



***Submission to the
Senate Community Affairs Legislation Committee's Inquiry into
the National Disability Insurance Scheme
Amendment (Getting the NDIS Back on Track No. 1) Bill 2024***

***Young People In Nursing Homes National Alliance
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Key recommendations

1. Introduce a **progressive disability pathway** that provides seamless entry and support in the NDIS full participants with progressive disability. This pathway should have:
 - Input from health and mainstream programs and have capacity for integrated services for participants
 - External service coordination
 - An on-demand funding model to respond to rapid escalations in support needs
 - A guarantee that families will be included in planning and recognition of their important role in supporting individuals
 - NDIA staff working in this pathway to have credentialled training in progressive disability and access to specialist advice when making decisions.
2. Include a **statutory duty of care** in the NDIS Act that mirrors the proposed duty in the new Aged Care Act. This will:
 - Underpin efforts by the NDIS Quality and Safeguards Commission and the NDIA to ensure effective safeguards and good provider practice; and
 - Ensure that providers (including Board members and management) take seriously the Code of Conduct and the commercial relationship they have with participants.
3. **Amend s45 of the NDIS Act** to ensure that:
 - The NDIS cannot delegate s34 decisions on supports for participants to other government funding bodies
 - The NDIS may only fund another government entity to provide NDIS supports to individual participants where those supports have been determined as reasonable and necessary by the NDIS under s34 of the NDIS Act.
4. **Remove the s10 provisions of the Bill** that enable the Minister for Social Services to unilaterally decide what is and what is not NDIS Support. These should be replaced by Rules that are agreed with state and territory governments about Scheme interface protocols and Foundational Supports.
5. **Amend the Bill's needs assessments provisions** to ensure that assessments are based on existing well-established and validated tools rather than new NDIS-specific assessment tools that are designed only to calculate NDIS funding levels.
6. **Amend the Bill's framework plans provisions** to ensure there are clear parameters for funding decisions, including for the selection of time limits and review criteria if participants need to seek review of flexible funding and time limits.
7. **Amend the Bill to make provision for the NDIA to**
 - a. engage in care and support system planning, and
 - b. commission specific services and support types, including in collaboration with State/Territory governments.

The Young People In Nursing Homes National Alliance (YPINHNA)

The Alliance is the national peak disability organisation advocating for younger people with disability living in residential aged care (YPIRAC) and those at risk of entry to aged care facilities, the vast majority of whom are NDIS participants.

The Alliance undertakes a range of functions including:

- Policy analysis and development;
- Research, cross-sector collaboration, consultation and service development; and
- Provision of systemic as well as individual support and advocacy.

Since its inception in 2002, the Alliance has argued for comprehensive policy solutions and collaborative arrangements between health, disability, aged care and housing portfolios. In recent years, the Alliance has concentrated much of its work on the development of approaches to cross sector service coordination and policy collaboration.¹

One of our current initiatives, the *Joint Solutions Young Onset Dementia Project*, is funded by the Department of Social Services to develop a system of care for the more than 30,000 Australians living with young onset dementia. We have undertaken this work because of a deep concern that, in the absence of the services and supports these young people need, Australians living with young onset dementia will form the next wave of younger people forced to consider inappropriate placement in residential aged care.

As well as the Alliance's collaboration and consultation with people living with young onset dementia and their families, clinicians and specialist service providers, a consortium of leading dementia organisations is working with us to map the services required by people living with young onset dementia and their families from diagnosis to end of life care; and identify those programs best placed to provide support at particular points.

Consortium members include the [Young Onset Dementia – Special Interest Group \(YOD-SIG\)](#), [Eastern Cognitive Disorders Clinic \(ECDC\)](#), and [Dementia Australia \(DA\)](#).

In focussing on systems responses for people with young onset dementia and their families, the Joint Solutions project will also identify service development opportunities across the disease course as part of an integrated system of care.

NDIS Amendment Bill Workshop with young onset dementia stakeholders

The Alliance has also consulted with a range of individuals and organisations involved with young onset dementia about the NDIS and the reform outcomes they believe are needed for

¹ University of Sydney, Centre for Disability Research and Policy (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA). *Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge*, Sydney, 2014.

the scheme.

On 15 April 2024, we convened an online workshop with these stakeholders to discuss the general implications of the NDIS Amendment Bill and its impact on participants living with young onset dementia in particular.

The results of that discussion have informed this submission and its recommendations.

Preamble

The Young People In Nursing Homes National Alliance welcomes the opportunity to provide this submission to the Community Affairs Legislation Committee's Inquiry into the NDIS Amendment Bill.

We have been closely involved with the introduction and development of the NDIS and understand the importance of adjusting the design of the Scheme for it to be effective, sustainable and impactful for Australians with disability.

The fact that the NDIS is under significant pressure is not in dispute. The NDIS Review canvassed the Scheme's cost drivers and design flaws and made a number of recommendations that have informed development of this Amendment Bill. However, if the NDIS is to deliver on its purpose as a social insurance scheme that delivers improved life outcomes for Australians with disability, more vigorous policy work than that represented in this Bill must be undertaken.

While the Alliance is wholly supportive of measures to make the Scheme more efficient and effective in supporting people with disability and supports the Bill's focus on reforming the NDIS Act and the Scheme's broader policy environment, sustainable companion reforms that reduce cost growth and improve scheme design are also required.

For instance, the proposed changes require that there also be a focus on the integration of the NDIS with other programs, better management of risk arising from a market driven care system, and the development of discrete planning and funding models for different participant cohorts.

Some of the Bill's proposals lack context and rely on future negotiations with state and territory governments as well as delegation to NDIS Rules. Others, such as the needs assessment and framework plans, rely on untested assumptions and a radical restructuring of obligations and powers that comes after a prolonged period of uncertainty and problems with the Scheme's implementation, especially for participants with progressive conditions like young onset dementia.

Despite this, neither the Bill nor the Explanatory Memorandum gives a clear indication as to how the proposed changes will achieve the government's aim of rapidly reducing growth in Scheme costs or indicates how these changes will affect participants. Although structural changes are indicated in the Bill, much of the important detail has been left to the Rules. As a result, the risk of unintended consequences is real and potentially unrecoverable for people whose needs are not well recognised by these changes.

Finally, the lack of a trial period or sunset clause in the event that the Bill's proposed changes do have unintended consequences, remains of significant concern.

Further legislative change, substantial policy development and collaboration with people with disability, their organisations and mainstream service programs is essential to realise the positive outcomes that Australians with disability are looking to this world first Scheme

to deliver. We recommend that this first tranche of legislative change incorporates provisions to address these issues.

Key concerns with the Amendment Bill

A lack of clarity

The Bill introduces a raft of new concepts and removes established concepts. The Alliance believes these changes would benefit from a guide or framework that explains:

- why this specific approach has been taken
- how it will practically affect participants and
- what vision for the Scheme has been adopted by the government.

Of particular concern for the Alliance and its supporters is that there has been no apparent consideration of the impact of the changes on people with progressive neurological disability and no consultation on how the risks to them will be minimised to avoid hardship or injury.

While we welcome moves to reduce gouging, waste, fraud and overservicing, we believe the proposed changes may introduce substantial additional risk for people with progressive disability. As a group that has not been well served by the NDIS design, there is understandable concern that this Bill will sideline them even further.

We also note that, in its current form, the Bill lacks alignment with the proposed aged care legislation currently under review by the Department of Health and Aged Care. We are particularly concerned about its potential to increase admissions of young people with disability to residential aged care under proposed new age limits on access to these facilities. We are also concerned the proposed Aged Care legislation has the potential to increase the risks for NDIS participants already living in residential aged care facilities.

We urge the Inquiry to recommend that debate on the Bill be deferred to allow a short period for the government to undertake intensive consultation on the proposed amendments and investigate what alternative approaches should be considered that avoid unintended consequences, are safer, more likely to lead to Scheme sustainability and have demonstrated support from the disability sector.

No requirement for care service planning or service integration

While we note that this Bill is the first step in what is expected to be a series of changes to the Scheme, the Bill does not include any requirement for the Scheme to undertake planning or integrate services. Both are key weaknesses in the current Scheme's implementation approach.

Planning of care service development

There is no requirement for the Scheme to plan for future service needs or address the lack of innovation in housing design, supported living models, use of new technologies, reduction in restrictive practices, communication protocols or preventative interventions/strategies.

As example, the Scheme has no duty or requirement to anticipate where housing should be built to meet participants' needs, lead on development of innovative models of supported living, or incentivise development of new technologies that reduce risk for participants and staff.

Integration of NDIS funded services with other service systems

In its current form, the Bill does not require the Scheme to ensure that its services integrate with other service programs used by NDIS participants that impact directly on NDIS support and funding, such as financial services, non-SDA housing (including accessibility standards), transport, health, education, justice (including corrections and forensic mental health), and family violence programs.

As example, the Scheme has no obligation to ensure that an NDIS participant is discharged from hospital once they are clinically ready to do so. Nor does the Scheme have a requirement to engage with state/territory housing services and social housing providers to guarantee that the timing of participant plans (including change of circumstances reviews) will not leave participants without required supports and thus jeopardise their tenancies.

Given that the lack of both planning and collaboration with other programs have been perennial Scheme problems and key cost drivers, it is surprising that there has been no move to address these early in the Scheme redesign.

While this first tranche of legislative change is well placed to address these fundamental risks for the Scheme and lay the foundations for a more open and collaborative NDIS, the Bill is silent on encouraging more effective arrangements with other systems, dovetailing of Foundational Supports, or the retro-fitting of interface structures that may be introduced in the future.

Impact of the Bill on people living with young onset dementia

Young onset dementia is a terminal condition caused by one or more of over 100 individual diseases, conditions or injuries. When they first experience symptoms, many individuals will be working, with young families and other family/financial commitments.

Because it is a condition that is poorly recognised and poorly understood, delays of up to four years in securing a diagnosis are common. The supports and services these young Australians need are significantly underdeveloped and sparsely located.

The Alliance has significant concerns about the adverse impact the Bill is likely to have on people living with young onset dementia. Its failure to introduce flexibility in planning and funding processes will leave the Scheme unable to respond to the rapidly changing support needs that are emblematic of the young onset dementia cohort.

Service Landscape

Australians living with young onset dementia require services from multiple service systems, often concurrently. As well as access to health services for diagnosis and treatment, they are likely to require specialist disability services and accommodation, access to financial advice,

employment and vocational support, post-diagnosis counselling and legal services, peer support and information.

Yet young onset dementia service options are few and mostly unconnected, particularly in the health and disability sectors. Poor recognition and response by health professionals is compounded by a lack of knowledge by NDIS and provider staff, systemic underfunding in NDIS plans, and a widespread lack of specialist young onset dementia disability services and accommodation including respite.

Their constant interactions with the health and disability sectors mean that people living with young onset dementia are constantly traversing the disability/health systems, but doing so in the absence of any identifiable connecting framework, without appropriate guidance and in the absence of agreed standards for young onset dementia services.

Misinformation and stigma about dementia *per se* continue to negatively impact people with young onset dementia and their families using a range of services. Diagnostic overshadowing is common and many clinicians assume that people living with young onset dementia do not have capacity to speak for themselves, give valuable information about their symptoms and responses to treatment, or understand the consequences of their condition. This was noted in the consultation outcomes report of the National Dementia Action Plan (NDAP) and the need for the NDAP to take steps to address these effectively.

Given this situation, it is vital that the NDIS reforms deliver a comprehensive suite of outcomes that protect this group. Unfortunately, it is not clear from the Bill or the Explanatory Memorandum that people with progressive disabilities have been considered when the Bill was developed.

Specialist services and pathways

A decade after the introduction of the NDIS, young onset dementia services remain immature and largely out of reach for most Australians. The lack of specific provisions in the new Bill to require the NDIA to address service and market gaps means that mechanisms to ensure development of appropriate services and infrastructure for people living with young onset dementia, as well as other progressive disability groups, do not exist.

The Bill makes no requirement for the NDIA to engage in the care and support system planning needed to manage market driven risks. Without this planning, and the commissioning of specialist services and integrated service pathways that such market stewardship would otherwise encompass, the NDIA risks having to fund substitute services that are often more expensive, unstable and not well-aligned to agreed outcomes.

Service integration and NDIS interfaces

Neither the Explanatory Memorandum nor the Bill makes mention of how other service systems can collaborate or interact with the NDIS. Nor do they indicate how the NDIS planning regime might incorporate concurrent services such as primary care, health services or palliative care into the plans for participants needing multisystem service responses.

Where the NDIS Review referred to the failure of the *Applied Principles and Tables of*

Support (APTOS) and recognised the risks for the NDIS in not connecting well with mainstream services, the Explanatory Memorandum is silent on how the Bill will address these risks or mandate the NDIA to engage in collaborative arrangements with mainstream service programs.

Needs Assessment

Many of the changes proposed by the Bill depend on or require articulation with the proposed needs assessment. There is, however, little clarity about the needs assessment itself, with the detail flagged for inclusion in delegated legislation.

Given the progressive and unpredictable nature of young onset dementia, any kind of needs assessment used to determine funding levels for support must have a sound clinical basis and be informed by a clinical assessment. The vagueness concerning the assessment tools, and how the results will be used, raises questions about how such a 'needs assessment' is different from or additional to a clinical assessment done for diagnostic and treatment purposes.

Any needs assessment tool for people with progressive disabilities including young onset dementia should have the following features:

- Be evidence-based regarding impairment and disability
- Use clinically validated tools with ongoing review over time
- Recognise disease processes and be prospective, especially for young onset dementia
- Avoid over-assessment and assessment fatigue in individuals and families.

No cost to participants and families

If additional information such as a neuropsychological assessment, trials of treatments, or special scans (MRI/PET/SPECT etc) are required to confirm or finalise the needs assessment findings, these must be clinically referred, funded by the NDIS or the Medicare Benefits Schedule, and supported by the person's primary treating professional.

This includes the collection of information for NDIS access requests. Funded coordination of assessments for access and review should also be available.

Requirements that clinicians complete administrative activities

Clinicians with expertise in young onset dementia are few and far between. Requiring these clinicians to undertake special NDIS needs assessments that are solely for access purposes is likely to disrupt existing services and referral pathways and result in poorer outcomes for participants.

To avoid over assessment, we recommend that additional NDIS-specific assessment templates should not be required for this group and that clinical assessments be used for access and planning needs purposes.

Capturing the holistic needs of a person living with young onset dementia

The first signs of this terminal condition can be relatively mild, insidious, difficult to diagnose, and may be denied or misunderstood by the individual. They may also later involve many life impacts including financial stress, parenting of young children, loss of relationships and social connections.

These impacts are highly relevant to the determination of a support package and may require a range of supports... only some of which would be funded by the NDIS. The integration of these supports will require skilled and comprehensive case management and coordination.

An NDIS planning process for people living with young onset dementia should be done by staff who are trained in this condition, and who understand disease stages and expectations in relation to progression over the course of the NDIS plan.

Consumer involvement in development of the needs assessment tool(s)

If separate tools are to be developed for people with young onset dementia, the design of these tools should include contribution from people living with this condition, their care partners (including care partners of those who have died of young onset dementia), clinicians, researchers and advocates.

An alternative to a template needs assessment model

Having a single tool for assessing funding levels may be administratively attractive, but is reductive and unlikely to be effective. Given the complexity of young onset dementia, a matrix model of planning that sees the needs assessment as one component in a range of evidence that includes family and clinical reports as well as objective clinical data, is needed to guide decision makers in relation to eligibility and/or funding.

Need for speed

Rapid progression of the condition and changes in support needs means that a needs assessment for people with young onset dementia must be conducted without delay so that the individual is not disadvantaged or left in hardship. As example, being required to remain in hospital and take antipsychotic medication when they could be living in the community; or losing the job they could have maintained if their employer understood their condition.

If needs assessments cannot be guaranteed to occur quickly for this group, the NDIS must make alternative arrangements and/or utilise other evidence for rapid decision making for people with progressive disability and rapidly changing needs.

Minimising restrictive practices

As their condition progresses, many people living with young onset dementia will develop behaviours of concern, even if only for limited periods.

The minimisation of restrictive practices must be intrinsic to any assessment model and any plan approved by the NDIA.

Needs assessment competency

As well as other available evidence, delegates of the NDIS CEO must be competent in interpreting the needs assessment results for people living with young onset dementia and other progressive conditions.

At present, delegates are not trained in understanding young onset dementia and this lack of knowledge is reflected in the poor planning outcomes experienced by NDIS participants living with young onset dementia.

Fast track access and planning pathway for participants with progressive disability

While a key provision in the Bill is the introduction of an *early intervention* pathway, there is no clarity on how this new pathway will operate and the policy rationale for its introduction. Instead, the Explanatory Memorandum indicates that rules and processes will be developed with the States/Territories and other stakeholders after the legislation is passed.

While there may be merit in having an early intervention pathway for some participant cohorts, we believe an additional pathway for participants with progressive disability is needed. This would recognise that people living with progressive conditions should not be expected to ever leave the Scheme (their disability is not only permanent but will increase); and they do not have stable disability needs (their plan needs to be either sufficiently flexible or large enough to accommodate 'spikes' in needs).

From the extensive consultations the Alliance has undertaken with individuals living with young onset dementia and their families, there has been strong and widespread support for a distinct NDIS access and planning pathway for people with progressive disability. The consultation the Alliance undertook for this submission also confirmed the clear-cut support for such a pathway that would need to be tailored much more extensively than the two pathways outlined in the Bill.

Until now, the early intervention pathway has been predominantly applied to children and people with psychosocial disability. Because progressive disabilities like young onset dementia do not have a linear path, it is hard to see how the early intervention pathway could be applied to these conditions.

If it is intended to apply the early intervention pathway to progressive disabilities, it is critical that such a pathway allows evidence-based, disability-specific approaches, structured links with other service systems, and not be NDIS-centric.

NDIS Participant Status

The distinction between the *early intervention* pathway and the *lifetime participation* pathway in the Scheme is unclear, particularly since it seems that a participant can have both early intervention and lifetime participant status at the same time.

Greater clarity is required about how decisions will be made about which of the two options the participant is referred to and what supports might be available under each pathway.

Like other progressive disabilities, young onset dementia is a lifelong and degenerative condition. To deliver for this group, any NDIS pathway must therefore anticipate the degenerative nature of the condition and be highly flexible. There should also be clarity about how a person is expected to transition between early intervention and lifetime participation.

Stakeholders who participated in the consultation for this Bill also indicated their concern about the CEO's unfettered power to suspend a participant's existing and future plans should the participant not meet the CEO's request to provide information or attend a medical assessment within 28 days.

Where a person's disability prevents them from complying with such a direction but also prevents them from providing an explanation as to their inability to comply, concerns were raised about how an individual reliant on critically important supports can be protected from the unintended consequences of losing those supports in these circumstances or through inappropriate application of s32.

Implement proven young onset dementia support models in the NDIS

With the emphasis in the Bill and the Explanatory Memorandum on evidence-based supports, proven models of support that benefit people living with young onset dementia include:

- Models developed for other neurodegenerative conditions (including Multiple Sclerosis and Motor Neurone Disease) that build linkages between clinical and social supports, have early engagement with palliative care, flexible AT arrangements (e.g. AT libraries/pools, rent to buy etc.) as well as peer and family support programs
- Dementia rehabilitation which has a strong focus on re-ablement (noting that the Bill refers for the first time to '*habilitation*' and '*rehabilitation*' regarding funding supports)
- The *Young Onset Dementia Key Worker Program* that supported the principles of consistency and continuity of support in relation to services and relationships that are considered key to successful outcomes
- Non-traditional, but evidence-based interventions such as non-PBS pharmaceuticals, parenting support, dementia-specific home or workplace modifications etc.

The Alliance is also pleased to see, and endorses, the establishment of the *NDIS Evidence Advisory Council* in the 2024 Budget. The NDIS has long needed the capability to understand and implement evidence-based approaches in its administration.

Rather than requiring people with complex and progressive disability, their clinicians and their providers, to 'adjust' language, practice and their identities to achieve desired funding outcomes, we expect this Council will open the way for cohort-specific pathways, and cohort-specific planning and funding models based on clinical and community best

practice.

We anticipate that this incorporation of evidence into NDIS business will reduce the need for over-assessment and repetitive planning reviews as NDIS decision makers become better equipped to understand the impacts and trajectories of different disabilities.

We look forward to people with lived experience of progressive disability, their clinicians and researchers becoming contributing members of this Council.

Families, care partners

Care partners (families, friends) play a central role in relation to outcomes for people living with young onset dementia. The NDIA already places a heavy reliance on care partners to supplement funded NDIS supports.

Any pathway in the NDIS for people with progressive disability must be cognisant that participants with these disabilities come with care partners and sometimes young children, all of whom need to be taken into consideration when defining the most appropriate support pathway.

It is also critical for planners to understand that there usually comes a point in the progression of the condition when people living with young onset dementia may not be able to continue living with their families, or families cannot provide the level of support required for the person to continue living in the family home. This point can come relatively quickly and the NDIA must be ready to respond with equal speed.

Structured integration with mainstream and foundational supports

Substantial evidence exists that best practice in young onset dementia support consists of a multidisciplinary team approach, timely access to services, smooth transitions between services, and access to the right services at the right time, regardless of who funds them. Accordingly, any pathway the NDIS uses to support Scheme participants living with young onset dementia must integrate supports from other service systems to ensure a comprehensive response.

Questions remain about how NDIS pathways and planning systems can effectively integrate services that are critical to the support and well-being of a participant needing multi-system service responses, when these services are delivered by other service systems.

Foundational supports

Of concern is the Bill's failure to indicate how the early intervention or permanent disability pathways will interact with Foundational Supports. Transitions between service systems, the different supports available in each, and the coordination model used to access services from these different systems, remain undefined.

In proposing a stratified approach to funding early intervention and lifetime pathways, the Bill has not clarified how it will accommodate funding lifetime support for people who need increasing or episodic support over the course of their progressive disability.

We recommend against funnelling groups of participants into a generic pathway primarily designed for ease of administration or to reduce costs. It is reasonable to expect that a Scheme as large and mature as the NDIS (with 600,000+ participants and 10+ years of experience) has the capacity and sophistication to tailor approaches for different groups of participants.

An appropriately structured progressive disability pathway would incorporate appropriately trained NDIS planners and decision makers, advice from the Evidence Advisory Council, input from health and other services as well as the participant themselves. We consider this is essential if the NDIS is to meet the needs of the 30,000+ Australians living with young onset dementia who look to it for vital support.

Framework plans

The proposal for framework plans with stated and flexible budgets must recognise the trajectory of progressive disability.

While the new plan structure is primarily designed to limit intra-plan inflation, the framework plan model needs to be sophisticated enough and fit for purpose for all participants with progressive disability. Funding that must respond to rapidly changing needs cannot do so if the funding is fixed, does not account for predictable escalations in need and has fixed instalment periods for payments. These impose impossible expectations on participants who cannot control the expression of their disability.

The proposed framework structure needs to carefully avoid penalising those participants with progressive conditions who require additional supports when their needs escalate.

While the forthcoming Rules may allow for reassessment and refunding of plans, this would need to be done in real time to avoid placing an intolerable assessment burden on participants and families who require simplicity and certainty of funding, and not place an unreasonable burden on NDIA systems. The consequences of a system that cannot cope with rapidly shifting support needs is that it will inevitably force young people with dementia into hospital.

We recommend that alternative funding models that are better suited to people with progressive disability, such as young onset dementia, be added as a core feature of the new Bill.

NDIS Supports

The new approach to defining what the NDIS considers to be a support (s10 of the Bill) raises particular concerns for people with progressive conditions. This is particularly the case if s10(a)(iv) has the effect of limiting or excluding essential health supports that have

previously been found by the Administrative Appeals Tribunal to be disability related health supports fundable by the Scheme.

Giving this provision empowers the relevant Minister to determine what the Scheme will fund, it also creates a number of risks for participants and the Scheme. It is a truism that the needs of people with disability are not easily divisible between the bureaucratic lines our various service systems have created.

It is also unclear whether participants will be able to appeal against the inclusion or exclusion of a support as an 'NDIS Support', or whether they can appeal against a decision to include a support on the 'green list' (supports determined to be 'appropriately funded or provided' by the NDIS) or the 'red list' (supports that are determined to be 'not appropriately funded or provided' by the NDIS).

If challenges to each of these decisions require the Rule to be the subject of objection by members of Parliament and then debated and voted on by both Houses of the Commonwealth Parliament, it effectively disenfranchises participants in the Scheme.

The Alliance recommends that participants be entitled to challenge decisions made as to what is included on these lists and what is excluded.

Minimum requirements for NDIS reforms for people with young onset dementia

To ensure the NDIS can best support people living with young onset dementia, the following minimum standards should apply to any new approaches proposed in the NDIS Act. These minimum standards cover the following areas:

Early intervention or other disability specific pathway

- The early intervention or other disability specific pathway should be comprehensive, start as early as possible and be continuous
- The experience of the individual in the pathway should be seamless with minimal assessment burden and conflict
- The NDIS should have a stated obligation to minimise conflict with applicants and have a positive duty to use best practice communication and negotiation approaches
- Early intervention should link to a sophisticated version of service coordination and be informed by clinical guidance and family input.

Assessment

- The Department of Social Services should be in charge of commissioning the development of assessment processes, tools and protocols from experts
- The needs assessment tool for people with young onset dementia should be part of the qualitative and quantitative evidence²
- Needs assessments should have maximum clinical utility and align with the needs of

² See <https://www.thedonetwork.com.au/training-and-professional-development-what-is-functional-cognition> and <https://pubmed.ncbi.nlm.nih.gov/28238815/>

the individual, families/friends, clinicians and rehabilitation personnel.

NDIS Supports

- Any supports included in a person's NDIS plan should be practically available and have an agreed funding source. If not funded by the NDIS, there should be prior agreement from the relevant service delivery agency that guarantees delivery of the supports
- New supports should be subject to a service development planning process that is codesigned with people with young onset dementia and their families/friends, clinicians and advocates
- Supports for people living with young onset dementia should be approved, governed and coordinated by young onset dementia specialists
- There should be strong consumer involvement in all decisions that affect supports available to individuals living with young onset dementia
- Given the whole of life impact created by young onset dementia there should be a comprehensive model of service coordination funded by the NDIS in collaboration with other programs.

Funding / NDIS administration

- Decision-making by the NDIA should be as dynamic as the changing needs of individuals living with young onset dementia. The NDIA should develop methods for delivering real-time responses to participant needs
- Funding should be reliable and should not be reduced or withdrawn without sound reasons and with sufficient time for participants to submit a request for review. Where a request for review of a decision to remove or reduce supports has been lodged, the NDIA should maintain those supports until the review and any appeal is finalised
- NDIS decision makers should have demonstrable expertise in young onset dementia, with external credentialing programs in place
- The NDIA should be required to demonstrate how it has collaborated with relevant stakeholders in developing a person's plan
- All funding decisions should include a statement as to how the person's social/family needs were taken into consideration
- Funding for a person with a progressive neurological disease (such as young onset dementia) should include a disease map that indicates how the intensity of funding has matched the disease stages.

Amendments missing from the Bill

Stakeholders who participated in the Alliance's Consultation Workshop on the Bill agreed the following amendments should be included.

Ensure consistency of planning and funding for all participants

The NDIS Act permits decisions by the CEO (or delegate) about reasonable and necessary support to be effectively outsourced to another service system – that is the Aged Care system.

Section 45 enables the CEO to fund supports in any manner they choose where there are no Rules in place.

Section 45 of the NDIS Act states:

Section 45

45 (1) An amount payable under the National Disability Insurance Scheme in respect of a participant's plan is to be paid:

(a) to the person determined by the CEO; and

(b) either:

(i) in accordance with the National Disability Insurance Scheme rules prescribed for the purposes of this subparagraph; or

(ii) if there are no such rules – in the manner determined by the CEO (emphasis added)

In 2013, when the Scheme began, this enabled flexible decision making at a time before Rules were in place.

However, while relevant Rules are now in place, the NDIA continues to act outside s34 and s31 of the Act in the funding decisions it makes regarding reasonable and necessary supports for participants living in residential age care facilities.

Specifically, the Agency has entered into a 'cross-billing' arrangement with the Department of Health and Aged Care (DoHAC) which allows for DoHAC to pay Residential Aged Care (RAC) providers the standard AN-ACC funding classification rate (set under the Aged Care Act 1997) to provide care for NDIS participants living in these services, and for DoHAC to then invoice NDIS for this amount. The NDIS effectively 'reimburses' DoHAC for the cost of care the residential aged care provider delivers to NDIS participants residing in their facilities.

Because these cross-billing payments are made to DoHAC rather than to individual Scheme participants or directly to the RAC provider, the NDIA is accepting aged care as a proxy for disability supports that need to be determined by applying s34 requirements. This effectively delegates the decision as to reasonable and necessary supports to the Aged Care system.

There is no provision in the NDIS Act or the NDIS Rules for the delegation of any function related to funding for participants, either directly or indirectly. The NDIS Act only authorises funding in plans for the direct provision of services to the individual participant.

There is also no provision in the NDIS Act for the NDIS to reimburse another government department (DoHAC) rather than make a payment to an NDIS provider. This reimbursement approach has continued even though RAC providers caring for NDIS participants have been automatically registered as NDIS providers since 2020. The cross-billing reimbursement to DoHAC appears to be a further exception to s34(1)(f) of the NDIS Act.

By supporting an aggregated funding and care model for its participants in RAC, the cross-billing arrangement also appears to breach s31 of the NDIS Act.

Section 31 lists the principles for the “*preparation, variation, reassessment and replacement*” of participant plans. The first principle states that plans should, so far as reasonably practicable, “*be individualised*”.

Another principle states that plans should “*support communities to respond to the individual goals and needs of participants*”.³ Yet the NDIA has no direct relationship with aged care providers.

This cross-billing arrangement leads to systemic underfunding of participants with complex needs requiring residential support and high-level care. Many are funded at rates that can be as little as a third of what they would receive in a SIL setting.

Over 1800 people under 65 remain in residential aged care.⁴ The vast majority of these individuals are NDIS participants who do not have a goal to move out of RAC⁵.

With the Exposure Draft of the new aged care legislation proposing that some groups of people under 65 will have eligibility for placement in residential age care⁶, and the risk that this could include NDIS participants living with young onset dementia, this issue requires immediate resolution via an additional provision in the NDIS Amendment Bill.

Include a statutory duty of care in the NDIS Amendment Bill

This NDIS Amendment Bill should contain a statutory duty of care for providers delivering supports through the NDIS Act.

The NDIS Review highlighted major deficiencies with the safeguarding capabilities of the NDIS Quality and Safeguards Commission. Although the Review recommended universal registration of NDIS providers and risk proportionate regulation, none of these can be expected to drive the required cultural change across the NDIS market without enforceable requirements on providers.

A statutory duty of care has existed for over 35 years in the Work Health and Safety (WHS) legislative framework and has delivered cultural change in workplace safety. It is now a recognised public health imperative and supports a strong regulatory system of proactive investigation, enforcement, public education, fraud detection and structured stakeholder engagement – something sorely missing in NDIS regulation.

³ The National Disability Insurance Scheme Act 2013 (Cth) s31.

⁴ See Australian Institute of Health and Welfare YPIRAC data:

<https://www.genagedcaredata.gov.au/resources/younger-people-in-residential-aged-care>

⁵ Reported by the NDIA to the YPIRAC Stakeholder Reference Group (date)

⁶ Exposure Draft Aged Care Act 2023: <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>, s40.

The statutory duty of care in the Work Health and Safety arena does extend to people with disability who are injured or who die as a result of breaches of the WHS laws when using disability services.

However, because it relies on providers reporting incidents to their WHS regulator, and because providers generally do not, the rate of referrals to WHS regulators in these cases is unfortunately very low.

As example, in the first 6 years of the NDIS Quality and Safeguards Commission's existence, not a single referral was made to a WHS regulator by the Commission⁷, making this WHS duty practically unenforceable.

One of the key recommendations of the Aged Care Royal Commission was a statutory duty of care for aged care providers, with civil penalties and compensation arrangements for affected older people. This duty is included in the Exposure Draft of the new Aged Care Act 2023⁸.

Given that 54% of aged care providers are also registered NDIS providers, not having a companion duty of care in the NDIS Act will create significant regulatory complexity.

Having two different regulatory standards will create further confusion for providers and for the NDIS – particularly when worker screening and information sharing between the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission is strengthened in the new Aged Care Act.

Leaving the 600,000+ NDIS participants to rely on other regulatory regimes to manage the inadequacies of NDIS regulations is lazy governance at best, and a failure to recognise the Scheme's duty of care to its participants at worst.

The NDIS Amendment Bill should address the need for a statutory duty of care in the NDIS legislation as a matter of urgency.

Appearing before the committee

A number of stakeholders the Alliance has consulted with, including people with lived experience of young onset dementia, have expressed interest in appearing before the Committee to speak about their concerns regarding the NDIS Amendment Bill and the need for NDIS reforms to respond to the needs of people with young onset dementia and other progressive disabilities.

We would appreciate the opportunity to appear before the Committee to further discuss the key points made in this submission.

⁷ FOI request to the NDIS Commission 2022.

⁸ See <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>, Part 5.

Endorsements

This submission has been endorsed by the following individuals:

Dr Monica Cations, Senior Research Fellow, College of Education, Psychology and Social Work, Flinders University.

Ms Nola Beagley, parent and carer of an individual living with young onset dementia.

Dr Margaret Pozzebon, Speech Pathologist.

Further contact

Dr Bronwyn Morkham
National Director
0437 178 078
bronwyn@ypinh.org.au