

individual & systemic advocacy



people with
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Submission

The Inquiry into the NDIS.

The Joint Parliamentary Standing Committee on the NDIS

People with Disabilities (W.A) Inc. (PWdWA) would like to thank the Joint Standing Committee on the NDIS for the opportunity to provide comment for their inquiry into the three areas of the NDIS,

- General Issues around implementation performance of the NDIS
- NDIS Planning
- Supported Independent Living (SIL)

PWdWA is a peak disability consumer organisation representing the rights, needs and equity of all Western Australians via individual and systemic advocacy.

PWdWA is run BY and FOR people with disability and strives to be the voice of all people with disabilities in Western Australia.

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People with disabilities WA (PWdWA)

People with Disabilities WA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with a physical, intellectual, psycho-social, or sensory disability via individual and systemic advocacy. We provide access, information and independent individual and systemic advocacy.

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 welcomes the opportunity to provide comment to the committee on the inquiry into the three areas of the NDIS;

- General Issues around implementation performance of the NDIS
- NDIS Planning
- Supported Independent Living (SIL)

People with Disabilities provides individual and systemic advocacy around issues experienced by individuals, families, carers and the community concerning the National Disability Insurance Agency (NDIA) and the Scheme (NDIS).

PWdWA provides ongoing advocacy to individuals engaging with the NDIS processes at all levels. There is a rising number of issues being considered by the advocates in relation to NDIS. In 2018-2019 Financial Year, NDIS represented one third of all issues dealt with by PWdWA. This is outside of the specific funding received to assist people with NDIS Appeals. The requests for advocacy support on NDIS issues continues to grow.

As part of the Western Australian Disability Coalition of advocacy and peak organisations, PWdWA is taking the lead in the systemic advocacy project “**NDIS transition and interface issues**”. The focus of the project is on addressing the systemic barriers that are arising from the transition to NDIS in WA including issues with the National Disability Insurance Agency policy and practices and other departments/mainstream agencies interface with the NDIS. The project is engaging with people with disability, peer groups, advocacy groups and the community to get feedback and identify the issues that are contributing to the barriers in the NDIS rollout and transition in WA. A key part of the information gathering is through a long running survey on the PWdWA website that is gathering feedback from individuals, families and the community on their experiences of the NDIS. A diverse group of people with disabilities has been engaged in a Co-Design group that is looking at a solution-focused approach to the issues both at an individual and systemic level.

The points raised in this submission are reflective of the hundreds of people we have assisted in advocacy on NDIS over the past year (300 in 2018-19).

Quotes and graphs are taken from our survey, which has over 300 respondents as of the first week of September 2019, and the focus groups we have attended and facilitated.

PWdWA is invested in working with Joint Standing Committee on NDIS to continue to raise and address the current issues and implementation of the NDIS.

Inquiry into NDIS Planning

On 1st July 2018, the National Disability Agency assumed responsibility of the full delivery of NDIS across WA. The process of implementation through the planners and planning processes has continued to be a concern raised across individuals, families, service sector and the wider community. The ongoing feedback from the Advocacy groups in the Disability Coalition in WA continues to raise the planning process, the planners, and now partners in community as one of the main barriers facing individuals and families in getting good outcomes from the National Disability Insurance Scheme.

The themes are consistent across the diverse range of disabilities and the experience of those at the receiving end. These reflect systemic issues that are the root cause of the lack of quality operational services to individuals and families.

The general principles that guide actions under the NDIS Act 2013 are in question under the current planning processes. These are some of the Principles in question but not limited to these:

- *People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime (section 4 (2))*

Individuals and families have reported that at planning meetings that they are told by the planners they are unlikely to receive the same level of support in their next plan.

- *People with disability should be supported to exercise choice, including in relation to taking reasonable risks; in the pursuit of their goals and the planning and delivery of their supports (section 4 (4))*

The sector still drives the services available to individuals and families and unless the family has the capacity to self-manage the funding package or they are offered the option, the final delivery of services is determined by the provider menu.

- *People with disability should be supported to receive reasonable and necessary supports, including early intervention supports (section 4 (5)).*

The feedback from families through peer groups, advocates, surveys indicate this is definitely not the normal experience. Parents are struggling to have what was in their previous state funded plans replicated, and previous block funded services that were received are being overlooked by planners.

- *People with disability should be supported in all their dealing and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs (section 4 (9)).*

The current limited time allocated to the planning process does not allow for people with complex and unique behaviours or communication needs to be involved in the process. The time allocated 1.5 to 2 hours in office environment is not conducive to families bringing their family members to the planning meetings. There is no culture of inclusion. Families have stated that they feel it's an interview process in which the need to go armed with all the evidence and facts that they then have to sell to the planner, who more often than not has not read the information previously provided. Families have reported that they take their family member just to prove to the planner that they require the supports and services they are requesting. Regular comments from parents have been "they hope their child is on their worst behaviour to prove they need support to the planner". People with disabilities feel they need the planner to see them on a bad day for them to be believed. Our advocates experience in working on reviews of plans is that planners have looked to the reference package rather than the individual and their circumstances.

If the principles underpinning the *NDIS Act 2013* are not being met at the point of planning, then there are serious agency culture and processes issues that need to be scrutinized and overhauled. Now is the window of opportunity whilst the scheme is in final roll out and moving into a steadier state to address this at a systemic level and fine tune processes that will ensure the integrity of the scheme provides the support and outcomes intended.

The experience, expertise and qualifications of planners;

The feedback from individuals and families has been that the quality, experience, expertise and qualifications of the planners varies markedly from planner to planner. This includes professionalism of the planners in engaging with people from the very outset of the planning session. Planners often came to planning meetings unprepared, they have not read the documentation previously provided by the individual and their family and are under a very tight time schedule.

The planners often use NDIS speak that families and individuals do not understand and people walk away thinking they have been understood and have what they need in their plan but end up with a plan that looks completely different. This very common theme is reported as an issue, with 45% of survey respondents saying they did not feel heard by the planner and 48% saying they did not know what they should be asking for.

“Planners and NDIS language. Planners are using legislation and "work speak" in planning meeting with individuals. There is a huge gap in understanding. I was in a meeting where I said three times - "I dont understand" and the Planner offered nothing, nor do the Support Coordinator. They just talked to each other. I felt excluded”

“I was very Proactiv and took time off work to study in detail the NDIS this is what helped me immensely, if I had NOT done this I would NOT have been able to even Understand the Jargon used. This is a BIG Problem for CALD group people, where language and culture are a huge barrier”

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NDIS Transition and interface survey 2019

People from cultural and linguistically diverse backgrounds have said that they 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.

Many clients accessing Individual Advocacy comment that the planner did 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 supports is not what ends up in the plan. While the NDIA have ‘disability guides’ which indicate the kinds of supports a person with a particular disability might need there needs to be better recognition by planners that people’s needs are diverse.

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 a number of therapy reports and evidence to demonstrate reasonable and necessary supports 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 supports or decisions about approved supports without having read, and considered the available information.

“Planners not being prepared. Don't send an email asking participants to send in documents well beforehand if you are not going to read them. It seemed they did not have enough clerical support too.”

“The last planner was wonderful, the previous planner in 2017 was dreadful, dismissive, condescending and elitist”

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NDIS transition and interface survey 2019

There is a 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. This is returning to the deficit model of the old State Combined Application Process (CAP).

The ability of planners to understand and address complex needs

The NDIS planners understanding of complex appears often to be limited and finite. Although there is an acknowledgement by NDIA there is a need for a "complex support needs pathway" that supports people with more complex support there is little acknowledgement that complexity for clients can be more than the pointy end situations that may involve mental health, homelessness or justice interface.

Complex supports could involve:

- multiple service providers,
- parent or carer capacity,
- Families who have other members in the same home with disabilities or mental illness.
- Refugee families who have experienced trauma
- Families with English as a second language from CALD backgrounds
- Individuals who have complex needs with communication or behaviour
- Multiple areas of support within a plan.

An example of the inability of planners to understand complex needs can be seen with a transition from state-based funding to the NDIS. The state-based funding plan had the incorrect dollar amounts attached, but provided clear information about the participants need for behaviour support and 2:1 supports. There were therapy reports and information provided for the planning meeting which all supported this as a reasonable and necessary support. The planner failed to review the content of the plan and the evidence of need and instead look at the dollar amount in the plan and based the NDIS plan off that. The result was a plan that only had half the required funding, leaving the participant without safe access to the community, limited support to develop his independence and the family without a safe home environment

The other concern raised by participants is planners having little or no understanding of unique or complex communication needs for participants. PWdWA recently engaged with the deaf/blind community holding a workshop with them to understand the issues and challenges they are experiencing in the transition to NDIS. The feedback was greatly concerning in that the majority of people felt they were not understood by the planner. The need for specific interpreters was denied. People had turned up to planning meetings

and interpreters were not booked. Planners suggested plans could progress by writing down questions and answers on paper.

“Anxious and feeling unprepared for the planning meeting. Would have preferred it not to be at the NDIS office but no option given”

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NDIS transition and interface survey 2019

Other areas of concern where that the plans were mirrored. A family reported that they had two children with same diagnosis of autism both children very different and requiring individualised plans. The planning meeting was set on the same day for both children with no gap between the planning meetings. The planner had not had time to read the reports provided by the family. The result was the plans were a basic mirror image of each other and very inadequate and requiring an internal review.

Planners are minimising the complexity by changing goals. e.g. 6 clear goals are condensed down to one goal and there is limited funding provided. Participants are meant to have full control over the goals included in their plans and this is in clear violation of the *NDIS Act 2013*. While a light touch review should be able to rectify this situation, it is not often used and people are being required to submit an s100 internal review.

“When explaining how my mental health issues affect my physical disabilities I was told that as this plan focuses my physical disabilities (primary) and my mental health issues are irrelevant”

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NDIS transition and interface survey
2019

The ongoing training and professional development of planners.

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

The survey to date conducted by PWdWA around the “NDIS transition and interface” clearly demonstrates this as a common theme. Of the feedback provided by the survey participants

45% of people felt that they “didn’t feel heard by the planner”

There is a need for planners to have ongoing training to understand the changes that are happening within the NDIA and maintain a consistent quality

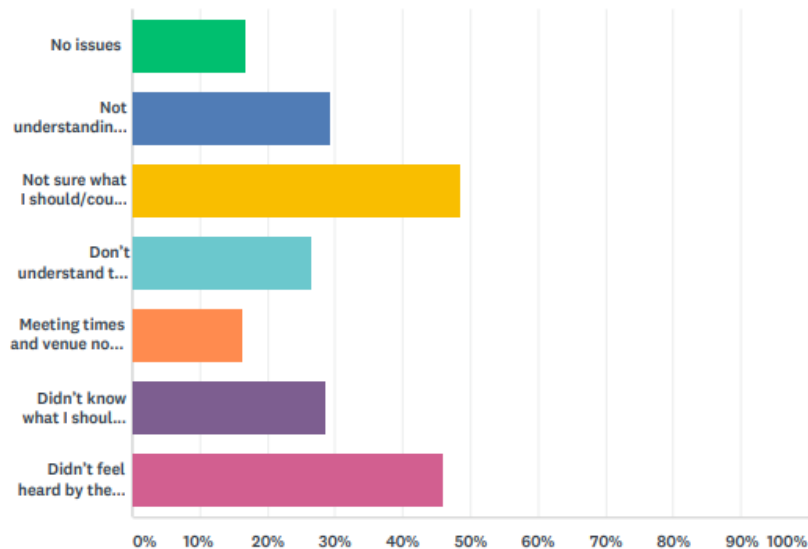
of interaction. The key job of the planner is to support and assist families and individuals at the planning meeting to ensure that everything is captured in the plan that meets reasonable and necessary support for the person. People should not feel penalised because they have a different planner who has less experience than their other family friend does. Consistency, transparency, knowledge, understanding, are all words that families use to express how they feel a service from a planner should be delivered.

A family member suggested in a community Peer group meeting that perhaps the families and individuals should be provided with the option to give feedback directly after their planning session through a survey to NDIA rating their experience and satisfaction of the planning meeting and process, and again after then seeing the plan.

Your NDIS Experience

Q7 Have you experienced any of the following issues with the NDIS planning process? (please tick as many answers as applicable)

Answered: 233 Skipped: 79



ANSWER CHOICES	RESPONSES
No issues	16.74% 39
Not understanding the preparation and pre-planning requirements for the meeting	29.18% 68
Not sure what I should/could ask for?	48.50% 113
Don't understand the process	26.61% 62
Meeting times and venue not providing flexibility	16.31% 38
Didn't know what I should bring to my meeting	28.76% 67
Didn't feel heard by the planner	45.92% 107
Total Respondents: 233	

“My sons goals were not reflected in the plan. I was also told I didn’t need reports as I would transition over with the same support we were already receiving”

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NDIS transition an interface survey
2019

The overall number of planners relative to the demand for plans;

There is immense pressure on planners in WA currently to get plans done in a timely manner. KPI’s of numbers of plans seem to be the priority not quality plans.

While NDIA guarantees a face-to-face meeting, planners have disclosed that they are being pressured into getting people to do plans over the phone because this allows them to do more plans per day. In a number of cases across advocacy organisations in WA, there have been unacceptably long delays between access being granted and planning meetings taking place – up to 12 months. This is a clear indication that there is not enough staff to meet the demand for planning needs. Planner fatigue is evident with the number of planner errors that are seen by participants. Things that have been discussed in the planning meeting have been left out of plans resulting in light touch reviews or internal reviews needing to be requested. This creates bottlenecks in the process, unnecessary stress for families and is not effective or efficient.

Additionally, because of the pressure on planners to get plans done they are not giving participants the time required to create a quality plan. They do not have time to read up on the participants background or the evidence submitted, and planning meetings are limited to an hour which means there is little time for the planner to ‘deep dive’ and ensure that all possible requirements for support are considered. The planner should be the person with knowledge about the types of supports available, and what supports a participant may require based on their disability – the onus should be on them, not the participant, to ensure all reasonable and necessary support are explored.

The introduction of LAC’s does not necessary solve this issue because the same quality and demand concerns exist and there is the added potential for information to get ‘lost in translation’ between the LAC and the NDIS delegate who approves the plan.

An example of this: a family that was supported to attend their child’s planning meeting was ushered out of their planning meeting after 1.5 hours as there was another planning meeting booked. This participant has extremely

complex needs with multifaceted supports required and the family was told the planner would use the documentation to complete the plan. There was no consideration to the wealth of knowledge that the family could provide as well as the therapist who has attended the meeting to support the participant. The final plan had the participant portrayed as able to do a number of things independently, which was completely incorrect and resulted in an internal review. This review process was undertaken 3 times before a plan was developed to reflect the child's complex needs.

“Planners are untrained, and /or have zero knowledge or experience of disability and what we BATTLE with everyday.
NOBODY at the NDIA/NDIS listens or cares about us or our needs!”

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NDIS transition and interface survey
2019

Participant involvement in planning processes and the efficacy of introducing draft plans;

PWdWA has noticed a trend for NDIA to not engage with a participant if there is a legal guardian involved, or where the person is younger e.g. 16-25 and has a parent supporting them. Effort should always be made to ensure the participant is at planning meetings, even if it is a child and this requires meetings to take place at the person's home. In many cases where the younger person has complex needs, we are seeing better results where the planner has met the younger person face-to-face. This also ensures that the younger person's needs and preference are taken into account as they can often differ from the needs and preferences of the family.

The other side to this issue of participant being present in a planning meeting is the planner directing all questions to the participant exclusive of the parent or guardians' input. An example was a young man with Down syndrome attending his planning meeting with his parents the planner directed all question to him and busily typed his responses. At no point was his parents asked their opinion etc. Even though documentation was provided by psychology reports demonstrating this young man had inappropriate sexualised behaviours whilst in public towards females the plan received did not reflect the need or support to address this issue and had minimal supports built into the plan this resulted in an internal review.

“Especially don’t know who to bring to the meeting. As a parent of a person with an intellectual disability I felt sidelined in the process. Planner said I need to have Guardianship to participate but I have been told that isn’t the case, I can be appointed Nominee for NDIS purposes. My child isn’t able to communicate effectively with the Planner so my input to the process is critical.”

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NDIS Transition and Interface survey
2019

Access to draft plans

In regards to making draft plans available – this would eliminate many common issues the PWdWA are seeing with participant plans including:

- wrongly categorised supports,
- funding discussed in planning meetings which are accidentally left out of plan,
- issues with the way funding management has been allocated
- Issues with transitions from WANDIS to NDIS which is guaranteed to be like for like but which is often not occurring.

While the option of a light touch review is available, PWdWA’s experience is that in practice, it is rarely used and people are instead being told to lodge an s100 Internal Review.

Individuals and families are reporting they are leaving planning meetings with the expectation that what was discussed in the meeting was captured by the planner and will transfer into the plan this is often not the case. This is a common theme that is being reported by people which results in the internal review process more often than not because the “light touch review “ is not offered. The other alarming message to people from planners is that if they are not happy with the feedback the planner is providing in the meeting the planners are saying” if you’re not happy when you receive the plan you can request an internal review” not explaining how long this process can take.

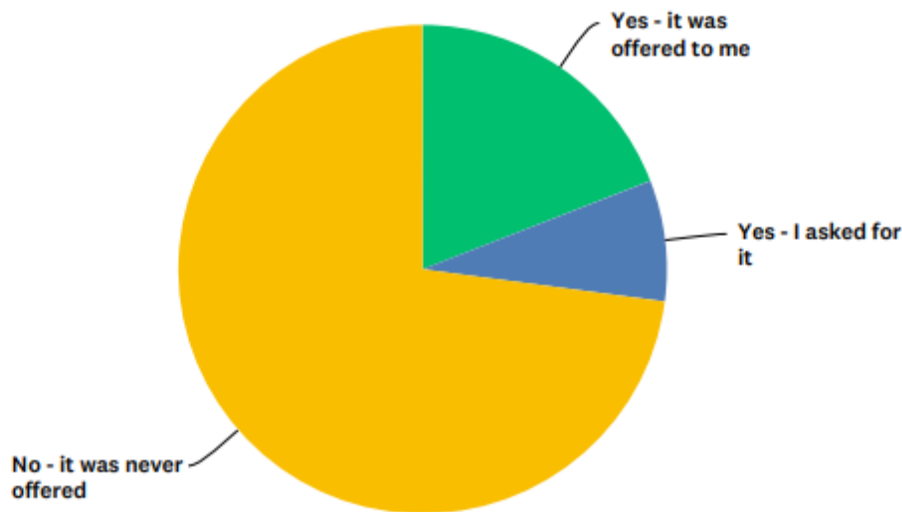
“The time between when a plan is approved and the way it is delivered to the participant is not acceptable. I think you should be able to read it as a document (as you would any other legal document) and have sufficient time to check it and ask for amendments if possible”

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NDIS Transition and Interface Survey

Your NDIS Experience

Q9 Were you given the opportunity to review your plan before it was finalised (a finalised plan is usually posted to you in paper format and put on the Participant portal)?

Answered: 225 Skipped: 87



ANSWER CHOICES	RESPONSES	
Yes - it was offered to me	19.11%	43
Yes - I asked for it	8.00%	18
No - it was never offered	72.89%	164
TOTAL		225

The incidence, severity and impact of plan gaps:

Over a 12 months period PWdWA assisted with 76 plan reviews relating to inadequate funding for reasonable and necessary supports. This included:

- lack of core support funding
- lack of therapy funding
- Assistive Technology not being approved or included in plans

Of those 76, 21 were related to significant gaps in funding. In some cases, the gap in funding amounts to up to \$100,000. In many cases, the gap in plans is placing the participant and their family at risk of harm. This includes where inadequate supports result in the participant being at risk of harming

themselves, harming family and has restricted access to the community because it is unsafe without adequate supports. It also includes risks of family breakdowns and burnout of informal supports. Additionally, the fight to address gaps in plans can have a severe and longstanding impact on the mental health of the participants and their informal supports.

A family at a peer support group PWdWA recently attended shared an example of the impact on primary carers. The single mother has mental health and depression issues and her daughter has complex needs and behavioural issues. The lack of supports built into the daughter’s plan resulted in her mother having a nervous breakdown and the elderly 80 yr. old grandmother having to step in and look after them both. There was nothing in the current plan to provide urgent support or back up because there were no supports in the plan. At the time of the initial planning meeting, the planner told the mother she was expecting too much from NDIS. The plan has been in the system to be reviewed and 7 months later the plan has yet to be reviewed and is coming up for a 12-month review.

PWdWA are only one agency, and we are aware the other advocacy agencies in WA have also had high numbers of NDIS reviews and appeals related to gaps in plan funding. We are also aware that many people submit reviews related to gaps in funding without the support of an advocate. Demand for assistance with NDIS plan matters has been so high that most advocacy agencies in WA now have a waitlist and PWdWA had to close its waitlist for 1 month because it became so high.

“Shocking leaving a family and child without support and the extra stress involved in trying to get it back”

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NDIS Transition and Interface Survey 2019

The reassessment process, including the incidence and impact of funding changes

As more yearly reviews are starting to take place in WA, PWdWA are seeing a rise in the number of participants seeking help due to decreases in plan funding. PWdWA are aware that many participants are having difficulties implementing their plans due to thin markets, and service refusing to work with ‘complex’ participants. There appears to be an assumption made by planners that if the funding has not been used then it is not needed in the next plan, which is often erroneous.

Additionally, there seems to be a shift towards an automatic yearly drop in funding, based on an assumption that the plan has built capacity and

therefore the person no longer requires the same level of support. It does not take into account that for many peoples need for core supports will not change, and that as goals are achieved new goals will be added to plan. This places people in the position of having to continually fight for reasonable and necessary supports and spend plan funding on ensuring they have adequate evidence to fight for continued or increased supports in their next plan.

The general feedback from participants and their families is that they are fearful going into the review process based upon the feeling that they will have their supports reviewed. This is often reinforced by comments made by planners and LAC partners to families at planning meetings. Comments such as “well this year you will have this support to build capacity and next year its likely not to be included in the plan”. There have been a number of participants and their families state that they are as nervous about their review meeting 2nd / 3rd/ 4th plan as they were at the initial planning meeting.

“Planning /Review meeting focused on what can be cut back on rather than on what’s required for progressing the next 12 months. Supplying funding for serviced that is requested by specialist that is 1/3rd of my budget that goes on report writing with for support not funded!”

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NDIS Transition and Interface survey 2019

In some cases, participant’s eligibility for the scheme is being revoked, or NDIA are threatening to revoke it as part of yearly reviews. This leads to uncertainty for the participant as there is often no specific timeframe given. There is also no clear explanation as to why the participant is no longer considered eligible.

The review process and means to streamline it

The current s100 internal review process is not timely, and in some cases the response from NDIA is undercutting natural justice.

The May 2018 Report by the Commonwealth Ombudsman highlighted the issues with lengthy delays with Internal Reviews.¹ The report noted that at the time one third of all complaints it received about the scheme were to do with the lack of timely handling of Internal Reviews. The NDIA in their response committed to:

- Develop and implement process for contacting participants who have a pending request in the national backlog and inform them of the process moving forward
- Develop streamlined process for correcting simple plan errors

E has¹ Commonwealth Ombudsman, May 2018, *Administration of reviews under the National Disability Insurance Scheme Act 2013: Report on the National Disability Insurance Agency’s Handling of Reviews.*

- A dedicated NDIA team being established to manage the backlog of reviews, including a process for resourcing

Currently there is still a long wait for Internal Reviews to be processed. Advocacy organisations across WA are aware of NDIA still taking up to 7 months to action Internal Reviews. Participants of the 'Your NDIS Experience' survey also indicated wait times of 3-9 months for Internal Reviews to be actioned.

Where the Internal Review has been submitted close to the 3-month deadline this means that a person is left under-supported for almost the entirety of their plan. Where the person has paid for reasonable and necessary supports out of pocket they are sometimes not reimbursed, as the funds are not always backdated. In some cases, annual reviews have occurred before the Internal Review has been considered. Due to the extremely long delays in actioning Internal Reviews and the growing demand for advocacy support, many of the WA advocacy organisations are also forced to close cases without a resolution being known, so that people on waitlists can be assisted.

There is a high level of frustration where simple planning errors such as a mistake in the number of hours cannot go through a streamlined process to be corrected quickly and efficiently. Despite a 'light touch review' mechanism existing many people are being told by NDIA staff to complete an Internal Review, which is taking months.

The reason for this appears to be two-fold. Firstly, there is no set timeframe for the completion of an s100 Internal Review in the legislation and the 'reasonable timeframe' is not currently guaranteeing a timely response. Secondly there is a backlog because there are not enough staff to process reviews, and where the review requires a new planning meeting, not enough planners to meet the demand.

Another worrying trend in relation to s100 internal reviews, especially where the person has complained to NDIA about the length of time taken to process a review, is the option to have an s48 unscheduled review in exchange for withdrawing an s100 Internal Review. This removes the right for a person to escalate the issue through to an appeal at the Administrative Appeals tribunal. Additionally, many participants report that when they attend these planning meetings the planner has no knowledge of the s100 Internal Review or the evidence and documentation that has been submitted to support an increase in funding. If a new planning meeting is required because of an Internal Review, the new plan should be considered the **outcome** of the internal review and a notice of decision should be issued explaining any changes to supports in the plan to enable the person to exercise their right to an appeal at the AAT.

Additionally, there are delays between Internal Reviews being finalised, and Notice of Decision being provided and new plans being received – up to a few months. This is meaning that in some cases families are continuing to be out of pocket for reasonable and necessary supports due to the delay.

The incidence of appeals to the AAT and possible measures to reduce the number

PWdWA has found there are an increasing number of people in WA seeking appeals at the AAT since mid-2019. The introduction of the Early Resolution team has meant that some cases have been able to be sorted before the need for an AAT case conference. However, if this is the case, then it is confusing as to why the matter was not resolved during an Internal Review and suggests that the review officer is not adequately trained to understand the needs of participants.

Often the Early Resolution process and conciliation process requests further evidence to demonstrate the need for reasonable and necessary supports. If the issue preventing the approval of funding is one of evidence, it would make sense for the planner in the first instance, and the Internal Review Officer during a review, provide feedback to the participant on what further information they need. If this can be provided in a timely manner, and the participant is given the opportunity to provide the information before a decision is made this could prevent the requirement for an issue to be escalated.

The circumstances in which plans could be automatically rolled-over;

At the time of review of a plan if it is demonstrated that the supports in the plan meet the needs of the participant and the goals in the plan are being achieved the plan should be considered to be automatically rolled over. The plans are developmental and focused on building capacity however there has to be an acknowledgement that some participants will always require support in their plans to meet their needs. Participants having to continue to fight for reasonable and necessary supports every 12 months cause unnecessary stress, anxiety and pain to participants and their families.

There appears to be an assumption by planners, or direction by the agency, that plans should be reduced each year. Where there are clearly established needs for supports these should be rolled over unless there is a change of circumstances resulting in increased needs. Similarly, where there is a clearly establish need for consumables and AT repairs these should be rolled over unless the participant indicates needs have increased.

An example of this is a family with a daughter who has profound and significant physical disabilities reported that in the second plan they went to the planner with everything documented about their daughters supports. This included all equipment, consumables, personal care, community and civic participation and demonstrated conclusively the last 12-month plan had been

successful in meeting their daughter’s needs no increase required. The planner commended them on how well prepared they were and said they had made her job easy. The plan came back rewritten with half the supports missing requiring an internal review.

‘Not enough funding in the plan initially. Each plan is looked at what \$\$\$ can be reduced. System does not consider issues like MS where there is multiple disabilities “

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NDIS Transition and Interface Survey 2019

The circumstances in which longer plans could be introduced

As outlined above there are definitely situations in which participants needs will not change due to the ongoing support required due to their disability. Examples of this especially relate to people who have complex personal care needs, daily living support, community participation, and will always require this level of support. This could relate to people who have spinal injuries, cerebral palsy, multiple sclerosis, neurological conditions or degenerative conditions.

A young man with cerebral palsy living in the community in an Independent Living Option (ILO) has reported that he has to demonstrate every plan that he still needs personal care, in home support, support to access his community and engage in work. Unless there is a significant change of circumstances in which case his needs would increase, he will always need the level of support he currently has in his NDIS plan. This situation could be considered for a longer plan unless there is a change of circumstances.

The adequacy of the planning process for rural and regional participants

The rural and regional areas in WA have their own unique issues in regards to the planning process in the NDIS. The distance to travel to planning meetings, gathering the necessary documentation required for planning meetings and the understanding of the planners about the barriers to receiving supports within small rural towns are only a few of the issues.

A family in Hyden reported they have two sons both with NDIS plans and the planner had no understanding about the distance required for her sons to access the activities that they wanted to pursue or the distance that support workers had to travel to work with her sons. This was completely let out of the plan and therefore an internal review is required.

PWdWA met with families in Geraldton and the feedback has been that the lack of service providers for the more remote areas has meant that families have to travel to Geraldton to receive services this requiring taking parents having to stay overnight due to distances travelled. The outer remote areas have participants with plans that they can't implement because there are no services.

The advocacy service in Geraldton reported that they spend all their time supporting people to get the documentation together to gain access to the NDIS.

A participant from Blind Citizens Group reported that she was requested to travel from her home in Pinjarra to a meeting at the NDIS office in Mandurah at 4pm on a week day. When she explained that she was blind and used public transport and that buses did not run at this hour the planner was dismissive and made her feel very uncomfortable. Eventually the planner agreed to come to her home however, the communication about the date and time was not clear and the participant was not at home when the planner came to her home and again made to feel uncomfortable and unreasonable.

“Communication. Very difficult to speak to anyone!”

“Excessive bureaucracy”

“Conflicting information with regards to AT and travel times for therapists”

“Lack of service providers and therapists charge too much. Funding won't stretch as much as required.”

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Issue with consent to enquire, or act on the behalf of a person with a disability

From the beginning of 2019, it has been increasingly difficult for nominees, family, and advocates to seek information, get advice and act on behalf of the person with a disability even though consent is present. This includes where informed consent has been provided or the person with the seeking information is a nominee but not a legal guardian.

There has been an alarming trend of the NDIS Call Centre staff advising parents and family of people with a disability over the age of 18 to apply for

Guardianship. There should be an inherent presumption of capacity of people accessing the scheme. There is the ability for someone to be appointed a nominee under the scheme. The Act also allows the NDIA to appoint a nominee if the person with a disability is unable to indicate their wishes or requires someone to communicate and act on their behalf. There should be no reason that a person is required to apply for Guardianship to act on a person's behalf in relation to the NDIS.

In addition to the issues faced by those accessing the NDIS, Advocacy agencies are also finding it increasingly difficult to enquire or act on behalf of participants. The important role advocates play in supporting people with disabilities to enjoy their full rights under the scheme is acknowledged in the *NDIS Act 2013*. However, since the beginning of the year advocates have found it increasingly difficult to do the role they are funded for by the government.

Inquiry into Supported Independent Living (SIL)

The historic model of congregated living options (group homes) in WA has resulted in many people living in shared accommodation for many years. The transition to NDIS and Supported Independent Living (SIL) tool and process has raised concerns for individuals, families, and service providers. The dilemma is how participants receive the necessary support to develop plans that are self-directed with choice and control when their current living arrangement hinges on numbers of participants in a house to make the option viable for the service provider.

The process of determining a participants needs based upon a shared care model limits the ability for that person to look at other options and models of support. The quoting tool requires a registered provider to provide a quote for the living arrangement. The quote is used to identify

- Individual supports to maximise the persons capacity to be as independent as possible in the home, personal care and household duties.
- Supports that are shared between participants to maximise efficient use of resources
- Supports available to all residents to ensure the smooth running of the household

(NDIS (SIL) Quoting Guidelines)

The concerns about the SIL process is that it limits the notion of an individual plan as it is based upon the shared living model. During transition this has meant that many individuals in shared accommodation have not had any input into their plan or an opportunity to be supported to get anything different.

NDIS also have a policy that vacancy management is the responsibility of the provider and will not be funded by the NDIS. This is providing a perverse

incentive for providers to keep people in shared accommodation wherever they can so as not to lose funds to run the support for the house.

People who have lived in congregated options for many years have little or no option to explore alternate models of accommodation. NDIS are requesting the information for the quote be based upon the service provider's detailed knowledge and understanding of the participant and their needs. The service provider provides the documentation to verify the level of support. At no time is an independent representation required to support the participant to explore and engage in the planning process. This leads to a breach of human rights.

The question is why is there SIL and ILO what is the distinction when every person deserves an individual plan that reflects the supports that they require and is not restricted to having to live with others that are not necessarily people of their choosing and is based upon economic viability for the service provider.

The other issue is that the SIL process does not provide surety of accommodation. Providers require the numbers in the shared living arrangements for viability, so if people leave or pass on and the viability of the option becomes an issue and there is an urgency to fill the bed space or move people from house to house to fill the vacant spaces.

Recently a family shared that their son who has very challenging behaviours, is highly anxious was moved 4 times by their last provider due to vacancy issues. This left the participant with no sense of home, surety, safety and consistency. He developed very high anxiety and became very aggressive. This resulted in him being hospitalised and without a home as the agency withdrew their services.

Conclusion

The current responses gathered from participants of the scheme and their families, advocacy services, and services clearly show that there are significant issues in the implementation and performance of the NDIS. The systemic issues are directly related to the deliverables at the grass roots. The planning process is currently flawed and does not provide participants with fairness, equity or consistency. The impact of these issues is creating unnecessary stress and anxiety for many people in the scheme.

The planning process seems to work well when people have had pre-planning support and understand what an NDIS plan will look like and what language to use. In WA the LAC Community partner role has just started and we hope will be providing a better planning service, however early indications show similar issues with training, listening, and understanding.

The aspects of the NDIS that participants say are working well are generally when they have flexibility and choice in their package. Individuals and families

“My family member with disabilities has funding to enrich his adult life after school without we have to quit job and stay home. We managed to find good service providers who can make this happen.”

“Level of support has significantly increased from before. Direct engagement with service provider, better choices. Able to build a relationship with Service Provider and Workers to suit needs”

‘The money provided to me has greatly increased my quality of life. I went from being a home bound person to having a big social & recreational calendar.’

“My son has a two year plan. As he has a lifelong disability it is so much better than having to front up every year. He previously had State funding but the NDIS funding is so much more flexible and allows him to lead a close to normal life (without always having to be with family).”

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need to be recognised as whole beings with a range of unique circumstances. Reference packages are useful, but not the default.

The recommendations below are based upon the experience of people with disability, their families and carers, and advocates. They aim to address the key issues raised by our submission.

Recommendations

PWdWA has made some recommendations for consideration below.

Recommendation 1.

PWdWA recommends that the NDIA invest in ongoing training for the planners and LAC partners to ensure that there is consistency between planners and the final plans. Training must include:

- Knowledge of the NDIS principles,
- Knowledge of NDIS policy and process
- Understanding of disability, particularly various communication needs,
- How to engage with participants and families,
- Reasonable and necessary in a variety of diverse contexts, and
- Person centred planning.

Training should not just be a once off, but annual refresher training in line with changes to policies, guidelines and pricing.

Recommendation 2.

PWdWA recommends that NDIA provide people with a draft plan that can be considered by the individual at the time of the planning meeting or immediately after and before final sign off, to ensure that all areas discussed at the meeting are included in the plan to avoid oversights and planner error.

Recommendation 3.

PWdWA recommends that the NDIA have a red flag in the plan builder system to notify if there is a large decrease in a persons funding at plan review. If a large decrease is noted then it should be investigated first for planner error, and second for appropriateness.

Recommendation 4.

PWdWA recommends that the review process consider longer term plans that are rolled over and reflect the ongoing supports that a person requires rather than having to provide evidence every 12 months to ensure continuity of supports.

Recommendation 5.

PWdWA recommends that the *NDIS Act 2013* is changed to enable minor amendments to be made to plans in a timely manner without need for full plan review, and to include a time frame for action to be taken from a formal Internal Review (s100).

Recommendation 6.

PWdWA recommends that independent planning support is funded for people living in shared accommodation (group homes) who have no informal support such as family or friends.

Recommendation 7.

PWdWA recommends that a formal working group be established which includes advocates and people with lived experience of group living to explore alternative solutions to planning and funding for current SIL.

Recommendation 8.

PWdWA recommends that Individual Advocacy funding is increased to match increased demand, and long term security of funding is guaranteed.

For further information please contact our Executive Director Samantha Jenkinson.