around pressure areas and osteomyelitis. She has a cvc line in which needs dressing weekly. The hospital system need to kick us out but Ndis won't fund an adequate amount for nursing care and a cvc line is not something that can be done by anyone as it has to be a completely sterile field.*⁷

A number of our survey respondents also raised the fact that health services and hospitals are still struggling to provide disability appropriate services. For example: communicating with people and working collaboratively with support people.

Education

PWdWA's 2019 research demonstrated a lack of communication between state education and the NDIS. In particular, concerns were raised by the schools about the lack of support for students transitioning from school. The feedback from the schools was that they were in the dark as to how to support families through this transition time and that the previous State System provided a pathway for school leavers to apply for support for transition from school. Families reported that the response from NDIS planners and partners was plans would not be developed for transition until the student was in their final term of their final year. This was a huge area of concern for families.

⁶ PWdWA (2020) *NDIS Transition and Interface Issues Report*.
https://www.pwdwa.org/documents/Full_print_PWdWA_NDIS_Systemic_Report.pdf

⁷ PWdWA Survey Respondent

Through our individual advocacy work we continue to see the gaps in support where the division of responsibility leaves people without any support to complete their education. Education is a critical foundation for inclusion, so it is important that students have the support they need to achieve their potential.

Schools are reluctant to allow external allied health services to attend to conduct therapy sessions forcing families to either absent the child from school or take them to after school sessions thus extending the day for children who already are fatigued and stressed from their school day.⁸

Case Study 4

Eloise is a young girl with a diagnosis of intellectual disability and suspected Autism. Several specialists' including Eloise's paediatrician, speech therapist and school psychologist, have confirmed her need for additional support to ensure she does not fall behind in her learning and development goals, including access the therapy. Eloise's mother is particularly concerned about the transition from primary school to high school for which they have received no support. Unfortunately, because Eloise's diagnosis of Intellectual Disability does not meet the WA Education Departments criteria for additional classroom support, she has only been able to access half an hour per week of educational support. Additionally, the NDIS often takes a hard-line approach to funding supports which may be related to education, and in Eloise's case no support was provided to assist with her learning and development. To make the situation even more complicated, obtaining a diagnosis of Autism, which may open up further support options with both the school and NDIS, is a slow process with long waitlists. The result of neither the WA Education department nor the NDIS taking responsibility for support is that Eloise falls further behind her peers in her learning and development.

⁸ PWdWA Survey Respondent

Aged Care

Although Aged Care Package eligibility is over 65's it is not uncommon for people to seek early entry into the Aged Care Support system because of NDIS ineligibility and lack of alternative community support. We also note that older Australians who:

- Were over 65 at the time of NDIS rollout or;
- Acquire their disability after the age of 65 or;
- See an increase in disability related support needs after the age of 65

are also left with inadequate access to necessary support. Home Care Packages are not designed to meet the support needs of people with disabilities. The four levels of packaging are capped at specific price points and may not offer the flexibility to meet a person's needs – such as the purchase of expensive custom assistive technology. Additionally depending on income and assets the Aged Care System requires co-payment of a basic daily fee. We also note that this outcome shifts costs and resources requirements to a system that is already struggling to meet demand e.g., blow-outs to wait times for packages.

Case Study 5

Lee is 58 years old and lives with an intellectual and physical disability. Lee did not have any formal or informal support around him and never knew disability-related support was available. PWDWA supported Lee to make an access request to the NDIS, however the NDIS rejected his access request stating the Aged Care Package would be enough to meet his needs. Lee went through the assessment process for early entry into aged care and was accepted at the highest package level. The assessment team noted grave concerns over needs the Aged Care System couldn't meet, specifically home modifications and assistive technology he required to remain independent in his own home. The assessment team supported Lee by writing their own letter of support, outlining the unmet needs, and the serious safety risks associated with not providing those disability-related supports. Lee made a second access request which was also rejected. He submitted an internal review and was finally accepted to the scheme.

Case Study 6

Bruce is an Aboriginal man with an acquired brain injury who lived with his wife in his own home for many years. Unfortunately, Bruce's wife passed away. As his wife had been providing him with significant informal care his NDIS package no longer provided enough support to keep him independent in his home. Despite requesting increased support, NDIS did not provide any additional support in Bruce's plan. Because of the risk to Bruce's welfare due to lack of support he could not continue to live in his home. The easiest option to meet his needs was to place him in an aged care home. Unfortunately, because he entered an Aged Care home after the age of 65, he is technically no longer eligible for NDIS. Bruce's guardian is adamant that his support needs are disability, not age, related and he was only placed in Aged Care as NDIS was not providing adequate support for Bruce. The result of this situation is Bruce is no longer able to live in the comfort of his own home within the community that he knows. He will also now be limited in the support he can access through the Aged Care system.

Justice

PWdWA have supported many people over the last few years who have either struggled to access disability specific supports while in prison, have been declined access and therefore faced delayed release, or been released without any supports required to live in, and access the community.

Psychological and behaviour supports appear to be a particular point of contention between NDIA and the justice system. Most psychological supports we have come across in prisons are not adequately trained to support people with disabilities, especially cognitive impairments and neurodiversity such as Autism.

The Prison Psychologist acknowledged the limitations of specific interventions a person needs, but the NDIS would not accept that the prison system does not have capacity for this particular support. Their viewpoint is that IF a support SHOULD exist (in NDIA's mind), then they will not fund it, even if it does not actually exist nor ever exist anyway. It means the person with disability could not access any disability-related

intervention/support while in prison. The person became known as a "bad" inmate, was physically abused 3 times by both inmates and prison staff, and prison staff told them to stop "pretending" to need help.⁹

Services such as Occupation Therapy, Speech Therapy and other allied health services routinely available. We note that the COAG Agreement does specify that NDIS is responsible for support to address behaviours of concern and building skills where needs are additional to that of the general prison population. However, there is a clear reluctance from the NDIA to fund any support while a person is incarcerated.

Case Study 7

Prior to entering the prison system, Jake received weekly Psychology support. Jake had only recently received a diagnosis of Autism and Psychosocial disability and was transitioning from school into the workforce. Once Jake was placed in remand, NDIS withdrew all supports stating that Justice is responsible for any ongoing psychology support. The prison could not provide the kind of support Jake needed – their health services are only designed to assess and treat mental health conditions within a limited timeframe. Jake required ongoing support to understand how autism impacted his everyday life, maintain his current functioning, and build his capacity to manage his functional capacity while in prison. Despite reports from professionals and Managers within Justice explaining Jake's needs were not clinical treatment, the NDIS rejected his internal review request. The NDIS told the Advocate that it did not matter whether a support exists within the justice system, if the NDIS believes it should exist, it will not fund it. PWdWA support Jake to appeal at the AAT. The AAT agreed that Jake's need for psychology was clearly around his functional capacity, not to treat his Autism. Jake now receives fortnightly psychology supports funded by the NDIS. Throughout this process Jake spent a year without access to the critical psychological supports he needed.

⁹ PWdWA Survey Respondent

It is also increasingly difficult for disability advocates to access people with disabilities within the prison system to provide them with support. A PWdWA advocate waited nearly eleven months for approval to access the prison, and by then the internal review case had finished. The lack of knowledge of justice workers, coupled with the lack of evidence available to incarcerated persons makes it incredibly difficult to make a successful access request. We are aware that some services which were visiting WA prisons to offer this support have been cancelled due to COVID-19.

Housing

Stable housing is a foundation to accessing services, building capacity and ensuring wellbeing. We note that accessing the NDIS has added difficulties for those who are homeless. The level of evidence required is incredibly difficult to obtain as many people who are homeless:

- Access multiple GPs and medical services meaning evidence is spread across several services
- May not have a clear diagnosis due to lack of consistent medical care
- Have difficulty accessing treatment and therefore may not be considered 'fully treated'

We note that many homelessness service providers cannot meet the intensive support needs of people with disabilities who are homeless and need to complete NDIS applications.

Another trend in housing issues which PWdWA has increasingly observed over the last year is insufficient NDIS funding forcing people to leave their preferred housing arrangements, many of which have been longstanding. In some cases, this has forced people who were previously living independently to move into group homes. In other cases, people are being evicted from group homes as providers are stating they cannot provide the required support on the funding available. Through our networks in the Southwest of WA, including Advocacy WA, we are aware of several individuals who

have been forced to move out from Department of Housing properties into group homes as a result of cuts to their NDIS plans.

My understanding, from talking with other participants with similar funding is that there is a push within NDIS to reduce funding for individual living support to “encourage” participants to choose cheaper accommodation support such as group homes. This has forced participants to appeal review decisions, up to AAT. The cost to NDIS to fight these legal challenges is large and reduced funding available for meeting participants’ need.¹⁰

One of our survey respondents had the following observation about the impact of housing issues:

Rental accommodation is extremely expensive. People have moved from the city to regions because of financial reasons but there aren't the services in regions to support them. People slipping through the cracks in regional areas.

We believe this to be reflective of both issues with planning and a cost-cutting agenda. Increasing NDIA are using the argument of financial sustainability to defend decisions not to adequately fund plans to enable independent living arrangements. It is fuelling group living arrangements rather than reducing them which is highly concerning given the increased risk of abuse, neglect and violence in these types of closed settings.

Case Study 8

Nial is a man in his 30s with Autism. He has been living independently for the last nine years, six of which have been in his current home, all with 1:1 support 24/7. Nial requires formal support to assist with all his daily activities and his current living and support arrangement has seen him thrive. Nial has explored many different types of accommodation options and it was previously determined this arrangement was the

¹⁰ PWdWA Survey Respondent

most suitable. This included two different group living arrangements which were found to be inadequate and led to a reduction in function and independence in addition to putting Nial and others at risk due to behavioural concerns. Nial received communication from the NDIS that his plan was being extended for 6 months and he had to provide evidence as to why he could not live in a shared support arrangement as the NDIS believed that Nial would manage on 1:2 or 1:3 supports. The impact of moving Nial to a group home setting would be 'catastrophic' according to her support team. Nial's support team has provided extensive reports on why 1:1 funding is critical to his functioning, but they are still waiting on the NDIS to provide his new plan to confirm there have been no changes to his funding.

Some of the referrals PWdWA receive come from LAC's requesting an advocate complete the application form for public housing so a NDIS participant can be placed on a waitlist that currently has a wait time of five to ten years. This is not the role of an advocate. If a person needs support to access adequate housing because of their disability this should be funded through their NDIS plan, including Support Coordination. Most people experiencing homelessness also experience other life-impacting crises where an advocacy referral is appropriate. This would be mitigated if the NDIS accepted that appropriate housing, and housing stability, can make a significant impact on someone's functional capacity.

c The reasons for variations in plan funding between NDIS participants with similar needs, including:

While we understand the focus of this enquiry is on the drivers of inequity, we would like to take this opportunity to highlight that policy directions around scheme sustainability are leading to widespread cuts to plan funding across the board. An example of this can be seen in the discussion above around housing.

The NDIA's sustainability mandate appears to be inappropriately applied to reducing expenditure on a plan-by-plan basis. In the last year alone PWdWA has supported over 140 people to review inadequately funded plans. We note that over one third of participants who have sought assistance have an Autism diagnosis. We also note that

12% of people access this support come from Culturally and Linguistically diverse backgrounds. In some cases, plans have been cut by up to 50% despite evidence suggesting increased need due to functional decline. Difficulty using plans due to waitlists for services and COVID-19 has also been used as a rationale to make funding cuts e.g., respite not being used to slashed in half.

This propagates the adversarial dynamic between the NDIA processes and imposes upon participants. For example, with every NDIS review participants experience anxiety and angst due to the uncertainty of what supports will continue to be funded and whether supports they rely upon will be arbitrarily cut without deliberation or negotiation.

While it is important to address inequity between participants it is critical that we address the real and ongoing battle people with disabilities are facing to access the basic supports they need to live a full and independent life. We have serious concerns for NDIS participants who continue to face unexplained, egregious cuts to the NDIS plans which places them at unacceptable risk.

c (i) the drivers of inequity between NDIS participants living in different parts of Australia,

Financial, cultural, social, educational and literacy factors, in addition to the barriers faced by regional and remote participants, all contribute to inequitable plan variations. While there is a level of nuance to these issues the basic fact is that people who are more educated, and better off financially have additional resources available to them to navigate an overly complex system. This includes accessing quality evidence used for access requests (as discussed above) which also form the basis of initial NDIS plans.

Results from PWdWA's 2020 report on NDIS transition in WA¹¹ specifically found that people from cultural and linguistically diverse backgrounds do not understand the process and what is expected and are often ill prepared for the meeting with the planner. Depending on the quality of the planner, families have left the meeting unsure of what has been put into their family member's plan.

¹¹ Ibid 6.

We also know that having access to knowledgeable support to help with NDIS planning is a significant factor in the quality of the plan received by a participant.

Regional and remote locations

PWdWA provides advocacy to regional and remote locations both directly and as a consortium with Advocacy WA and Sussex Street Community Legal Service. We wish to highlight the following issues which we believe contribute to plan funding inequity for people living in regional and rural areas.

Access to appropriate professionals to provide supports, assessments, and reports

Assessments and reports form the basis of funding decisions for plans. We have already detailed some of our concerns over access to quality reports in this submission. However regional and remote areas face additional barriers to accessing quality reports and assessments. There is a critical shortage of health professionals in regional and remote areas who are qualified to provide the types of evidence required by the NDIS for access and funding decisions. In many cases specialist medical practitioners are only available in the metro areas – which comes with a significant cost in terms of travel, accommodation etc to the individual. Although telehealth options exist in our experience face-to-face interactions provide the best and most thorough means of eliciting quality evidence of support needs. Without quality evidence, written in NDIS language, it is unlikely that a person will receive all the support they require.

An additional issue that occurs in regional and rural areas is the lack of service providers to deliver NDIS services due to thin markets. Again, while telehealth may be available for some capacity building supports it is not always an appropriate way to deliver services. Many individuals feel that unspent funds are being used as justification to cut plans.

Access to advocacy and informal support

PWdWA often hears from NDIS Participants and those seeking access to the Scheme that having the support of an advocate improves outcomes. While advocacy services

cover the whole of WA there are limitations to the level of support that can be provided. Limited staff numbers, and large distances between regional communities make it hard to provide face-to-face services. Additionally, not all people have reliable access to phone and internet to access support.

Additional regional issues impacting plan variability include:

- Access to adequate communication devices and connection to services
(Regional digital connectivity)
- Access to adequate infrastructure
- Access to appropriate services in indigenous communities

c(ii) whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and

PWdWA strongly believe that inconsistent decision-making contributes to inequitable variations in plan funding. Decision-making at all levels in the NDIS needs to be far more transparent if there is to be any improvement in plan variability. This includes the release of information about cases settled at the AAT.

PWdWA has clear examples of where different people within the agency will make different decisions based on the same information. For example, an individual tried on three occasions to access NDIS for vision impairment and was deemed eligible for the scheme on the third attempt. Each time the individual had submitted the exact same application, and no further information was ever requested hence demonstrating discrepancy between assessors. Although this example relates to access it clearly demonstrates a lack of consistent decision making within the NDIA.

Vision Therapy; Like a lottery. Some clients receive, we never did, even tho application from same Optometrist was the same. NDIS wanted to argue about it and take it as far as the AAT to do so. I have a family and a home

*loan to cover. Who do you think had the time during the day to attend this?
I didn't, because I have to work for a living.¹²*

LAC and planner quality

Far-removed public servants, without lived experience, making decisions about people and places they know little or nothing about.

Depends on who your LAC is and whether or not they will advocate for you, or meekly follow the NDIS line.¹³

We have no doubt that the quality of LAC and NDIA planner impacts on decision-making and ultimately the plan a person receives. PwDWA's 2019 report on NDIS transition issues in WA¹⁴ found the planning processes, planners, and LACs were one of the main barriers facing individuals and families in getting good outcomes from the NDIS. The report found that 45% of people did not feel heard by the planner and 48% saying they did not know what they should be asking for. People stated that planners often used NDIS language that families and individuals did not understand, and people walked away thinking they had been understood and had what they needed in their plan only to end up with a plan that looked completely different. Participants have noted a lack of knowledge about disability possessed by employees of the NDIA resulting in differing eligibility and plan outcomes amongst different employees viewing or reviewing each case. NDIA participants continue to hold the view that the quality of their plan will come down to the luck of the LAC or planner they receive. In our experience this is true.

Respondents to our current survey identified the following two issues as the top reasons for inequitable plan variations:

- Lack of planner/LAC knowledge – specific disability (88% of respondents); and
- Planner/LAC unpreparedness e.g., not reading reports/evidence (76% of respondents).

¹² PwDWA Survey Respondent

¹³ NDIS Survey Participant

¹⁴ Ibid 6.

The other main issues identified as contributing to inequitable plan variation included (68% of respondents):

- Recommendations from participants health professionals not accepted
- Lack of transparency e.g., internal guidance for decisions not publicly available
- No access to review draft plans before approval

Many clients accessing PwDWA Individual Advocacy since the rollout in WA comment that planners do not seem to understand the needs of the person with a disability, especially where they were complex. They find that what is being discussed in planning meetings regarding support is not what ends up in the plan.

Many people feel that planners make assumptions about what is and is not required and that the planners are not prepared when meetings occur. Often people submit several therapy reports and evidence to demonstrate reasonable and necessary support and planners have not read this information, or state they do not have time to read them. People will bring copies of evidence submitted before planning meetings to the meeting and planners say they have never seen it before. It is concerning that planners are making recommendations about support or decisions about approved supports without having read and considered the available information.

There is an ongoing feeling amongst participants that planner's roles are to provide the least amount of supports possible, rather than exploring all the possible support options available. Individuals and families are preparing for planning meetings going in with the worst-case portrayal of their family member for fear that they won't get the supports that are required.

It is evident from the general feedback from individuals and families that the quality and expertise of planners varies tremendously across the state. Professional knowledge, preparation, interaction and engagement from planners with families and individuals sets the scene for a successful planning meeting.

Health and Allied Health Recommendations

PWdWA also wishes to highlight the disturbing trend of NDIA decision-makers ignoring the recommendations of medical and allied health professionals. Although not always the case, there is an increasing number of people seeking support to review plans where therapy recommendations have been ignored with no explanation. We are aware of the NDIA's position on sympathy bias in allied health professions. We categorically disagree with this belief, noting that there is no evidence to support it. Often the result of ignoring these recommendations is a decline in function or increased risk to the participant.

c(iii) measures that could address any inequitable variation in plan funding;

Below are a series of recommendations relating to various aspects of planning and decision-making processes.

Ensuring access to quality reports:

- Developing clear guidelines around the type of functional evidence needed to inform decision making
- Creating a capability framework for functional assessments
- Providing training for people who wish to conduct functional assessments for the purposes of the NDIS
- Providing training for health professionals who are supporting people around report writing
- Provide adequate funding in plans where decision making evidence is required

Well trained and knowledgeable NDIA and partner staff:

- Developing better training and guidelines for decision makers to ensure fairer, consistent decisions
- Ensure ongoing training to keep decisions makers abreast of changing policies
- Decision-makers who specialise in areas of complex need, or disability types

- KPIs should focus on quality of decision making which will lead to decreases in review and appeals
- Ensure decision makers have the appropriate qualifications to understand clinical and medical advice

Consistent, transparent decision making:

- Ensure therapy recommendations are given proper weight during decision making
- Ensure all people can participate in planning meetings and have adequate support and time to communicate their needs
- Provide all participants with a draft plan and the time necessary to review and provide comments before a plan is finalised
- Publish a summary of all AAT decisions that are made during settlement
- NDIA to provide a full explanation for decisions, including but not limited to access, planning and review decisions

Many of these recommendations were also called for by respondents to our survey:

Read therapists reports. Be more knowledgeable about impact of disabilities on daily life. Run draft by participant for their feedback.

Access to disability advocacy Access to low cost services to prevent any further decline

communication and transparency

The staff that read medical reports and make decisions based on those reports MUST have clinical experience. It is unfair for a participant to have an allied health professional make clinical recommendations only for a person with no clinical knowledge/qualifications to reject the support. If there are any concerns with a clinical recommendations, another allied health professional MUST oversee and provide clinical reasoning for the rejection for it to be fair.

Don't rush planning process. do face to face plans. Listen to families. Understand disability. Believe specialists. Understand impact on families and Carers.

Communication. Better planner training. Time for planners to read files before planning meetings. Reduce frequent changing of planners to enable them to know their clients needs better over time

More than half the respondents to our survey indicated decision makers need a better understanding of disability and more training. Several also indicated the need for formal and informal advocacy support.

g(ii) planning policy for personalised budgets and plan flexibility;

PWdWA made a submission to the NDIA consultation on personalized budgets and plan flexibility in collaboration with WA Individualised Services. We have provided a copy of that submission for your reference.

h(ii)

Advocates access to NDIS/Consent

PWdWA would like this opportunity to once again raise issues relating to advocacy supporting individuals to navigate the NDIA. Issues with consent to advocate, and access information required to support a person, have been ongoing over the last four years. In many cases advocates play a critical role in ensuring decisions which impact on the safety and wellbeing of participants are addressed. On the whole advocacy plays a key role in bringing the NDIA to account for inequitable and poor decision making. The continued barriers faced by advocates include:

- Refusal to share information despite consent forms being on record
- PWdWA consent forms are never recognised despite advice from NDIA that they are appropriate

- PWdWA Advocates try to provide early intervention by calling NDIA with client on phone, but the consent is only once-off
- Only one Advocate per organisation can contact NDIA – makes this difficult if the Advocate changes throughout a case.
- Consent forms sent to enquiries email inbox can take many weeks to be actioned. Some wait over a month.
- Slow response to escalation of critical issues

PWdWA recommends the NDIA work with advocates and people with disabilities to co-design policies and processes which acknowledge and respect the role of advocates within the NDIA.