

# National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]

# Submission to the Community Affairs Legislation Committee

17 May 2024

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# **About AFDO**

The Australian Federation of Disability Organisations (AFDO) is a Disabled People's Organisation (DPO) run by and for people with disability, reaching over 4 million Australians.

We are a unique representative organisation covering both disability specific and population-based disability communities and the pre-eminent national voice representing people with disability across Australia and internationally.

Our Members are 37 national and state disability advocacy organisations run by and for people with disability and their families, representing Australians with disability.

Our vision is "That all people with disabilities must be involved equally in all aspects of social, economic, political and cultural life."

# **Our Members:**

Advocacy for Inclusion Inc. - ACT

Arts Access Australia

Autism Aspergers Advocacy Australia

Blind Citizens Australia

Brain Injury Australia Deaf Australia

Deafblind Australia

Disability Advocacy Network Australia

Disability Resources Centre - Vic

Down Syndrome Australia

Enhanced Lifestyles - SA

Physical Disability Australia

People With Disabilities WA Polio Australia

South West Autism Network - WA Women With Disabilities ACT

Women with Disabilities Victoria National Mental Health Consumer & Carer Forum

Advocacy WA All Means All AED Legal Centre - Vic AMAZE - Vic

Arts Access Victoria

Disability Advocacy & Complaints Service - SA

Integrated disAbility Action - NT

Aspergers Victoria

Explorability Inc - SA

Leadership Plus – Vic

Multiple Sclerosis Australia

National Union of Students - Disabilities Dept. National Organisation for Fetal Alcohol Spectrum

Disorder

TASC National Limited - Qld Star Victoria Inc

Youth Disability Advocacy Service - Vic Tourettes Syndrome of Australia

# **Acknowledgement**

AFDO acknowledges Aboriginal and Torres Strait Islander people as the traditional custodians of the land on which we stand, recognising their continuing connection to land, waters, and community. We pay our respects to the peoples of the lands on which these operate and to their respective Elders past and present. We also pay our respects to the traditional owners of all lands on which we operate or meet around the country.

AFDO acknowledges people with disability, particularly those individuals that have experienced or are continuing to experience violence, abuse, neglect, and exploitation. We also acknowledge their families, supporters, and representative organisations and express our thanks for the continuing work we all do in their support.

# 1. Introductory comments

Thank you for providing AFDO and our members with an opportunity to provide feedback on the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024.* This submission has been informed by a consultation forum we held with our member organisations in April 2024. We would like to thank all members who participated in this forum for their subject matter proficiency, lived experience expertise, and the spirit of collaboration in which they have approached this work. We have done our best to ensure the perspectives and views of all Members are incorporated into this submission. We acknowledge, however, that each of our Member organisations reserves the right to express an alternative view on any aspect of the Bill.

The overall sentiment amongst our membership is that the Bill has been rushed and does not adequately reflect many of the findings and recommendations arising out of the Independent Review of the NDIS (NDIS Review). As an example, Recommendation 25 from the Review refers to Government coordinating and consulting on amendments to relevant legislation to enact the proposed reforms.

The Government's initial approach to the development of this Bill is inconsistent with this recommendation. Not only is the Bill problematic, but people with disability and their representative organisations were only provided with a very narrow time frame in which to provide feedback.

While the deadline for submissions was eventually extended, this process has not provided us with much confidence in the fact that the substance of this recommendation will be effectively upheld into the future. We also note that the Department of Social Services later published a correction to the explanatory memorandum accompanying the Bill relating to a number of typographical errors contained within Schedule 1. The correction was not due to be tabled in Parliament until 14 May – just 3 days prior to the deadline for submissions to this inquiry.

It is critical that history does not repeat itself as Government approaches the recommendations arising out of the Review. We believe that many of the longstanding issues that plague the scheme to-date are a result of its original implementation and rollout having been rushed due to political factors. This was acknowledged in the Review, which stated:

"Notwithstanding deep engagement with the disability community by governments between when the Productivity Commission reported in 2011 and the commencement of the NDIS on 1 July 2013, the initial NDIS roll-out has been criticised for its emphasis on meeting short-term targets and unrealistic deadlines. This meant implementation was not always aligned with the original intentions for the scheme. The speed and complexity of the rollout also meant that despite best intentions, elements of the previous systems found their way into the NDIS."

We understand the current political cycle has been a driving factor behind the rushed nature of the new Bill. It is critical, however, that we take the time to get the reforms right.

While several of our Members wanted us to reject the Bill outright, most Members have asked us to work collaboratively with the Committee, and with Government, to strengthen the Bill and ensure it better-reflects the needs of current and future scheme participants. We present this submission with this aspiration in mind and would welcome the opportunity to discuss the matters raised throughout this document in greater detail.

# 2. Summary of recommendations

# **Recommendation 1:**

The Bill must be amended to state that all rules and legislative instruments specified under the Act must be developed through a process of genuine consultation and codesign that aligns with:

- Article 4:3 of the Convention on the Rights of Persons with Disabilities
- General comment No.7 on the participation of persons with disabilities through their representative organisations, in the implementation and monitoring of the Convention
- The Australian Public Service Values and Code of Conduct.

## **Recommendation 2:**

The Bill must be amended to include the following provisions relating to consultation and co-design processes that are outsourced to third party providers:

- A requirement to reimburse people with disability for their time and expertise must be specified in all contractual agreements with third party providers, with this being factored into the overall project budget
- Accessibility requirements must be clearly stated in all requests for tender and contractual agreements with third party providers
- There must be checks and balances in place to ensure accessibility requirements have been adequately met by third party providers
- There must be repercussions for any provider who fails to meet the accessibility requirements specified under a Government contract.

# **Recommendation 3:**

Government must have regard to the following as it approaches the task of developing the range of rules and legislative instruments specified under the Bill:

- Recommendations from the report entitled, "Good practices of support systems enabling community inclusion of persons with disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2023.
- Recommendations from the report entitled, "Habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2019.
- Recommendations from the report entitled, "Access to rights-based support for persons with disabilities", published by the Special Rapporteur on the Rights of Persons with Disabilities in 2017.
- General comment No.5 on Article 19 the right to live independently and be included in the community from the CRPD.

### Recommendation 4:

The Bill must state that needs assessments are to be undertaken by allied health practitioners or social workers with disability expertise. These staff would either be employed, or contracted by the NDIA and must be independent of service providers. The Bill must also specify:

- What qualifications assessors will be expected to hold.
- What level of registration will apply to the assessment workforce.

# **Recommendation 5:**

The wording at Subclause 32L(3) must be amended to ensure people are assessed according to the totality of their disabilities, and are not required to nominate a primary and secondary disability. This approach would align with:

- Previous determinations made by the Administrative Appeals Tribunal, and
- Recommendation 1 from the Inquiry into the Capability and Culture of the NDIA.

#### Recommendation 6:

The Bill must specify that the tool, or tools used to conduct needs assessments must be developed through a process of genuine consultation and co-design with people with disability and their representative organisations. Government should also consider the recommendations contained within the paper entitled, 'A human rights approach to disability assessment' as it approaches the implementation of this recommendation.

### **Recommendation 7:**

The Bill must specify that all needs assessments are to be funded by Government. Should a participant require additional support, such as translation and interpreting services to enable them to participate in the assessment process, this should also be funded by Government.

# **Recommendation 8:**

The Bill must be amended to specify that participants must:

- Have an opportunity to see a copy of, and meet with an assessor to discuss the draft report from their needs assessment prior to it being finalized
- Be provided with a copy of the final report from their needs assessment in a language and format that is accessible to them.

# **Recommendation 9:**

The Bill must clearly articulate the steps a Participant can take if they do not agree with the final outcome of their needs assessment, including:

- Their right to request a secondary needs assessment
- Their right to appeal the agency's decision not to undertake a secondary needs assessment
- Their right to access independent advocacy and decision-making support to appeal decisions made in relation to needs assessments.

# **Recommendation 10:**

The wording at subclause (I) underneath Section 10 (A) must be amended to: "is necessary to support the person to live independently and/or be included in the community, or to prevent isolation or segregation of the person from the community"

## **Recommendation 11:**

The wording at subclause (II) underneath Section 10 (A) must be amended to: "will facilitate personal mobility, communication, or self-care of the person in the manner and at the time of the person's choice"

# **Recommendation 12:**

The wording at subclause (III) underneath Section 10 (A) must be amended to: "aids, assistive technology, live assistance or intermediaries that will facilitate personal mobility, communication and/or self-care"

# **Recommendation 13:**

It is critical that the Bill and associated rules do not place a blanket ban on the funding of 'standard household appliances and whitegoods'. This approach would erode participant choice and control and may also prevent participants from accessing supports that represent better value for money.

# **Recommendation 14:**

The new rules for NDIS supports must not be developed until such time that there is greater clarity around how foundational supports will be funded, and exactly which supports will be funded outside the scheme.

## Recommendation 15:

The Applied Principles and Tables of Support ('APTOS') must not be used as an interim measure to determine which supports will be funded under the NDIS. There should not be any changes to the supports the NDIS will fund until the new Rules for NDIS supports are developed and negotiated between Commonwealth and State and Territory Governments.

# **Recommendation 16:**

Subsection 7(A) must be amended to clarify how the agency will determine that a participant is likely to "suffer physical, mental or financial harm".

# **Recommendation 17:**

Subsection 7(B) must be amended to the following:

"The participant has demonstrated a repeated and intentional failure to spend NDIS funds in accordance with their plan."

# **Recommendation 18:**

The Bill must differentiate between information-gathering powers that apply to participants who entered the scheme under the early intervention pathway and those

who entered the scheme under the disability pathway.

# **Recommendation 19:**

Government must provide a formal response to Supporting Action 6.6 from the Independent Review of the NDIS as a matter of urgency. AFDO's view is that this Supporting Action should be accepted in full, with Lead Practitioners for Children and Families playing a key role in relation to information-gathering and reassessment of children who have entered the scheme under the early intervention pathway.

### **Recommendation 20:**

The Bill must clarify that:

- The NDIA will be responsible for covering the cost of any reports that have been requested by the agency
- Participants must be permitted to request information and reports from their own treating professional, rather than a professional that is selected by the agency
- Participants must be offered navigation support to enable them to satisfy any requests for assessments
- Participant's being reassessed must be notified of their right to access independent advocacy, and must be provided with information about how to access such services in a language and format that is accessible to them
- Assessment requests and outcomes must be provided to the Participant in a language and format that is accessible to them.

#### **Recommendation 21:**

Clauses 30 and 30A, and subclause 36(3) must be amended to clarify that a participant need only demonstrate that they have taken steps to comply with the agency's request for information within the timeframes specified in the Bill. Participants must also be provided with navigation support to enable them to satisfy the agency's request/s for information.

# **Recommendation 22:**

The Department of Social Services and the National Disability Insurance Agency must work collaboratively with the Department of Health and Aged Care to ensure the legislative environment resulting from the establishment of Australia's new Aged Care Act, and amendments to the NDIS Act, do not prevent people with disability from accessing the supports that are most appropriate to their individual needs and circumstances. In undertaking this work, Government must have regard to Recommendation 2.11 from the Independent Review of the NDIS, noting that AFDO's view is that:

Older people with disability who would qualify for the NDIS if not for the age eligibility requirements (but are now forced to access their supports from the aged care system), should be able to concurrently access specialist disability supports from the NDIS while maintaining their access to aged care services

The new Aged Care Act must include an early entry pathway for cohorts who may need to access aged care services prior to turning 65.

# **Recommendation 23:**

Government must accept Supporting Action 2.12 from the NDIS Review as a matter of urgency, which states that participants of the Disability Support for Older Australians Program should be transitioned to the NDIS.

# **Recommendation 24:**

Government must provide increased and sustainable funding to enable the Australian Federation of Disability Organisations (AFDO) to effectively engage in consultation and co-design processes surrounding the Independent Review of the NDIS and other important reform agendas.

# 3. Developing the rules and legislative instruments specified in the Bill

We have significant concerns that many of the rules and legislative instruments referred to throughout the Bill, which will have a significant impact on current and future participants, are yet to be developed. We have been assured that these instruments will be developed through consultation and co-design with people with disability and their representative organisations. a requirement for such measures has not been written into this bill, nor has Government clearly defined it's intended approach to consultation and co-design.

Given the lacklustre approach to these activities to-date, we would like the Bill to be amended to explicitly state that all rules and legislative instruments specified under the Act must be developed through a process of genuine consultation and co-design that aligns with:

- Article 4:3 of the Convention on the Rights of Persons with Disabilities.
- General comment No. 7 on the participation of persons with disabilities through their representative organisations, in the implementation and monitoring of the Convention.
- The Australian Public Service Values and Code of Conduct.

When undertaking consultation and co-design, government entities must take steps to include the most diverse range of voices possible, ensuring representation from:

- First Nations people with disability.
- People with disability from disability specific communities.
- People with disability from rural, regional, and remote locations.
- People with disability who are digitally excluded.
- People with disability from culturally and linguistically diverse backgrounds, and
- LGBTIQA+ people with disability.

Critically there must be absolute transparency and accountability around future consultation and co-design processes. This means abiding by the following section of General comment No. 7 issued by the Committee on the Rights of Persons with Disabilities:

"Public authorities should give due consideration and priority to the opinions and views of organizations of persons with disabilities when addressing issues directly related to persons with disabilities. Public authorities leading decision-making processes have a duty to inform organizations of persons with disabilities of the outcomes of such processes, including an explicit explanation in an understandable format of the findings, considerations and reasoning of decisions on how their views were considered and why."

One of our current frustrations involves government departments outsourcing consultation and co-design projects to consultancy firms that have no expertise around disability. These consultancy firms then come to organisations such as AFDO for advice, or to ask for our assistance to find people with lived experience of disability who are available to be involved in their work. Rarely is there a budget built into these projects to reimburse Disability Representative Organisations and/or people with lived experience for their time and expertise.

Our staff have also recently experienced several situations where they have been prevented from undertaking aspects of their work due to important government reports and consultation documents not being provided in accessible formats. This often, although not exclusively happens when a government department has outsourced a project to a third-party consultancy firm.

The NDIS review report and associated fact sheets provide a perfect example of such oversights. These documents were released in a format that did not provide people who use screen reading software with equitable access to these materials. This matter has taken more than four months to resolve, and also necessitated a complaint being lodged under the Commonwealth Disability Discrimination Act 1992 (Cth).

To ensure people with disability and their representative organisations can participate equitably in consultation and co-design processes, accessibility requirements must be clearly stated in all future requests for tender and contractual agreements with third party providers. There must also be checks and balances in place to ensure these requirements have been sufficiently met.

We also implore Government to have regard to the following as it approaches the task of developing the range of rules and legislative instruments specified under the Bill:

- Recommendations from the report entitled, "Good practices of support systems enabling community inclusion of persons with disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2023.
- Recommendations from the report entitled, "Habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2019.
- Recommendations from the report entitled, "Access to rights-based support for persons with disabilities", published by the Special Rapporteur on the Rights of Persons with Disabilities in 2017.
- General comment No.5 on Article 19 the right to live independently and be included in the community from the CRPD.

### **Recommendation 1:**

The Bill must be amended to state that all rules and legislative instruments specified under the Act must be developed through a process of genuine consultation and codesign that aligns with:

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- General comment No. 7 on the participation of persons with disabilities through their representative organisations, in the implementation and monitoring of the Convention
- The Australian Public Service Values and Code of Conduct.

### **Recommendation 2:**

The Bill must be amended to include the following provisions relating to consultation and co-design processes that are outsourced to third party providers:

- A requirement to reimburse people with disability for their time and expertise
  must be specified in all contractual agreements with third party providers, with
  this being factored into the overall project budget
- Accessibility requirements must be clearly stated in all requests for tender and contractual agreements with third party providers
- There must be checks and balances in place to ensure accessibility requirements have been adequately met by third party providers
- There must be repercussions for any provider who fails to meet the accessibility requirements specified under a Government contract.

## **Recommendation 3:**

Government must have regard to the following as it approaches the task of developing the range of rules and legislative instruments specified under the Bill:

- Recommendations from the report entitled, "Good practices of support systems enabling community inclusion of persons with disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2023.
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- General comment No.5 on Article 19 the right to live independently and be included in the community from the CRPD.

# 4. Needs assessment

The move towards being respectful of participants episodic or fluctuating support needs and the general move away from short, activity-limiting plans is acknowledged and promising. There are, however, several aspects of the Bill we find problematic in relation to needs assessments. We are concerned that these measures may create additional barriers for many people with disability and may have the effect of limiting participant choice and control.

# Who will undertake needs assessments?

The Bill does not currently specify who will be responsible for undertaking needs assessments. We are uncomfortable with this lack of clarity given the long-standing issues that have arisen because of the NDIA outsourcing its planning function to community partners. Current participants note that Planners and Local Area Coordinators can be extremely inconsistent with their decisions and often lack disability expertise.

We assert that many of these issues stem from the fact that the NDIA has outsourced its planning function to community partners who each have their own work culture and entrenched issues around the operationalization of the planning process. We remind the Committee that Local Area Coordinators were never intended to undertake planning when the scheme was first established. This is just one of several aspects of the scheme that has not been operationalized as originally intended. It is critical that history does not repeat itself with the new assessment workforce that will be required to support the proposed reforms.

The NDIS Review recommended needs assessments be undertaken by allied health practitioners or social workers with disability expertise who would either be employed, or contracted by, the NDIA. This must be reflected in the Bill, in addition to clarification around:

- What qualifications assessors will be expected to hold
- What level of registration will apply to the assessment workforce
- How far removed the assessment workforce will be from the NDIA, Local Area Coordination agencies, service providers, etc.

Oversight mechanisms must also be established to ensure assessors have received sufficient disability, cultural and diversity awareness training, are trauma informed and are undertaking assessments in a uniform, consistent manner that aligns with core human rights principles.

## **Recommendation 4:**

The Bill must state that needs assessments are to be undertaken by allied health practitioners or social workers with disability expertise. These staff would either be employed, or contracted by the NDIA and must be independent of service providers. The Bill must also specify:

- What qualifications assessors will be expected to hold.
- What level of registration will apply to the assessment workforce.

# What will the needs assessment tool look like?

Subclause 32L(3) states that needs assessments will be limited to impairments that meet the disability or early intervention requirements. We echo the concerns raised by our colleagues at the Public Interest Advocacy Centre, who state:

"...this may fail to achieve a 'whole of person' approach by imposing artificial distinctions in the way a person with multiple and interrelated disabilities accesses supports."

This approach also appears to be in conflict with Recommendation 1 from the Inquiry into the Capability and Culture of the NDIA. Recommendation 1 refers to people being assessed according to the totality of their disabilities and not being required to nominate a primary and secondary disability.<sup>vi</sup>

AFDO stresses that needs assessments must be based on the social model of disability, and must consider factors such as:

- Comorbidity
- Intersectionality
- Where the person lives, and what services are available.
- Social and environmental barriers
- The person's age, and any relevant life stage factors
- The person's goals and aspirations.

The needs assessment process must also be:

- Accessible
- Inclusive
- Flexible
- Person-centred
- Disability-informed
- Trauma-informed
- · Culturally safe
- Transparent
- Fair and equitable, and
- Open to review.

The assessment process needs to be strength-based and must seek to avoid the pitfalls associated with the deficit-based nature of the current planning process. One of our member organisations, the National Mental Health Consumer & Carer Forum, has stated:

"Many people find such interactions are in fact more 'disabling' and exacerbate the very conditions that have led them to apply for the NDIS."

The deficit-based nature of the planning process has ultimately resulted in many people with disability choosing not to participate in their own planning meetings, which is at odds with the aspirations of the scheme. AFDO member, Down Syndrome Australia, explained that many families undertake pre-planning with their child or adult child with Down Syndrome to safeguard them from the final planning meeting. This is due to the negative impact the planning process is likely to have on their psychological health and wellbeing.

It is critical that the new assessment tool is developed through an open and transparent co-design process. We also encourage government to refer to the paper entitled, "A human rights approach to disability assessment' as it approaches the implementation of this recommendation.

Finally, all needs assessments must be funded by Government. Should a participant require additional support, such as translation and interpreting services to enable them to participate in the assessment process, this should also be funded by Government.

## **Recommendation 5:**

The wording at Subclause 32L(3) must be amended to ensure people are assessed according to the totality of their disabilities, and are not required to nominate a primary and secondary disability. This approach would align with:

- Previous determinations made by the Administrative Appeals Tribunal, and
- Recommendation 1 from the Inquiry into the Capability and Culture of the NDIA.

# **Recommendation 6:**

The Bill must specify that the tool, or tools used to conduct needs assessments must be developed through a process of genuine consultation and co-design with people with disability and their representative organisations. Government should also consider the recommendations contained within the paper entitled, 'A human rights approach to disability assessment' as it approaches the implementation of this recommendation.

## **Recommendation 7:**

The Bill must specify that all needs assessments are to be funded by Government. Should a participant require additional support, such as translation and interpreting services to enable them to participate in the assessment process, this should also be funded by Government.

# **Review of needs assessments**

The Bill does not include a requirement for the participant to be provided with a draft, nor a final copy of their needs assessment. It also fails to establish what steps a Participant can take in the event that they do not agree with the outcome of their needs assessment.

The current provisions included in the Bill would only enable a participant to seek a review of the CEO's decision to approve the Statement of Supports, but not the needs assessment, or the resulting budget.

The NDIA can agree to undertake a secondary needs assessment, but it does not appear as though a decision not to undertake that needs assessment is reviewable. This gives the agency far too much discretion and may lead to negative consequences for participants.

Participants must have an opportunity to see a copy of, and meet with an assessor to discuss, the report from their draft needs assessment prior to it being finalised. This would enable the participant to correct any errors or oversights or seek clarification on any aspects of which they are uncertain.

This is likely to reduce requests for review and external appeals – particularly given needs assessments represent a new model which is likely to result in initial teething problems for participants and assessors alike.

Not only should participants be able to request a secondary needs assessment, but the agency's decision not to undertake a secondary assessment must be open to review. Participants must also be provided with:

- Detailed and evidence-based explanations about any decisions made in relation to needs assessments.
- Information about their right to appeal decisions and access advocacy support or representation.

The aforementioned information must be provided in a language and format that is accessible to the individual.

# **Recommendation 8:**

The Bill must be amended to specify that participants must:

- Have an opportunity to see a copy of, and meet with an assessor to discuss the draft report from their needs assessment prior to it being finalized
- Be provided with a copy of the final report from their needs assessment in a language and format that is accessible to them.

# **Recommendation 9:**

The Bill must clearly articulate the steps a Participant can take if they do not agree with the final outcome of their needs assessment, including:

- Their right to request a secondary needs assessment
- Their right to appeal the agency's decision not to undertake a secondary needs assessment
- Their right to access independent advocacy and decision-making support to appeal decisions made in relation to needs assessments.

# 5. Definition of NDIS supports

AFDO is concerned that the changes proposed by the amendment Bill at Clause 10 represent a significant departure from the 'reasonable and necessary' criteria set out in section 34(1) of the current NDIS Act. The wording included in the Bill is far too restrictive and may have very negative consequences for participants if not rectified.

At Section 10, clause (A), the Bill states that a support is an NDIS support if it:

"is necessary to support the person to live and be included in the community, and to prevent isolation or segregation of the person from the community."

Some of our members have raised concerns about the fact that in-home supports may not neatly fit into this definition. This wording is also inconsistent with Article 19 of the Convention on the Rights of Persons with Disabilities, which has a strong focus on "living independently and being included in the community".

We are concerned that the wording of this clause may be used as a way of Operationalising the one to three support ratio for supported independent living that was proposed in the NDIS Review report; which is incredibly problematic and discriminatory.

Even more concerning is the fact that it appears as though this arrangement is already being operationalised prior to any consultation having taking place with NDIS participants and/or their representative organisations. AFDO member, Advocacy WA, for example, has been supporting a client who lives in her own home. She was recently informed by the NDIA that she needs to move out and rent with 2 strangers in order to continue accessing SIL support, which would only be funded at a ratio of one to three.

The wording included underneath this section of the Bill also has a disproportionate emphasis on personal mobility to the exclusion of other life domains. The Bill states that a support is an NDIS support if it:

"will facilitate personal mobility of the person in the manner and at the time of the person's choice; or

is a mobility aid or device, or assistive technology, live assistance or intermediaries that will facilitate personal mobility of the person"

We would like to see the wording underneath the two above clauses amended to broaden their scope so that they reference communication and self-care in addition to mobility.

Of great concern is the fact that the explanatory memorandum states that items such as 'standard household appliances and whitegoods' do not meet the definition of NDIS supports. AFDO strongly opposes the blanket rejection of these items and argues that this approach will erode participant choice and control and prevent participants from utilising supports that may represent better value for money.

Whitegoods increasingly have accessibility features built into them, such as audio controls. This is, however, often only the case with more expensive models or bespoke

items. Ruling out all mainstream items and whitegoods will become increasingly problematic in a world of product convergence and digitisation.

We understand that new NDIS rules will be developed to provide greater guidance around what supports the scheme will fund. Importantly, however, the current provisions included under the Bill rely heavily on State and Territory Governments funding and providing foundational supports outside the NDIS. It is therefore critical that the new NDIS rules developed in relation to NDIS supports are put on hold until such time that there is absolute clarity around how foundational supports will be funded, and exactly which supports will be funded outside the scheme.

# Recommendation 10:

The wording at subclause (I) underneath Section 10 (A) must be amended to: "is necessary to support the person to live independently and/or be included in the community, or to prevent isolation or segregation of the person from the community"

# **Recommendation 11:**

The wording at subclause (II) underneath Section 10 (A) must be amended to: "will facilitate personal mobility, communication, or self-care of the person in the manner and at the time of the person's choice"

#### Recommendation 12:

The wording at subclause (III) underneath Section 10 (A) must be amended to: "aids, assistive technology, live assistance or intermediaries that will facilitate personal mobility, communication and/or self-care"

# **Recommendation 13:**

It is critical that the Bill and associated rules do not place a blanket ban on the funding of 'standard household appliances and whitegoods'. This approach would erode participant choice and control and may also prevent participants from accessing supports that represent better value for money.

# **Recommendation 14:**

The new rules for NDIS supports must not be developed until such time that there is greater clarity around how foundational supports will be funded, and exactly which supports will be funded outside the scheme.

# 6. Interim measures for NDIS supports

At subclause 71B(2), the Bill states that until the new rules for NDIS supports are developed, the existing Applied Principles and Tables of Support ('APTOS') will be used to determine which supports will be funded by the NDIS, and which supports will be funded by State and Territory Governments. The APTOS principles are extremely outdated and are no longer fit for purpose. As such, we are perplexed as to why the Bill places such a strong emphasis on the APTOs; particularly given its shortfalls were well-documented in the Review report. The report states:

"The principles, roles and responsibilities outlined in APTOS have not translated into consistent collaboration on the ground. The underlying structure of APTOS may be part of the problem - it assumes people with disability will be supported by the NDIS or another system. In reality, they need support from both. This leaves people with disability confused about how and where to find and use supports, and in some cases with no access to support at all."

# The report goes on to state:

"instead of using the entry of the NDIS to encourage much needed, more sophisticated program intersection protocols and collaboration opportunities, the APTOS have reinforced program boundaries and the one dimensional, transactional approach of the old disability systems. In doing this, the APTOS have made it more difficult for people using the NDIS concurrently with other programs to get the 'joined up' services they need. The APTOS have been neither reviewed nor amended as the scheme has evolved. Rather than a level playing field of program responsibilities, their existence has entrenched the historical divide between programs and ensured program interactions focus on who pays, rather than the needs of the person with disability requiring their concurrent support." Viii

# **Recommendation 15:**

The Applied Principles and Tables of Support ('APTOS') must not be used as an interim measure to determine which supports will be funded under the NDIS. There should not be any changes to the supports the NDIS will fund until the new Rules for NDIS supports are developed and negotiated between Commonwealth and State and Territory Governments.

# 7. Restrictions on plan management and spending flexible funding

The Bill would provide the NDIA with increased powers to change a participant's funding from self-managed to Agency Managed. AFDO is concerned that the powers defined in the Bill are far too broad, and would enable the agency to move a Participant to agency managed after only one breach of the following conditions specified under subsection (7):

- (a) the participant would likely suffer physical, mental or financial harm;
- (b) NDIS funds have previously not been spent in accordance with a participant's plan; and/or
- (c) a circumstance to be prescribed in new 'Category A' Rules.

The Bill does not clarify how the agency would assess whether a participant is likely to "suffer physical, mental or financial harm". This must be clarified to avoid these powers from being misused.

Clause (B) is incredibly problematic, as there may be various reasons for a participant not having utilised their budget. In particular, this may present barriers for people with disability who:

- Are new to the scheme.
- Have fluctuating or episodic needs for support.
- Reside in thin market areas where there aren't always services available, and/or
- Require support to understand how to utilise and spend their allocated funds.

Our members frequently see participants who have NDIS plans that have not been implemented. The NDIA does not provide any support or funding to help participants implement their plans in these situations. Moving a participant from self-managed to agency managed is not the answer to this problem and is also not in the best interest of the financial sustainability of the scheme. The Agency must prioritise building the capacity of participants to understand and utilise their plans where necessary and provide the appropriate supports to facilitate this process. Restrictions on plan management should only take effect when a participant has demonstrated a repeated, and intentional, failure to comply with the necessary requirements.

# **Recommendation 16:**

Subsection 7(A) must be amended to clarify how the agency will determine that a participant is likely to "suffer physical, mental or financial harm".

# **Recommendation 17:**

Subsection 7(B) must be amended to the following:

"The participant has demonstrated a repeated and intentional failure to spend NDIS funds in accordance with their plan."

# 8. Information-gathering powers

AFDO is incredibly concerned at the discretionary powers imposed by the Bill in relation to requests for information and assessment reports, and the repercussions imposed on those failing to comply with such requests. The Bill would provide the NDIA with the power to request health assessments, such as medical and psychological assessments, in the event that it wishes to:

- Consider revoking a participant's status, or
- Prepare a new framework plan.

The explanatory memorandum provides some reassurance of the fact that people with permanent, life-long disability will not be forced to justify their reason for being on the scheme on an annual basis. We do, however, find these powers incredibly problematic at face value and believe they may have a number of unintended consequences.

Of significant concern is the fact that the NDIA would have the power to compel a participant to speak to, or be assessed by, a professional who has been selected by the agency. Many of our members are incredibly concerned that this framework replicates the model for independent assessments that was overturned by the disability sector in 2021

We are very concerned about some of the ramifications this may have; particularly for the many people with disability who have experienced significant trauma as a result of their interactions with the Scheme to-date, and those who have had to fight tirelessly to be granted access in the first place. Assessments are also quite expensive and may be cost-prohibitive for many participants. As such, we agree with the Review Panel's assertion that any reports requested by the NDIA be paid for by government. This must be reflected in the NDIS Act. ix

The explanatory memorandum accompanying the Bill states:

"National Cabinet agreed that the Commonwealth would work with state and territory governments to implement legislative and other changes to return the NDIS to its original intent of supporting people with permanent and significant disability as part of the larger landscape of supports outside of the NDIS."

Bearing this in mind, we understand that one of the reasons these information-gathering powers have been proposed relates to the need to monitor outcomes for participants who have entered the scheme under the early intervention pathway; as the intention was never for all of these participants to remain in the scheme long-term. We understand the need for individual accessing early intervention supports to be periodically reassessed to determine:

- The impact and outcomes of early intervention supports that have already been provided.
- Whether early intervention supports are still required by the participant

- Whether the participant will require lifelong support and should thus be transitioned to the disability stream
- Whether the participant should be exited from the scheme because the early intervention supports provided have been successful, or the individual would be more appropriately supported by foundational supports that exist outside the scheme.<sup>x</sup>

In light of the above, we question whether different information-gathering powers should exist in relation to participants who entered the scheme under the early intervention pathway, and those who entered the scheme under the disability pathway. We assert, however, that the current measures outlined in the Bill are inconsistent with key recommendations arising out of the NDIS Review. In the case of early intervention, the Review report states:

"The National Disability Insurance Agency should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.

This should involve the Lead Practitioner working with the family and the Navigator to develop a plan of action to guide the family and the team around the child. The plan of action should be regularly and informally reviewed. This should be reinforced by more formal periodic case conferencing with the team around the child to check in on progress and effectiveness of the interventions, and identify any adjustments that need to be made. Families should be actively involved in these discussions to feel empowered and help them understand their child's progress and how they can best support them."

- Supporting Action 6.6

Alarmingly, the Bill would also give the NDIA the power to impose punitive consequences where the participant does not comply with the agency's requests for information. For example:

- At clauses 30 and 30A, the CEO may revoke a participant's status In the event that they do not provide the requested assessment report or information within 90 days.
- At subclause 36(3), the NDIA may suspend a participant's existing NDIS plan and upcoming NDIS plan if they fail to comply with the agency's requests within 28 days.

AFDO asserts that these powers are far too broad and will negatively impact upon many participants who experience barriers to accessing information and assessments. Barriers are likely to be compounded for:

- People with fluctuating or episodic needs for support; for whom point in time assessments are often completely unsuitable.
- Participants who require information in alternate formats. To-date, the agency still continues to provide critical correspondence to participants in formats that are

- not accessible to them. A participant may therefore not have immediate access to the request for information that has been issued by the NDIA, which would impact upon their ability to comply with the timeframes specified in the Bill.
- Deaf and Deafblind participants who require interpreting services to facilitate their participation in assessment processes. There is an extreme shortage of interpreters that may further prevent participants from complying with the timeframes specified in the Bill.
- Participants living in rural and regional areas where there may not always be suitably qualified medical practitioners available to conduct the necessary assessments.

# **Recommendation 18:**

The Bill must differentiate between information-gathering powers that apply to participants who entered the scheme under the early intervention pathway and those who entered the scheme under the disability pathway.

### **Recommendation 19:**

Government must provide a formal response to Supporting Action 6.6 from the Independent Review of the NDIS as a matter of urgency. AFDO's view is that this Supporting Action should be accepted in full, with Lead Practitioners for Children and Families playing a key role in relation to information-gathering and reassessment of children who have entered the scheme under the early intervention pathway.

### Recommendation 20:

The Bill must clarify that:

- The NDIA will be responsible for covering the cost of any reports that have been requested by the agency
- Participants must be permitted to request information and reports from their own treating professional, rather than a professional that is selected by the agency
- Participants must be offered navigation support to enable them to satisfy any requests for assessments
- Participant's being reassessed must be notified of their right to access independent advocacy, and must be provided with information about how to access such services in a language and format that is accessible to them
- Assessment requests and outcomes must be provided to the Participant in a language and format that is accessible to them.

# **Recommendation 21:**

Clauses 30 and 30A, and subclause 36(3) must be amended to clarify that a participant need only demonstrate that they have taken steps to comply with the agency's request for information within the timeframes specified in the Bill. Participants must also be provided with navigation support to enable them to satisfy the agency's request/s for information.

# 9. Interfacing arrangements between the NDIS and the aged care system

Supporting Actions 2.11 and 2.12 from the NDIS Review align with recommendations we have made in previous policy submissions. These measures would significantly improve the experience of the many older people with disability who have continued to fall through the cracks since the inception of the NDIS. They also promise to improve access to services for any older people who acquire disability into the future. We encourage the Committee to access our briefing paper on equitable access to disability services and supports for older people for further information and recommendations on these matters.

Regrettably, Supporting Actions 2.11 and 2.12 have been completely overlooked in this Bill. Supporting Action 2.11 refers to amending legislation to allow NDIS participants to access support from both the NDIS and the aged care system once they turn 65. We would like to see this Supporting Action effectively operationalised under the Bill. This measure should not, however, be restricted to NDIS participants who are ageing in the scheme. Older people with disability who would qualify for the NDIS if not for the age eligibility requirements (but are now forced to access their supports from the aged care system) should also be afforded the same level of flexibility.

We also reject the arbitrary age of 65 for eligibility for the aged care system. There must be an early entry pathway for cohorts who may need to access aged care services earlier. For example, People with Down Syndrome and acquired brain injury, typically experience higher rates of dementia, including early onset dementia, than the general population. In fact, 50 per cent of people with Down Syndrome develop Alzheimer's disease by the age of 60. Eepople with disability may also experience ageing differently due to having a shorter life expectancy. According to the Australian Institute of Health and Welfare (AIHW), people who use disability services are more than four times more likely than the general population to die before reaching their 65th birthday. This demonstrates the need for NDIS participants to be able to concurrently access supports from the NDIS and the aged care system should their circumstances necessitate this.

Supporting Action 2.12 from the Review report refers to Disability Support for Older Australians (DSOA) recipients being granted access to the NDIS. We implore the Australian Government to accept and implement this Supporting Action as a matter of urgency.

# **Recommendation 22:**

The Department of Social Services and the National Disability Insurance Agency must work collaboratively with the Department of Health and Aged Care to ensure the legislative environment resulting from the establishment of Australia's new Aged Care Act, and amendments to the NDIS Act, do not prevent people with disability from accessing the supports that are most appropriate to their individual needs and circumstances. In undertaking this work, Government must have regard to

Rcommendation 2.11 from the Independent Review of the NDIS, noting that AFDO's view is that:

Older people with disability who would qualify for the NDIS if not for the age eligibility requirements (but are now forced to access their supports from the aged care system), should be able to concurrently access specialist disability supports from the NDIS while maintaining their access to aged care services

The new Aged Care Act must include an early entry pathway for cohorts who may need to access aged care services prior to turning 65.

# **Recommendation 23:**

Government must accept Supporting Action 2.12 from the NDIS Review as a matter of urgency, which states that participants of the Disability Support for Older Australians Program should be transitioned to the NDIS.

# 10. Adequate and sustainable funding to enable DROs to engage in consultation and co-design processes

If Government is serious about its commitment to developing the rules and legislative instruments referred to throughout the Bill through genuine and meaningful consultation and co-design, Disability Representative Organisations such as AFDO must be effectively resourced to support this work.

AFDO has a unique point of difference, as we come to Government with considered positions that represent the views and concerns of our 36 member organisations across Australia. Collectively, we represent the needs of:

- Women with disability
- · People with disability living in regional and remote Australia
- People with sensory disability, including people who are Deaf or hard of hearing, people who are blind or vision impaired, and people who are deafblind
- People with physical disability
- People with psychosocial disability
- People with acquired brain injury
- People with Down Syndrome
- People with Autism
- People with disability form other specific cohorts

Our current funding only enables us to employ two part-time policy and advocacy staff to support this important work. On Friday 10 May 2024, Minister for Social Services, the Hon Amanda Rishworth MP, announced the results of the Disability Representative Organisations funding round.xiv AFDO made a bid for funding as part of a consortia of six organisations. This bid was successful, securing us just over \$1.7 million over the next two financial years. Once split across our six organisations, this will represent a 30% decrease from our current systemic advocacy funding at a time when our workload is more demanding than ever before.

Unless we are provided with adequate and sustainable funding that reflects the full scope of our workload, we will not be able to meet the increased demands that are being placed on us subsequent to the recommendations arising out of the NDIS review and the Disability Royal Commission. We stress that this is not business as usual, with these two reports requiring significant expertise, lived experience input, collaboration and codesign over many years to come. Given people with disability aged 65 and over are still expected to access their support through the aged care system, much of our time and resources have also been, and will continue to be, taken up with advocacy relating to Australia's aged care reforms.

In light of the above, we are calling on the Department of Social Services to urgently increase our funding to enable us to properly engage with the breadth of work arising out of the NDIS Review and the Disability Royal Commission. Importantly, this approach would align with:

- Recommendation 6.21 from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
- Recommendation 26 from the Inquiry into the Capability and Culture of the NDIA, and
- Paragraph 6: G of the Concluding observations on the combined second and third reports of Australia's performance under the Convention on the Rights of Persons with Disabilities.

# **Recommendation 24:**

Government must provide increased and sustainable funding to enable the Australian Federation of Disability Organisations (AFDO) to effectively engage in consultation and co-design processes surrounding the Independent Review of the NDIS and other important reform agendas.

# 11. Concluding comments

We thank the Committee once again for providing AFDO with an opportunity to represent the concerns of its members by way of this submission. We look forward to being involved in future consultation processes, and hope Government will adequately fund us to undertake this important work. Should you have any questions in relation to any of the matters raised throughout this submission, please contact our Senior Systemic Advocate, Lauren Henley, via the below information.

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<sup>&</sup>lt;a href="https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction-to-explanatory-memorandum#:~:text=Correction%20to%20the%20Explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction-to-explanatory-memorandum#:~:text=Correction%20to%20the%20Explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction-to-explanatory-memorandum#:~:text=Correction%20to%20the%20Explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction-to-explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction%20to%20the%20Explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction%20to%20the%20Explanatory%20Memorandum,Parliament%20on%2014%20May%202024.>">https://www.dss.gov.au/disability-and-carers-programs-services-ndis-reforms/correction-to-explanatory%20Memorandum,Parliament%20on%2014%20Memorandum,Parliament%20000Memorandum,Parliament%200000Memorandum,Parliament%200000Memorandum,Parliament%2000000Memorandum,Parliament%20000000Memorandum,Par

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<sup>&</sup>lt;sup>iii</sup> United Nations Committee on the Rights of Persons with Disability (2018) General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, CRPD/C/GC/7, 9 November 2018, ss 2(23), accessed 7 March 2024.

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