

Access and Eligibility Policy with Independent Assessments & Planning Policy for Personalised Budgets and Plan Flexibility – Consultation Submission

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For more information regarding this submission, please contact:

Melissa Noonan, Chief Executive Officer

Limbs 4 Life Incorporated

PO Box 282, Doncaster Heights, Victoria 3109

1300 27 22 31

melissa@limbs4life.org.au

www.limbs4life.org.au

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1. Introduction

Limbs 4 Life is Australia's national peak body for people of all ages living with limb loss. It was founded as an incorporated charity in 2004, is supported by 170 amputee peer support volunteers and offers evidence-based support to many thousands of Australians facing and living with limb loss each year.

Limbs 4 Life is pleased that the NDIA has broadened consultation with the community in relation to the introduction of independent assessments and the planning policy for personalised budgets and plan flexibility. Like many other disability organisations, we were concerned that the original independent assessment trial was too small and brief to genuinely and meaningfully capture insights from a broad and diverse range of people living with various disabilities.

While we acknowledge that the new policies have been informed by recommendations of the Tune Review and the Productivity Commission, with a genuine intention to make functional assessments more holistic and deliver consistent outcomes and decisions for NDIS participants, it is vital that broad consultation into how independent assessments will be implemented prior to its 2021 trial and future roll-out.

We trust that this consultation will provide a greater number of current NDIS participants, disability organisations, practitioner bodies and members of the public with an opportunity to guide the introduction of these significant changes to NDIS policies in 2021.

The NDIS has greatly improved the lives of many Australians living with disability since its landmark introduction. We, and members of the limb loss community, strongly support the choice and control philosophy that the NDIS offers and the transformative impact that it has had for our members. It is our position that the introduction of an NDIA assessment process be "simpler, faster and fairer" has significant scope to result in making functional capacity assessments more consistent, however any changes must take account of insights from individuals with disability and members of the disability sector that understand the unique needs of their communities.

Limbs 4 Life welcomes the opportunity to work with the NDIA to ensure that the introduction of independent assessments will achieve its aspiration to improve the access and supports available to people living with limb loss.

This submission provides responses to the consultation paper questions, raising issues and concerns that must be considered prior to full roll-out. Our responses, recommendations and concerns are drawn from internal knowledge as well as insights shared by the limb loss community.

2. Issues and concerns in relation to an enhanced assessment process

Limbs 4 Life welcomes further piloting of the Independent Assessment process and approach, in order to identify any issues or concerns that can be incorporated into a new model. In addition, any issues and concerns must be taken into account if a successful, sustainable and fair independent assessment approach is rolled out.

Limbs 4 Life suggests the following independent assessment related matters and recommendations be taken into consideration:

- The independent assessment pilot currently underway must be broad, incorporate a wide range of demographics and be delivered in various locations (i.e. metropolitan, regional, rural and remote) as doing so will ideally tease out any issues or concerns prior to a full roll-out.
- A large majority of people with limb loss have an acquired disability, and enter into the NDIS for the first time after their amputation. Such participants are struggling to come to terms with their new disability, the impact it will have on them and those around them, and changes in their socio-economic lives; making navigating the new NDIS system challenging. All of these factors can make people with limb loss vulnerable to mental health issues and illnesses. As such it is critical that independent assessments are delivered quickly with minimal impact to the individual, particularly in the initial phase, so that they have a chance to adjust to their newly acquired disability and reduce the risk of short or long term mental health impacts.
- Determine at what point independent assessments should take place in a recent amputee's recovery journey, given that a person with newly acquired limb loss will require very different supports in the earlier stage (e.g. 6 – 12 months) to that of one who has had the lived experience of this unique disability for a longer period of time.
- Ensure that the allied health practitioners delivering independent assessments have adequate post-graduation field experience, prior to being approved to deliver the selected instruments/tools.
- While we understand what has driven the independent assessment approach and the selection of instruments/tools to determine a person's functional capacity, it is vital that Delegates who are not allied health practitioners fully understand the results in order to approve and develop reasonable and necessary plans and budgets.
- Ensure that participants clearly understand how, when and what constitutes an opportunity for a plan to be re-assessed, thus ensuring they understand their right to a review should circumstances change for the better or worse.
- Clearly identify the complaint mechanisms available to individuals should they not be accepted into the NDIS, if they don't agree with the independent assessment results, or the budget allocated to them.
- Fund organisations specific to a disability type and their peer workforces to support their unique communities, develop resources and provide information that will assist people to: prepare for a plan meeting; understand their plan and how funding can be spent; and, identify any issues with the NDIA so systemic issues can be resolved.
- Fund peak disability organisations and allied health bodies to train and broaden the knowledge base of NDIS Delegates, enabling them to gain detailed information about specific

disabilities and impacts, thus helping to ensure that high quality plans and budgets are developed.

- Recognise that recommended retail prices for prosthetic consumables should be made available to amputee participants, thus enabling them to compare costs and effectively financially manage their NDIS budget.
- Understand that it is unclear within which funding bucket maintenance and major repair costs for complex assistive technology will be allocated, and that as these needs are often emergency or unanticipated needs it is near impossible to include this in a flexible funding stream.
- Establish new disability specific Independent Advisory Reference Groups (e.g. 'other physical', 'intellectual', 'neurological' etc) comprised of NDIS consumers and peak bodies with lived experience of, or expertise in, those categories of disabilities. These disability specific reference groups would best represent and understand the needs of their specific disability communities and be well positioned to independently evaluate and provide guidance regarding plan budget levels, and be in the position to provide sound advice to the Independent Advisory Council or the NDIA more broadly.
- Maintain funding for the Information, Linkages and Capacity Building (ILC) Program, to enable disability support organisations and peer support networks assist in sharing information about and planning for independent assessments, and other matters, to their unique and connected disability communities.
- Conduct an external review into independent assessment trials and roll-out, and publish the results of these, to allow for future consultations with NDIS participants and the wider disability sector.

3. The potential benefits of an enhanced assessment process

Limbs 4 Life recognises that making changes to the current NDIS assessment processes can help to ensure that Australians living with limb loss have equitable access to complex assistive technology and other supports available through the NDIS. In turn this can increase their opportunities for greater socio-economic participation.

A range of reviews, such as the Tune Review and Productivity Commission Inquiries, have highlighted issues associated with existing assessment processes and made recommendations for improved assessment processes in an effort to overcome these. The benefits of the introduction of a functional capacity assessment process include:

- NDIS adequately funding independent assessments to remove barriers that the upfront cost of acquiring these can place on current and potential NDIS participants.
- Transparency of decision-making processes through use of standardised assessment tools and provision of rationale for decisions to participants.
- An assessment approach and policies that can enhance quality and mitigate concerns in relation to inconsistent decision making.

- Assessing people on the basis of functional capacity, rather than diagnosis, provides an opportunity for people to be considered on the basis of their individualised challenges, barriers and functionality.

4. Access and Eligibility Policy with Independent Assessments

4.1 What will people who apply for the NDIS need to know about the independent assessment process? How this information is best provided?

As a significant shift in how people are assessed to enter and remain within the NDIS, it is critical that information about the independent process is extensively shared with, and understood by, current and future participants. This will mitigate the risk of misinformation being shared and assist in reducing fears on people with disability retaining choice and control and access to the supports they so rightly deserve.

People who apply for NDIS supports and/or those who are already in the scheme, need simple, clear and concise information about the assessment process and why it is in place. This should include:

- The recommendations that have informed this policy shift, particularly current participants.
- The intended outcomes and the purpose of independent assessments, coupled with rationale as to why instruments that have been selected.
- How the independent assessment decisions will be independent of, or not influenced by, the NDIS or NDIA-funded organisations (e.g. 'Partners in Community' funded organisations).
- That the provision of reports and evidence from a person's treating medical or health professional can still be submitted as evidence where required.
- Clarity about how and to whom people can challenge an independent assessment decision.
- How those in regional, rural and remote locations, with limited or no access to independent assessors, will be facilitated to participate in functional capacity tests
- How those from CALD, Indigenous and other minority groups can be supported in the lead up to or during an independent assessment appointment.
- How and when a review of the independent assessment policy will be conducted.

The NDIS could work towards sharing information about independent assessments by:

- Using a wide variety of accessible communication tools, including ones in Easy English and translated into different languages
- Providing timely access to NDIS staff dedicated to explaining these changes and the processes involved, for those who express confusion and/or concern
- Funding organisations specific to a disability type and peer support networks to assist in sharing information about this change and in doing so alleviate concerns by their members.

4.2 How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or likely to be, permanent and life long?

The introduction of independent assessments will result in a significant change to the current Access Request Form. Seemingly, a treating practitioner will no longer be required to respond to questions regarding a person's functional capacity. We know of examples whereby doctors do not recognise a person's disability, taking a medical model rather than a social model approach, and this practice needs to be mitigated. Practitioners will need a greater understanding about disability to correctly complete the new Access Request form. Failure to complete the form correctly can lead to lengthy delays for future participants or inaccurate exclusion from scheme altogether.

When clarifying evidence-based requirements from health professionals this should include:

- Identifying what types of health professionals are eligible to complete the Access Request Form.
- Indicating the length of time the health professional has known or treated the individual.
- The date, if known, when the person's disability developed or was acquired.
- A list of any assessments and other health professionals, if known, that have assisted in determining the type of primary disability and any secondary disabilities.

4.3 What are the traits and skills that you most want in an assessor?

As independent assessments will assist in informing a participant's plan and budget it is critical that they are conducted by experts with the professional knowledge and skills to administer the functional capacity assessments. Pleasingly, independent assessments will, as noted by the NDIS, be conducted by qualified and AHPRA registered allied health professionals with the skillset to administer these tests. With respect to people with limb loss, such professionals will largely be those with occupational therapy or physiotherapy qualifications and skills. It is Limbs 4 Life's position that a person who is conducting independent assessments should be at a minimum of three (3) years post-graduation level with hands-on skills and experience.

Desired assessor traits and skills should include:

- Clinical skills and experience using instruments to determine individual capacity.
- Clinical skills and experience in observing a potential participant carrying out a functional task/s, within their scope of practice.
- An understanding that individuals have different goals, supports, environments and abilities which must be taken into consideration.
- An understanding that discussion with a person's support network, such as family members and other health professionals, can play a critical role in conducting a thorough and holistic independent assessment.
- An ability to clearly communicate with the person, and their support network, demonstrating humility, patience and understanding.

4.4 What makes this process the most accessible it can be?

Limbs 4 Life has some concerns that limiting an independent assessment to three or four hours may not be sufficient time to garner a complete picture of the person's functional capacity. This could be due to a range of factors, such as: the state of the person on the day of the assessment; cultural or language barriers; lack of insight into their disability; poor confidence; inability to fully disclose intimate personal details; multiple disabilities; and, lack of support person or advocate to attend the appointment. These factors could impact on the independent assessor gaining a complete picture of the person's capacity and needs, which in turn could lead to a person not receiving a plan and associated budget which will adequately support their needs and goals.

To make the process accessible, it is important to recognise that:

- New amputees, joining the NDIS for the first time, will have minimal insight into their newly acquired disability. It is those people who have recently acquired a disability who may need longer periods than up to four hours, as proposed, to have a thorough assessment conducted.
- People who have newly acquired a disability such as limb loss may have very different levels of functional capacity in the first six months post amputation, than they will have in the proceeding 18 months. Traditionally a new amputee will begin their journey at a K1 or K2 activity level and within a six-month time frame increase their activity level to a K 2 or K3. As such prosthetics prescribed at the four-month mark will not be sufficient to sustain their increasing activity level for the following two to three years, begging the question whether an assessment be flexible enough to determine and identify future changes? For example:
 - A person with an above knee amputation who is six months post-surgery will be allocated a basic prosthesis, be reliant on a wheelchair and possibly require ramps to access their home. However, that same person 18 months post amputation may no longer require ramps and/or have very little use for a wheelchair.
- Plans need to be flexible and work to suit the individual, particularly those still within the acute recovery process period.
- Assessments need to be offered after hours and/or conducted on a weekend as needed.
- Organisations specific to a disability type are best placed to provide support and peer guidance to assist participants during the transition process, and these organisations and their peer workforce should be funded to undertake such a vital and important role.

4.5 How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

To ensure cultural safety and inclusion, the NDIA should work with the First Peoples Disability Network Australia, National Ethnic Disability Alliance and other cultural bodies to ensure that independent assessments, and the underpinning policy guiding this, are conducted in a manner that takes account of NDIS participant's cultural needs.

4.6 How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

As a new approach and policy it is critical that those organisations funded to deliver independent assessments, and the independent assessors themselves, are subject to robust and regular evaluation reviews themselves. Such reviews will assist in ensuring that the assessment process is working as intended and allow for changes where concerns and issues are identified.

Potential means of achieving these include:

- Seeking robust feedback from NDIS participants to gain personal insight into the process. It is critically important that participants understand that any feedback will not impact on their relationship with the NDIS, thus encouraging open and honest qualitative information.
- Seeking feedback from disability peak organisations (such as Limbs 4 Life), as these bodies are often the ones that NDIS participants first approach when scheme-related issues arise and independent advice is sought.
- Seeking feedback from advocacy organisations who, like peak disability organisations, are bodies approached when NDIS issues and the need for appeals support are sought.
- Conduct an independent external review of the 2021 individual assessment trial to identify any quality assurance concerns prior to full roll-out, seeking insights and feedback from participants and the disability sector. This should be made publicly available to allow for further consultations and/or amendments to the policy and processes.

Upon roll-out, it is also important that the results of annual evaluation reports are made publicly available. This will enable participants and the disability sector to review annual outcomes and ensure opportunities for regular consultation and feedback from participants, the disability sector and support networks are built into continuous improvement and sustainability planning.

4.7 How should we provide the assessment results to the person applying for the NDIS?

The provision of assessment results should be delivered in a sensitive manner, taking account of the person's ability to comprehend and preferred delivery style. As it will be the Delegate providing the results, the onus should be on them to engage with the participant and allow them to self-determine how they would like information provided. All accessible communication approaches (electronic, hard-copy, phone, face-to-face meetings) should be offered, including the involvement of a support person and translator where required. Critically, if electronic portals or hard-copy materials are shared the person's privacy must be maintained at all times.

If a person questions the assessment results, including proposed plan budget, the Delegate should advise of review mechanisms available to them, including what bodies are available to assist in making a complaint.

The outcome of the 2021 independent assessment trial needs to be reviewed and dissected. Any concerns that are identified and raised need be addressed prior to full roll out.

5. Planning Policy for Personalised Budgets and Plan Flexibility

5.1 How should a participant's plan be set out so it's easier to understand? How can we make it easy for participants to understand how their funding can be spent?

Limbs 4 Life is of the opinion that moving to just two buckets of funding – fixed and flexible - will be more responsive to participant's needs should changes be required. However, prior to the independent assessment roll-out concerns about how Delegates develop plans, plan lifespans, and the provision of transparent costs for budgeting purposes must be considered.

Delegate knowledge and plan development

As the draft plan and budget will be developed by the NDIA Delegate it is vital that Delegates have a clear and concise understanding of types and ways that a participant can carefully utilise their funding. It is acknowledged that Delegates cannot be expected to deeply understand all disabilities, but a lack of understanding by NDIA Delegates will lead to development of a poor plan and budget that does not reflect participant's needs or goals.

This could be mitigated by:

- Providing disability specific training to NDIA Delegates.
- Providing funding to organisations specific to a disability type to develop and deliver training materials and modules to Delegates and participants alike.
- Connecting participants to key Delegates who hold specific knowledge and understanding of a participant's primary disability, so that information about how and where funding can be appropriately spent is conveyed during planning meetings.
- Enabling the key Delegate to support people with multiple disabilities to seek out information from a peer Delegate with expertise in secondary disabilities that the participant lives with, thus ensuring a reasonable and necessary plan, budget and funding is created and conveyed to the participant.

Plan timeframes

While participants will have the opportunity to request a plan review earlier than five years should their circumstances change, it is unclear how participants will be supported to determine whether a life change necessitates this. Key considerations include:

- Some more experienced NDIS participants with the long-term lived experience of disability will be better placed to identify the need for a plan review.
- Participants who lack self-advocacy skills or confidence, are less likely to feel comfortable seeking a review.
- How will a person who has only recently acquired a disability, or live with one that is progressive in nature, and likely require plan and budget changes in the early stages and/or quite regularly be supported to realise and initiate this? For example, the support needs of a participant who had an amputation six months ago is likely to be very different from what they

need in 18 months or more; making the offering of a five-year plan during their first NDIS planning meeting quite inappropriate.

What is unclear is who will be responsible for plan timeframes oversight? And if 'check-ins' are deemed the most suitable mechanism, then what individuals and organisations need to be involved to ensure that people's rights and access to reasonable and necessary supports is protected.

Budget planning and transparent costs

While NDIS price guides indicate the costs for certain prosthetic services, there are no prices or even a list of recommended retail prices (RRPs) for prosthetic products available to the participant. This lack of transparency naturally impacts on a person's ability to adequately and effectively financially manage their NDIS budget.

One clear example of this relates to prosthetic consumables (e.g. liners, sleeves, socks, stockings, shrinkers, gels and lotions). Amputees are unable to source current RRP's for the consumables they need, making effective budgeting virtually impossible. It also allows for price gouging practice, because if the NDIS or participants managing budgets are unable to compare costs there is scope for providers to mark up costs with no one any the wiser. For a person to apply sound financial budgeting practice, then access to RRP lists is vital.

Another concern is the way in which flexible versus fixed cost items will be determined. Again, in relation to amputees, it is unclear within which funding bucket maintenance and major repair costs for complex assistive technology will be allocated. This is a critical consideration as no amputee plans for unexpected maintenance or repairs in one or more years, and therefore it is almost impossible to include this in a flexible funding stream.

Take the case of an amputee who unexpectedly and unintentionally breaks their prosthesis, rendering it unable to be worn. If repairs for assistive technology sits in the flexible budget, and there is no funding currently available in that stream, the person will instead need to request an urgent review to access additional funding; a lag time during which the delay will result in the person losing their mobility or functional capacity.

5.2 How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?

As the draft plan and budget will be provided to a participant prior to a planning meeting, it is critical that the person understands what types of supports sit in the different categories of funding. Based on what has been revealed in the independent assessment report, the NDIS can assist participants to understand how their funding can be spent in a variety of ways:

- Participants will need a clear understanding of their requirements if a plan is going to last for five years. Coaching and assistance may be required to help a participant recognise their needs both now and into the future – even if a major change to circumstances does not occur during that time period.

- Encourage participants to engage with Limbs 4 Life and our peer workers who have expertise and knowledge about the needs of people with limb loss, thus enabling the participant to make informed decisions about use of their plan funding.
- Fund organisations specific to a disability type to undertake this role, recognising that recommending participants to engage with these will lead to increased workloads, the development of new resources, utilisation of technologies for information and training delivery, and the need to respond to queries in a timely manner.
- Engage organisations specific to a disability type to develop a range of resources, including case studies, that highlight the various ways in which participants have used and managed their funding.
- Clarify how unspent funds in a persons plan be addressed and managed.

It is critically important to realise that people who have recently acquired a amputation, are less likely to understand the complexities of their disability or are yet to adjust to living with a disability and the impacts it may have on their lives and those around them. It is participants in this situation, as well as those experiencing a life transition or event, that are in greatest need of support from a peak body and peer workforce, as it is those with the greatest lived experience and knowledge able to understand a participant’s needs in the immediate and longer-term future.

5.3 Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?

The limb loss community are extensive users of complex assistive technology such as prosthetics, mobility devices and home modifications. With respect to prosthetic provision, which has a thin and limited specialist services market across Australia, it is vital that prosthetic assistive technology, and repairs and maintenance, remains within the fixed budget category. This will help to ensure that non-competitive practices are mitigated and participants are provided with access to prosthetics that have been therapeutically determined and recommended.

5.4 How can we assure participants that their plan budgets are at the right level?

As independent assessments are being introduced to address inequalities and more fairly standardise plan and budget supports, it is vital that plan budgets are made at the right level for participants. A number of existing and new approaches and mechanisms could be used to assist in assuring participants of this. These include:

- Continuing to use the Independent Advisory Council to conduct six-monthly reviews of learnings and suggest improvements.
- Establish new disability specific Independent Advisory Reference Groups (e.g. ‘other physical’, ‘intellectual’, ‘neurological’ etc) comprised of NDIS consumers and peak bodies with lived experience of, or expertise in, those categories of disabilities. These disability specific reference

groups would best represent and understand the needs of their specific disability communities and be well positioned to independently evaluate and provide guidance regarding plan budget levels, and be in the position to provide sound advice to the Independent Advisory Council or the NDIA more broadly.

5.5 What new tools and resources should we provide to support people using their plan and new plan flexibilities?

Moving towards new plan flexibilities, and associated funding, is welcomed and enables participants with greater choice and control in managing their support needs. However, to ensure that people are equipped to adequately manage a flexible budget the provision of up-to-date and relevant knowledge, resources and training is vital to reduce the risk of limited or drained funding during an annual plan. This is equally important to assist in ensuring that participants can make fully informed budgetary decisions.

A range of possible approaches to empower participants, and their network of supporters, to plan for and manage flexible funding include:

- Encouraging participants to engage with organisations specific to a disability type and peer workers who have expertise and knowledge about the types of reasonable and necessary supports that people living with particular disabilities often seek, thus enabling informed decision making.
- Funding organisations specific to a disability type to undertake this role, recognising that recommending participants engage with these will lead to increased workloads, the development of new resources, utilisation of technologies for information and training delivery, and the need to respond to queries in a timely manner.
- Funding disability organisations to develop plan and plan flexibility management resources that are specific and relevant for their individual disability community.
- Develop a range of NDIS resources, including case studies, that highlight the various ways in which participants have used and managed their funding.

5.6 How best to handle the timing of the release of funds into plans and rollover of unused funds?

While the proposed policy indicates that the Delegate will ascertain the timing of funding releases, in consultation with the participant, taking into account potential risk factors it is unclear what matters will be considered a risk. This must be more clearly identified and explained prior to the role-out of independent assessments.

Other critical considerations include an understanding that:

- Amputees are often put in the position that they are unable to receive their complex assistive technology until it has been paid for in full. Therefore invoices received for assistive technology, as part of fixed NDIS funding, must be paid with immediacy. Failing to do so means amputees

will wait long periods of time before their prescribed device, which offers them positive socio-economic outcomes, is received. Surely the NDIA can determine an agreement with providers in relation to complex assistive technology payment terms.

- As many participants are likely to be accessing more flexible supports on a regular basis, and providers generally have payment terms of 14 to 30 days, it seems that a monthly release of funds will mitigate the risk of individuals who are self-managing from acquiring bad personal credit ratings if unable to pay a provider within a reasonable payment period.

5.7 How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check-in?

As the new independent assessment approach brings with it an opportunity for plan reviews of up to five years, unless one is requested earlier, it seems sensible that, at a minimum, annual 'check-ins' take place with all participants. However, participants who recently acquired a disability may benefit from quarterly check-ins during the first 12 months. Ideally, the number of check-ins should be determined by the participant and their needs. In addition, a participant should be able to easily and quickly make contact with their key Delegate to discuss issues and concerns should they need to do so.

Additional considerations include:

- The key Delegate, assigned to the participant, be the representative who liaises with and conducts a check-in, enabling for a positive relationship to be maintained.
- If a participant does not feel adequately supported by the key Delegate or where a complaint has been made, the participant should be able to request for a check-in to be conducted by another NDIA representative.
- The key Delegate should be reviewing the person's plan and utilisation of funds on a regular basis, and should critical issues emerge (e.g. inaccurate or over-expenditure, regular changes to providers or other identified risk matters) a check-in should be flagged and arranged.
- External check-ins could also be offered to consenting participants, by linking them with an approved and funded organisation specific to a disability type. This would enable immediate access to a subject matter expert or peer worker with a thorough understanding of the person's disability who could act as a support person or intermediary should any issues or challenges be identified.