



Submission in response to Consultation Paper – Planning Policy for Personalised Budgets and Plan Flexibility (NDIS)

People with Disabilities (WA) Inc. (PWdWA) and WA's Individualised Services (WaiS) would like to thank the NDIA for the opportunity to provide comment and recommendation on their proposed Planning Policy for Personalised Budgets and Plan Flexibility, along with the proposed implementation of independent assessments.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy. PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

WaiS is a niche, member-based, organisation. WaiS support people, families and services providers to understand, design and develop supports and services that are individualised and self-directed. Through individual and service provider memberships WaiS seek to provide strategic advice to Government.

Please note that PWdWA and WaiS are providing this submission in conjunction with a submission on Access and Eligibility Policy – Independent Assessments.

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People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer 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.

PWdWA receives both state and federal funding to provide advocacy around issues experienced by the community concerning the National Disability Insurance Scheme (NDIS). In particular we are funded by the Department of Social Services to provide support with NDIS Appeals.

WA's Individualised Services (WAI S)

Western Australia's Individualised Services (WAI S) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and advance individualised, self-directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have evolved to become thought leaders in this space, providing comprehensive, intentional support with integrity, passion and authenticity at our core. By leveraging our extensive local, state, and international network, we seek to lead, influence, innovate and inform to create meaningful and lasting change, supporting people to build capacity and live their lives on their own terms.

Unlike any other organisation, we partner and work with all sector stakeholders, as well as providing vital links, ensuring that disability services respond to the unique needs of people. We work to ensure that people can access and navigate the services and the sector to achieve their goals.

WAI S is the only organisation that has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Co-ordinators and government, specifically in the area of individualised, self-directed supports and services.

Introduction

Fundamental to the NDIS are its legislated Objects and the Principles that underpin it that are strongly embedded with Human Rights. The very first object is to “give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities”. In doing so, the Scheme is to “support the independence and social and economic participation of people with disability” and “enable people with

disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports”.

Consequently, people's access to adequate, appropriate, responsive and individualised supports funded under the NDIS to support them to live a good life is an extremely important aspect of both PWdWA's and WAI'S's work at both a systemic and individual level. Our joint submission is compiled based on the experiences of people with disability, their families and carers as well as advocates and advisors who provide information and support to people. We have provided scenarios where appropriate to furnish our statements.

We are extremely concerned with the proposed changes from NDIA and the lack of meaningful co-design or consultation that is occurring. PWdWA, in particular, continues to see a rise in people seeking significant advocacy support in relation to NDIS. We believe that the proposed changes will further exacerbate the entrenched disadvantaged experiences by many of the people we support, expose them to an increased risk of harm and will further increase the burden on the advocacy sector. The points raised in this submission are reflective of the hundreds of people we have assisted with information, support and advocacy in relation to the NDIS over the past year.

Section 1: Summary of Recommendations

This submission provides a number of positions and recommendations that PWdWA and WAI'S strongly urges the NDIA to consider. These perspectives and recommendations have been developed as a result of issues brought to our attention through our work, and consultations and surveys with people, families and carers. Our responses are also informed through PWDWA and WAI'S collaboration with the disability and advocacy sectors.

Recommendation 1:

Halt the implementation of the Independent Assessment Framework and the Access and Eligibility Policy

Recommendation 2:

The NDIA fundamentally re-think its independent assessment framework and proposed planning process and re-develop its policy through co-design with people with disability, their families and carers.

Recommendation 3:

If independent assessments are to be used as a basis of determining budget, that this is done subsequent to a planning meeting and incorporate information that is acquired during the planning meeting.

Recommendation 4:

The NDIA, if it is to continue with the use of independent assessments, people need to be leading the assessment, involved across all parts of the assessment, provided with a draft of the assessment, together with being able to sign off or note if they agree or disagree with the assessment prior to it being submitted.

There needs to be a way for the outcome of the assessments to be reviewable if people are to have any choice and control as to the outcome, particularly given the potential impact of that outcome.

The assessment, given it is about the person, their needs and circumstances, should be held and owned by the person, regardless of how this assessment is funded and by whom. **'Nothing about me without me'**.

Recommendation 5:

Increase the availability and quality of support for plan implementation available from delegates, Support Coordinators, Local Area Coordinators

Recommendation 6:

Develop clear guidelines as to when and what parts of a budget needs to be fixed and/or flexible to ensure maximum flexibility is retained by people in using their budgets.

Recommendation 7:

People have access to their full budget upfront to allow for maximum flexibility and control, throughout the year.

If, the regular release of funds is an option, make it only at the request of the person, and ensure easy, swift and responsive processes if people require top-ups prior to the next release.

Recommendation 8:

If, the regular release of funds is an option, enable funds to be rolled over for as long as the plan is for.

Recommendation 9:

Provide clear and transparent guidelines about the purpose and process with check-in's, ensuring these check-ins are based on peoples' choice and control and not mandatory in nature.

Provide clear and transparent guidelines as to who can do the check-in's.

Section 2: Highlighted Issues

2.1 Independent Assessments as the basis of Draft Budgets

We highly welcome the intention of the NDIA's proposed processes, which is to create a way for people with disability to have a total funded support budget, that can be utilised flexibly and responsively in line with the persons vision and goals. We also highly welcome exploring ways to make the scheme equitable and sustainable.

PWdWA and WAI S disagree with the NDIA's decision to use mandatory Independent Assessments as the method to achieve the outcomes they seek. We have a number of concerns in relation to the Independent Assessment Framework and the proposed Planning Policy.

2.1.1 Design and Development

The General Principles of the NDIS Act are clear that people with a disability have the right to be "*equal partners in decisions that will affect their lives*".¹

PWdWA and WAI S fundamentally disagree with the approach the NDIA has taken in the design and development of both the Independent Assessment Framework as well as the Access and Eligibility Policy and Planning Policy. Instead of adopting a co-design approach which would engage people with a disability to develop a policy to address issues of inequity seen within the scheme, the NDIA have come up with an approach and are asking for feedback on how to implement it. They are not asking people whether they believe the approach is suitable, or if it will address instances of inequity seen within the scheme. This lack of co-design approach is reflective of a system that seems to be going back to a 'we know what's best for you', medicalised professional approach, which is in direct conflict with the principles of the NDIS.

2.1.2 Fundamentally flawed premise and approach

PWdWA and WAI S have fundamental concerns in relation to the NDIA independent assessment framework (please see our other submission) and its consequent use to create a draft budget. There is very little detail nor transparency about how Independent Assessments will be translated to budgets. This will undermine people's ability to both (a) trust the process; and (b) understand the justification for the draft budget.

¹ NDIS Act 2013 Part 2: 4(9)

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People have strong concerns about the ability of an independent assessment, undertaken by someone with no previous relationship nor depth of understanding of the person, their situation, history and context and within a proposed 3-4 hour time period, to appropriately be translated into a budget appropriately aligned with peoples' individual needs and goals.

It is a near practical impossibility to be able to effectively assess not only a person's functional capacity, but also their support needs and environmental context in such a short period of time, by people who don't know the person, particularly for people who have complex communication access needs, and/or who are living in challenging or complex situations. PWdWA and WAI S disagree with the NDIA's proposition that: "Unlike the TSP, the personalised budget will ensure a stronger link between a participant's level of functional capacity, including their environmental and personal context, and their level of plan funding."

We strongly disagree that a functional assessment directly correlates with someone's ability to be socially and economically participating.

It is also inherently illogical and completely counter to individualised, person centred planning and principles outlined in the NDIS Act itself to have a draft budget BEFORE any planning has taken place. This proposed planning process is in direct conflict with the very principles the NDIA's planning policy espouses:

- a) provide **personalised budgets** which balance individual circumstances and the sustainability of the NDIS
- b) **recognise participants as experts in their own lives** and maximises flexibility and participant control over their personalised plan budget
- c) maximise the opportunities for community participation with support from mainstream and community services, and/or funded supports
- d) **recognise the participant's autonomy and independence in decision making processes that affect them**, and support them to make decisions for themselves

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- e) maximise the participant's opportunities for informed decision-making based on the best available evidence about supports and recognises the dignity of risk
- f) be as accessible as possible, **holistic and strength-based**, where participants can adapt their supports to their life circumstances and environment

In particular, we draw your attention to the principles relating to participation of people with disability legislated for in the NDIS Act, section 17A:

- (1) People with disability are assumed, so far as is reasonable in the circumstances, to have **capacity to determine their own best interests and make decisions that affect their own lives**.
- (2) People with disability will be **supported in their dealings and communications with the Agency** so that their **capacity to exercise choice and control is maximised**.
- (3) The National Disability Insurance Scheme is to:
 - (a) **respect the interests of people with disability** in exercising choice and control about matters that affect them; and
 - (b) **enable people with disability to make decisions that will affect their lives, to the extent of their capacity**; and
 - (c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

And, we also draw your attention to principles relating to plans legislated for in the NDIS Act, section 31. In particular, these sub-clauses:

The **preparation, review and replacement** of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (a) be **individualised**;
- (b) be **directed by the participant**;...
- (j) facilitate **tailored and flexible responses to the individual goals and needs** of the participant

Through our consultation process people stated that:

“The barriers are that an assessment team – some of whom have no experience in the disability sector are making decisions that affect the lives of [people] – without even meeting the individuals...Some NDIS people – in fact most do not understand my particular disability.”

“My belief is that the IA will be a BLUNT tool.”

“Deciding how much to allocate to an NDIS recipient should be based on need. Allocating fixed amounts will mean some people get far less than will meet their needs, while others receive more than needed. Needs can't be identified in 3 hours stacked in with an independent assessment for access performed by someone who can't possibly be qualified enough to understand the complexities of living with rare or complex conditions, or even common conditions within a complex social context.”

“Independent Assessments will NOT make good Plans and Budget, No assessment done in 3 hours by a stranger can give a NDIS plan, this is a step completely against what NDIS stands for ie Human Rights and Choice and control of PWD, To make independent assessments the basis for funding amounts is total disregard to the person with disability, it's extremely harmful and nothing good can come of this type of assessment.”

We note that section 3.3 of the Consultation Paper states that changes to draft budgets will only be made in specific circumstances including:

- where a participant has extensive and/or complex support needs
- there are additional high cost supports that are not accounted for in the independent assessment e.g. Specialist Disability Accommodation, AT or home modifications

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There is no clear guidance on what would constitute extensive and/or complex support needs. If a plan budget is inadequate, we are concerned that people who are already particularly vulnerable are going to have to argue that their support needs are extensive and/or complex in order to access changes.

There is also no explanation as to what changes can be made when a person meets this criterion. Additionally, if a person does not meet the above criteria, they will be forced to go through a review process, rather than being able to address issues at the planning stage itself. We have supported many people who have been left vulnerable and at risk by inadequate access to supports and have concerns that this proposed process does not alleviate this issue.

It was identified through a consultation process that people have strong concerns about how much flexibility there will be for draft budgets to be adjusted as a result of a planning meeting to take into consideration individual circumstances, in particular, people with complex support needs.

“People need to have the right to access support to live a good life. This process shows a distrust of people and people’s capacity to know what’s best for themselves. It’s a real departure from the NDIS premise of choice and control.”

“I don’t think independent assessors will make good plans and budgets, because its changing the process and reversing the order. People are going to get a budget and plans will be built around that. As it stands now, people’s needs are assessed and then get a budget according to their needs and their goals. There’s no mention of goals in this independent assessors stuff and that really concerns me. It’s changing the focus.”

Even before the introduction of these new policies, many people have had concerns in relation to significant short comings and inadequacies of planning meetings.

“Despite two reviews where the planners took no notice of...supporting documents I had to go through AAT who saw sense in my request for increased support. The NDIS needs planners who have knowledge, understanding and are skilled... My experience with NDIS over the past 12 months has been anything but person centred. It was a completely non transparent procedure.”

These concerns will only be significantly heightened by the proposal to have independent assessments lead to draft budgets and then to a planning meeting, with fears that these planning meetings will inherently be a tick and flick approach.

Recommendation 1:

Halt the implementation of the Independent Assessment Framework and the Access and Eligibility Policy

Recommendation 2:

The NDIA fundamentally re-think its independent assessment framework and proposed planning process and re-develop its policy through co-design with people with disability, their families and carers.

2.2 Relevance of Goals

The NDIS Act states that the NDIA *must* have regard to a participant’s statement of goals and aspirations when deciding to include supports in a participant’s plan (section 33(5)(a)).

Secondly, before including *any* support in a participant’s plan, the NDIA *must* also be satisfied that the support will assist the participant to pursue the goals, objectives and aspirations included in the participant’s statement of goals and aspirations (section 34(1)(a)).

Therefore, the link between participant’s statement of goals and aspirations and the statement of participant supports is explicit and ensures that the participant’s

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statement provides the important foundation for the subsequent selection of supports.

We note that in the NDIS consultation paper, it is stated that “The NDIS Act does not provide that a participant’s goal or aspirations determine their reasonable and necessary supports, or that a particular support must be linked to particular goals in the plan, or vice versa”.

This is in direct conflict with the Act.

In order for there to be a meaningful link between goals and a personalised budget, it requires an approach that flows from goals to support needs to budget. It is, meaningless to identify goals and support needs after a budget has been set.

We note that the NDIA has indicated there may be changes to the NDIS Act 2013 (the Act). We are concerned by the suggested legislative changes that would be required to make both the proposed Eligibility and Access and Planning policies possible including changes to section 34’s “reasonable and necessary” criteria.

The reasonable and necessary criteria are the fundamental basis of being able to access personalised supports. There was no recommendation from the Tune Review to make any changes to the criteria. The AAT have also stated that the criteria are “straightforward and pragmatic” ([2020] FCAFC 79). There is no evidence that the criteria itself lead to inconsistent outcomes, more so, concerns centre around the inconsistent implementation of section 34 of the Act by NDIA. This is consistent with the experiences of PWdWA advocates supporting people to review the reasonable and necessary supports in their plans.

We do not support significant changes to Section 34 of the Act without adequate consultation.

Recommendation 3:

If independent assessments are to be used as a basis of determining budget, that this is done subsequent to a planning meeting and incorporate information that is acquired during the planning meeting.

2.2 Review of budget decision

PWdWA and WAI S acknowledge that the final decision in relation to a personalised budget will be made by the delegate and that these decisions will continue to be reviewable. However, it remains unclear how the outcome of the assessment and subsequent budget allocation will be able to be reviewed given there is little transparency as to how independent assessments will be converted into a budget and given the independent assessments themselves are not reviewable.

Without knowing how individual assessments will be translated to plan budgets, there will be insufficient information available for people to determine whether their plan budget meets their needs. As a consequence, people may be forced to provide evidence of a comprehensive list of their specific needs for a review, rather than just being able to focus on the area of funding that the NDIA did not fund, as is currently the case. The current system enables a person to specifically identify what supports the NDIA has and has not determined are reasonable and necessary.

Other concerns arise. For example, what happens if the issue lies with the independent assessment itself? Will a delegate be able to make a review decision that is inconsistent with the independent assessment? Will the delegate have authority to request a new or amended independent assessment? Will the participant be required to go through both a complaints process about the independent assessment as well as seek a review of their budget?

This is another demonstration of how the 'we know what's best for you' professional and medicalised approach is applied and reinforced.

Recommendation 4:

The NDIA, if it is to continue with the use of independent assessments, people need to be leading the assessment, involved across all parts of the assessment, provided with a draft of the assessment, together with being able to sign off or note if they agree or disagree with the assessment prior to it being submitted.

There needs to be a way for the outcome of the assessments to be reviewable if people are to have any choice and control as to the outcome, particularly given the potential impact of that outcome.

The assessment, given it is about the person, their needs and circumstances, should be held and owned by the person, regardless of how this assessment is funded and by whom. **'Nothing about me without me'**.

2.3 Fixed and Flexible budgets and release of funds

2.3.1 Fixed and Flexible budgets

PWdWA and WAI S fully endorse the ability for people to have flexibility with their budget. This would be the ultimate endorsement of people having choice and control. However, flexibility is great as long as budgets are actually fundamentally flexible in implementation. If the NDIA decides to dictate that certain types of supports need to be fixed leaving very little able to be flexible, this would then negate this promoted intent for budget flexibility.

With a move to more flexible budgets there must also be greater support for people to understand and implement their plans. The experience of both PWdWA and WAI S has been that people have difficulty understanding how they can use their NDIS

funding, even when it has been allocated to specific types of supports. The NDIA has proposed that there will be an in-depth discussion with the planner about how a person could use their budget to meet their goals. Based on our experiences, however, we believe that further support will be required outside of this initial planning meeting. While the proposed 'check-in' could be a proactive way for the NDIA to support people with the implementation of their plan the person doing the check-in must have adequate knowledge of the person and their plan and cannot be the only ongoing support available.

Recommendation 5:

Increase the availability and quality of support for plan implementation available from delegates, Support Coordinators, Local Area Coordinators

Recommendation 6:

Develop clear guidelines as to when and what parts of a budget needs to be fixed and/or flexible to ensure maximum flexibility is retained by people in using their budgets.

2.3.2 Release of funds

PWdWA and WAI S have strong concerns with the concept of regular release of funds. Our concerns include:

- (1) Increased administrative burden and stress on people in being able to manage their budget from period to period
- (2) Increased confusion by people as to how this would work, especially in relation to when funds can and cannot be rolled over
- (3) Reduced flexibility reflecting the reality of life and possible fluctuating need for supports dependent on a wide variety of circumstances
- (4) Presumption that a plan budget is adequate and will not be reviewed

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“Giving funding monthly is taking away choice and control and condescending and degrading.”

“My support needs are not constant throughout a year - whilst my disabilities are stable, my support needs are not.”

This will be extremely problematic for most people, and I have reiterated these issues to NDIA repeatedly with no response or outright dismissal of the concerns. -

Providers often get behind in invoicing, sometimes as much as 3mths. And you don't know until you receive the bill how much you have been charged for [for example] non face-to-face work. This mean we could be hit with a large bill ... and be unable to cover [other] costs.”

The NDIA has outlined that “unspent funds can continue to roll over from one period to the next for up to 12 months”. It is unclear how this would work within the context of plans that are longer than 12 months. If the proposal is that plans can be for more than 12 months, however, budget cannot be rolled over for more than up to 12 months, this unnecessarily restricts the flexibility with which people can use their budgets.

Currently, where a plan has been substantially underfunded people have utilised large portions of their plan up front to help cover the shortfall while in the process of seeking a review. There is no clarity around how this new proposed release of funds process would work in the case of someone seeking a review due to inadequate funding. For example, whether the person would need to apply to access funds ‘early’. If people cannot access adequate funding whilst they are seeking a review of their inadequate plan budget, there is the risk they will not be able to access critical supports while they are waiting for the review to be finalised.

Recommendation 7:

People have access to their full budget upfront to allow for maximum flexibility and control, throughout the year.

If, the regular release of funds is an option, make it only at the request of the person, and ensure easy, swift and responsive processes if people require top-ups prior to the next release.

Recommendation 8:

If, the regular release of funds is an option, enable funds to be rolled over for as long as the plan is for.

2.4 NDIA check-ins

PWdWA and WAIIS conceptually welcome NDIA check-ins as a safeguard for people.

It is of concern that the NDIS states that people are “able to book and re-book the time for their check-in, **but not cancel it**. The check-in **must occur within a reasonable period** of the original date.” This suggests a mandatory approach to check-ins and limited choice and control with the person as to the need for and details of a check-in.

To ensure it does not impinge on people’s rights, we suggest the following:

- (1) Requirement for check-ins is driven by the choice of the person, not mandated by the NDIA. As such, there are no punitive consequences if people do not participate in check-ins.
- (2) When, where, how and with whom check-ins are done is the choice of the person, not the NDIA.
- (3) Where it has been identified as someone being at significant risk or highly vulnerable (for example a person has extremely complex support needs, a

critical incident history and/or is living alone or working with only one support provider with limited or no informal supports), regular set check ins are implemented to ensure their continued safety and wellbeing.

“Check-ins need to be framed carefully and the approach needs to be considered so it’s a **check in not a check-up** approach. It needs to be a positive engaging supportive check in not a big stick approach.”

“Good idea but maybe better to have it so we can contact them if we need it. Most people can just get on with it.”

Recommendation 9:

Provide clear and transparent guidelines about the purpose and process with check-in's, ensuring these check-ins are based on peoples' choice and control and not mandatory in nature.

Provide clear and transparent guidelines as to who can do the check-in's.