Submission to the Review of the NDIS Act and Participant Service Guarantee (Tune Review)

Young People In Nursing Homes National Alliance

November 2019

Introduction

The Alliance welcomes the opportunity to provide this brief submission to the Tune Review.

We believe this review is long overdue. The original legislation was drafted for the trial phase of the NDIS with the expectation that it would be reviewed at the end of the 3 year trial. Now 3 years beyond the move to full scheme, we have enough experience with the scheme to understand what is working and what elements are creating problems that now require adjustment.

Overall, the Alliance believes the scheme design is sound. We do not support changes to the scheme that cap or limit funding for supports to participants, or to further limit eligibility. The changes we propose below are not fundamental to the design of the scheme, but are aimed at prescribing better processes that will enable the NDIS to effectively address participant needs. These improved processes will also give the NDIS greater capacity to manage its liabilities into the future.

From our experience with the scheme, we see that many of the well publicised issues that participants, advocates and providers have expressed about the NDIS (planning, review, funding, delays and cumbersome processes), are not scheme design issues but are the product of poor administrative systems and decisions. Unfortunately, the frame of reference for these poorly fitting systems has been that of capped government programs rather than the insurance based lifetime support entity the NDIS is intended to be.

Instead of pursuing corporate goals like achieving absolute national consistency and the centralised decision making that is an all too commonly a feature of government departments, the NDIS must model itself on such lifetime support schemes as the Victorian Transport Accident Commission or NSW's iCare insurance agency. These schemes prioritise relationship management (with participants and providers) as well as localised decision making alongside process and fiscal management, and are able to achieve positive customer ratings and outcomes for participants with disability as a result.

Instead of working on collaborative social policy initiatives, the NDIS has relied too heavily on market forces to resolve complex policy dilemmas in its development thus far. When administrative arrangements have been contrived to implement its operations in the community, the results have been mixed. In particular, local area coordination and support coordination roles have manifestly failed and should be replaced with a model that better supports and integrates with community sector infrastructure.

These flawed administrative systems and implementation approaches are not prescribed in the legislation and as such, can be fixed or replaced without recourse to the Act. To make the required changes, however, the scheme requires a policy function independent of any government department. This will enable it to improve

its engagement structures and most importantly, change its culture to better value relationship development and local connection with service systems rather than the command and control environment that currently predominates.

There are parts of the NDIS Act that must be amended to improve scheme process (such as planning and review; to remove the requirement for a statement of goals and to alter the governance arrangements); and allow new provisions that enable shared planning/funding with other service systems that should be considered.

The Alliance has proposed changes to the scheme in submissions to previous reviews and inquiries, some of which are reiterated in this submission.

The YPINH National Alliance

The Alliance is a national peak organisation that promotes the rights of young Australians with disability living in residential aged care facilities or at risk of placement there.

The Alliance undertakes a range of functions including

- Policy analysis and development;
- Research, cross sector collaboration, consultation and service development;
- Provision of individual support and advocacy;
- As the pre-eminent national voice on issues concerning young people in nursing homes, the National Alliance's primary objectives are to
- Raise awareness of the YPINH issue and how in impacts on individuals, families and service systems
- Contribute to local and systemic reforms required to resolve the YPINH issue
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver "lives worth living" to young people with disability and complex health needs;
- Provide support to YPINH, their friends and family members.

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] Since its inception in 2002, the Alliance has argued for comprehensive policy solutions and collaborative arrangements between health, disability, aged care and housing portfolios.

Areas requiring revision in the legislation and rules

Scheme intersections with mainstream service programs

As well as meeting the needs of its participants, the capacity of the NDIS to manage functional relationships with other service systems is critical to its long term viability.

[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 fact that this has consistently been highlighted as a policy challenge but remains unresolved points to a failure of scheme governance.

In late 2015, the Council of Australian Governments (COAG) agreed to a set of Principles that were to guide the relationships the NDIS would establish with mainstream programs, particularly around the contributions these programs would make to NDIS participants requiring their assistance.[2] However, the scheme's interpretation of the COAG Principles has seen it make unilateral decisions about the contributions of other programs without reference to the operation of these programs or negotiation with them.

While the COAG Principles include scope for joint work, there has been no evidence that this is occurring. Instead, the NDIS has applied the COAG Principles unilaterally and from an isolated and defensive position when planning with participants with complex needs who require concurrent service delivery from multiple programs.

The lack of collaborative working relationships at the interfaces of the aged care, the NDIS and State health systems is one of the reasons younger people continue to enter the aged care system. These interfaces and cross program policy settings are immature and completely ineffective.

Human services programs like these have evolved historically as separate agencies mandated to provide services to distinct target groups. With separate budgets, languages and processes, these siloed programs have never developed different, more multidisciplinary working arrangements with each other despite recent government attempts at reform.[3]

The entry of the NDIS into this space offered a unique opportunity to develop the partnered approaches YPINH depend on to access the multi program, joined up service responses they need. Unfortunately this has not happened. One of the key reasons for this is that it appears the need for this change has not been made apparent to these programs or the NDIS, that they need to work differently and more collaboratively with one another.

Another reason is the reliance of the NDIS on the COAG Principles to justify its refusal to fund certain services as well as to declare what the scheme expects other service programs to fund, whether other programs provide these services or not. This instrumental approach to the scheme's engagement with other programs has

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[2] See https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

[3] See Department of Human Services, *The Case for Change*, Victorian Government, Melbourne, December 2011; Shergold, P. *Service Sector Reform. A roadmap for community and human services reform. Final Report,* for the Victorian Department of Human Services, Victorian Government, Melbourne November 2013; Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services,* Report No 85, Canberra, October 2017.

been at best unhelpful and at worst, prevented the development of good cross program policy and the delivery of comprehensive multi program supports to participants.

Drafted before full scheme implementation, the Principles are underpinned by a lack of awareness or incentive for programs to collaborate; and have made interface interactions primarily concerned with the binary debate of who pays for a service rather than articulation of the multidisciplinary 'joined up' responses that are needed. This is particularly so in the case of the scheme's interactions with the health and aged care systems. These Principles have fed an antiquated "closed shop" bureaucratic imperative and simply allowed the NDIS to become another siloed program itself.

As example, despite most disabilities being the result of a health event of some sort and disability often resulting in poor health, the NDIS continues to ignore the 'enmeshed' nature of health and disability to argue that some supports are the funding responsibility of health services alone. Far from looking to embrace a more multidisciplinary approach, the Disability Reform Council's (DRC) recent decision that the NDIS would pay for a "range of disability-related health supports",[4] has simply codified the decisions of a number of Administrative Appeals Tribunal (AAT) rulings that have found against the NDIS in these areas.

Similarly, the DRC's agreement in the same Communiqué that its Hospital Discharge Delay Action Plan "…will address NDIS related issues to promote timely discharge of NDIS participants from public hospitals…",[5] fails to consider just where NDIS participants facing timely discharge from acute care are to be discharged to. Indeed, without attention to the NDIS administrative processes that determine eligibility, deliver one dimensional planning and inherent delays; without consideration of other elements such as interim accommodation, rapid response home modifications or designing integrated service responses, simply speeding up the discharge 'timetable' from hospital will also speed up placement in residential aged care (RAC) for too many NDIS participants.

The inherent limitations of the COAG Principles were well described by the Deputy President of the AAT in the Burchell case in June:

> *The COAG Principles are a high level, general, statement about what the health authorities are responsible for, and make no allowance for gaps in the service provided. There appears no intention in the COAG document to state how the Act and rules should be interpreted. In my*

[4] Disability Reform Council *Communiqué*, 28 June 2019. See https://www.dss.gov.au/sites/default/files/documents/07_2019/communique-drc-28-june-2019.pdf Accessed 3 August 2019.
[5] Disability Reform Council *Communiqué*, op.cit: 1.

opinion, the COAG principles are not of assistance in understanding the Act or the rules…'[6]

In the Burchell case, the finding was that the NDIS must recognise what is actually provided by health systems rather than deciding for itself what should be provided. Where there is a gap, it is S34(f)(1) of the Act that must be exercised as it is written.

Rather than being used as intended to assist with decisions at the individual level, the Principles have instead been used by the NDIS to make unilateral policy at the system level.. The legislation, requires the scheme to make separate decisions on the basis of individual circumstances. This application of the Principles by the NDIS to resolve what the scheme believes are the responsibilities of other systems (without confirming systemic agreement), has resulted in the prevention of localised collaboration and made development of tailored solutions with health services needed by some NDIS participants, virtually impossible to deliver.

The Alliance recommends that the COAG Principles be redrawn to enable and prioritise collaborative arrangements with mainstream services. In addition, the NDIS must follow the AAT's Burchell direction to both look at mainstream intersections at the individual level; and implement a model that enables local cross service negotiation and integrated service plans. In the health area, this means giving the NDIS the capacity to make local agreements and engage in joint funding and governance processes with local health organisations.

In responding to the challenges involved in applying the COAG Principles to individual decision-making, the then Manager of the NDIS Hunter region said in 2017

The interface between the NDIS and other mainstream agencies has always been a grey area. We have the applied Principles that were published when the scheme came into being, and they have just been revised and republished. Those are the Principles that inform the interface between us and other jurisdictions, but they are not specific enough for us to make a clear decision in every case.

There are still some gaps that continue to emerge – things that we have not had to deal with before…. Hopefully in all cases the conclusion is the correct one and then is applied consistently. One of our biggest challenges is to apply it consistently.[7]

[6] https://jade.io/article/647731, at [52]

[7] Lee Duncombe, Hunter Trial Manager in *Hansard*, Joint Standing Committee on the NDIS, 7 March 2016. See http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommjnt%2Fb02490da-1f4b-458b-a978-57e36ade0fa5%2F0006%22

This dilemma is as true in 2019 as it was in 2017. But the approaches to address it have not evolved as they should have over this time.

As much as the NDIS and government agencies want universal certainty, the business of a social insurance scheme that relies on 'reasonable and necessary' judgements will, by its very nature, be fluid and variable across different regions and demographic groups. Reducing this complexity to a yes or no response to requests in individual plans is simply not sufficient.

In regard to the determination of supports for participants, we believe that S34 is a well-crafted section that provides a rigorous test for funding and enables individualisation of support that can be used to deliver the flexibility, choice and control the legislation demands. The 'reasonable and necessary' test is an appropriate one for the scheme and is fit for purpose.

Planning

The current NDIS planning system has significant limitations for people with complex support needs.

This is something the scheme itself has partially recognised in its recent development of a Complex Participant Pathway. While this new pathway improves the administrative capacity of the scheme to work with this group, it remains scheme-centric in its approach. It does not utilise any kind of joint service planning and delivery with health, aged care or other service systems.

While the introduction of the new NDIS Complex Participant Pathway is an important step in the scheme's recognition of its need to work with other systems, it does not deliver the comprehensive approach described in the project's Principles for Collaboration. However, the Alliance strongly believes the NDIS' new pathway can be a catalyst for the development of effective cross sector collaboration, particularly with health services. While joint planning is a significant part of this approach, it cannot occur in isolation from joint service delivery, service review, shared program governance and protocols for joint funding.

To this end, the planning rules need to be amended to enable the NDIS to collaborate with other service programs to deliver an integrated plan with service commitments from the programs required by a participant. The NDIS and the jurisdictions will have to establish governance and accountability systems for this, but this is a system that should have been part of the scheme design from the outset.

NDIS plans also do not record any unmet needs for disability or other services. This is problematic, as it provides no guidance to providers or participants about how service gaps are to be addressed, or how mainstream services can be utilised in conjunction with NDIS supports to contribute to the achievement of participant

goals. The Alliance believes this is a critical shortcoming of the current planning methodology.

The requirement for a participant statement of goals must be rescinded from the ACT. Goals are important where there is capacity building in a plan. However, core supports that are intended to meet core (necessary) disability support needs are irrelevant to the process of setting and attaining goals. Plans can include capacity building goals in the context of the planning process and goals are appropriate in this context. However, we would like to see the requirement for goals to underpin core supports dropped from the Act and the rules.

Service Coordination

The Alliance's experience is that the Local Area Coordinator role and the Support Coordination role are failing.

These roles were contrived as part of the NDIS' initial approach to implementation during trial, but they have not worked and must be reformed. While the NDIS relies on support coordination to manage plan implementation, providers are struggling significantly with the cross program demands this work entails.

The LAC and support coordination workforce that has been employed to undertake these roles largely lack the capacity to work with mainstream programs such as health and aged care.

Instead, service coordination and community linking require a working knowledge of other service systems. Embedding this function in community organisations inside and outside the disability sector will generate and protect the community goodwill that is so important to community connection.

The other significant imperative in this area is to make cross sector service coordination possible, and indeed routine. This is not supported by the legislation at present, but is critical to the effective provision of support for participants with complex needs, as well as the success of initiatives such as the Complex Participant Pathway. It is important to amend S31(k) of the NDIS Act to mandate service coordination that works across NDIS and mainstream services, not just across different disability supports.

Funding methodologies

The fact that there is only one funding method available for participants (individualised packaged funding) is a limitation. There are a range of participants who would benefit from different funding options for their supports that can be chosen depending on circumstances and preference.

For example, where people have a cognitive impairment and cannot effectively execute service agreements with providers, a community commissioning system

would enable more effective agreement making with providers (including provider management) than making individual disbursements to participants

For people with rapidly changing needs, a 'line of credit' funding methodology that can have funding allocated decision by decision as things change (including people with ABI in the first 3 years post injury and people with degenerative conditions) this can be a viable alternative to packaged funding.

While these variations maintain the individualised nature of the scheme, the ability to better target funding methodologies to participant needs and choices would markedly improve the scheme's design.

The Alliance believes this Review should investigate the feasibility of having opt-in choices for participants for the most appropriate funding methodology for individual support.

The arguments that have been made across the disability sector for selective block funding of some services (including community linking services, transitional housing and services in Aboriginal communities), are also worth consideration by this Review.

People over the age of 65

NDIS participants at risk of losing eligibility

There is a significant difference in what the aged care system and the NDIS can provide for people with disability, be that in the community or in residential aged care. People with disability over the age of 65 needing customised equipment, community access and therapy support cannot access these types of support in aged care.

S29(b) of the Act forces NDS participants to lose their NDIS eligibility if they enter residential aged care for the first time after turning 65 years of age. Given that the NDIS is the sole funder of support to participants living in residential aged care this provision is both discriminatory and illogical. It simply leaves a person without the support they would have had if they lived in any other place in the community. This section must be repealed. The Alliance is firmly of the view that people who become NDIS participants and enter a residential aged care service for the first time after they turn 65, should retain their NDIS eligibility.

People with disability who acquire disability after 65 years

People who acquire a severe disability or whose disability progresses after the age of 65 (including brain and spinal cord injury, Motor Neurone Disease or post polio syndrome) need specialised disability services responses that are not available in aged care. Provision must be made to enable people over 65 who have acute needs for specialist disability service to be appropriately supported so they are not institutionalised, underserviced or at risk of accelerated disease process, avoidable illness or premature death.

This can be done by either prescribing the diagnostic conditions that the NDIS will approve for full support for people over 65 in the Act or the rules; or defining specialist disability supports (to distinguish them from aged care and other services) in S9 of the Act to enable concurrent service funding from the aged care system and the NDIS for this group of people. This joint funding arrangement locates the person in the aged care system but allows the NDIS to complement the aged care offering with specialist disability services (including customised equipment, therapy, personal and community support).

The use of the term 'general supports' in S9 of the Act has been made deliberately broad to enable the flexible use of plans by participants. Given that disability supports are mostly indistinguishable from aged care services in their delivery, they will need to be defined differently if this concurrent eligibility is to operate effectively. The rules on becoming a participant (to define a category of participant to enable funding of people over 65) and defining support for participants, will also require amendment to describe how this will work in practice.

The NDIS and the Commonwealth Department of Health may need to strike a funding arrangement for this group similar that used to fund the support of NDIS participants under 65 in residential aged care or the Continuity of Support program for residents of disability accommodation who are over 65. Rather than create new classes of aged care packages for this group as part of an aged care system not designed to provide specialist disability supports, the Alliance believes it is preferable to provide for this group in the NDIS legislation.

Eligibility and Access

Scheme access must be streamlined to improve the timeliness and quality of decisions.

The Alliance is seeing growing numbers people with health and rehabilitation needs overstay their discharge date in hospital because access requests are taking far too long. We have also seen poor decisions made that refuse scheme access on technical grounds for people with manifest disability related impairment. In some cases, we have seen people self fund their equipment (both purchase and hire) from very limited financial resources because they could not wait for the NDIS.

It goes without saying that delayed or refused access adds stress, cost and diminished life experience for people with disability and their families. It also represents a cost shift to other service systems that is false economy for the country.

We are pleased that the focus on the service guarantee will mean that access can be improved. It is one of the areas of NDIS operation that can be improved without legislative change.

The NDIS should consider activating different streams for access to ensure that there is barrier free entry to the scheme for groups of people currently finding it difficult. This should include a 'light touch' or automatic entry for anyone with a brain or spinal cord injury who is an inpatient in a rehabilitation hospital. Given that section 34 of the NDIS Act has cost implications, not S24, the risk to scheme sustainability for a system of automatic or rapid entry is minimal.

Early intervention

The Alliance has had a number of cases where access to the NDIS has been refused or delayed for a number of reasons. These have mostly been with people with acquired brain injury and progressive neurological conditions.

Our experience is that the scheme does not operationalise this access provision well for adults. The rules for early intervention are contradictory and are not delivering the effect that was intended.

S25 was designed for people with particular conditions to enable them to maintain employment, remain at home, or increase the capacity of their informal supports without having to meet the full provisions of S24 before accessing the supports needed to delay or prevent further deterioration or to improve capacity where needed.. Amending the rules and making them more workable will provide significant benefit to individuals, families and the scheme.

The current rules for Early Intervention require ALL of the listed criteria to be met for a person to be accepted into the NDIS under S25. The rules should be amended so that *some*, not *all* of the criteria need to be met for this purpose.

Currently the bar is set so high that, instead of focusing on being a specific gateway to the scheme, it operates to exclude people where possible and does not enable the value of early intervention support to be captured. For example, it is inappropriate to apply the permanent or likely to be permanent disability test alongside all other requirements in these rules (particularly one of improving a person's capacity) if the goal is to enable a person to access supports to maintain or improve their capacity and keep them active in the community.

The Early Intervention rules stipulate that a person:

> *i. has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent (section 25(1)(a)(i)); or*
> *ii. has one or more identified impairments that are attributable to a psychiatric condition that are, or are likely to be, permanent (section 25(1)(a)(ii)); or*
> *iii. is a child who has developmental delay (section 25(1)(a)(iii)); and*

- *the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by reducing their future needs for disability related supports (section 25(1)(b)); and*
- *the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by:*

i. mitigating or alleviating the impact of the person's impairment upon their functional capacity to undertake communication, social interaction, learning, mobility, self-care or self-management (section 25(1)(c)(i)); or

ii. preventing the deterioration of such functional capacity (section 25(1)(c)(ii)); or

iii. improving such functional capacity (section 25(1)(c)(iii); or

iv. strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer (section 25(1)(c)(iv)); and

- *the NDIA is satisfied early intervention support for the person is most appropriately funded or provided through the NDIS (section 25(3)).*

Note, in certain circumstances, a person with a degenerative condition could meet the early intervention requirements and become a participant in the NDIS[8]

These rules make it very difficult to pass the combined tests and as a result there have been very few successful S25 access requests by adults.

The early intervention gateway is an important one for the scheme but needs to be reconstructed so that it is fit for purpose. It would make sense to create an interim participant status (similar to that used by the State and Territory lifetime support schemes) to create a participant experience and support packages that are specifically targeted at early intervention rather than being 'lite' versions of the lifetime support NDIS plans.

The interim participant provisions work well for people with catastrophic injury in the lifetime support schemes. As adults with ABI and progressive neurological conditions were envisaged as targets for the S25 early intervention entry to the NDIS, introducing this participant status would work equally well in the NDIS.

2017 Amendment to Section 24 to limit scheme eligibility

The Alliance did not agree with the proposed amendment to Section 24(1) that sought to add a test of whether the person's support is better provided by another service system.

The Alliance does not believe that the determination of service system responsibilities can be used as part of considerations of eligibility as it is simply too subjective, and cannot be made by the NDIS alone without substantial investigation

[8] https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-early-intervention-requirements

of the dynamics of the applicant's situation, the interaction of their health needs with their disability, and the reality of whether their support needs can in fact can be met by another service system. This is best done under the provisions of S35 in determining reasonable and necessary supports where detailed information about the person can be obtained and discussions held with other service programs.

Many people with complex needs will need concurrent service delivery from multiple service programs, of which the NDIS could be one. A need for a person for one type of support (e.g. health services) should not preclude the NDIS also providing specialist disability supports. The challenge is for the NDIS planning process to identify the person's various needs and to facilitate the integration and coordination of linked supports.

The Alliance is aware that NDIS planners are already making arbitrary determinations about the responsibilities of other service systems and denying liability for particular supports under S35(f)(1) without reference to those programs. These decisions are based on a theoretical appreciation of the split in service responsibility rather than a real appreciation of the service landscape existing around a participant.

We are concerned that similar ill-informed decision making will be applied to eligibility decisions making it an unfair means of exclusion for people needing NDIS support.

When so much is still to develop at the boundaries of the scheme, including development of more effective avenues to better manage scheme liabilities than restricting entry to the scheme, the proposed amendment to S24 in the 2017 Amendment bill should not be revisited. Rather than reaching for legislative change, the NDIS and DSS should make a serious investment in cross sector policy development, including recasting the COAG Principles for determining the responsibilities of the NDIS and other service systems.

Governance

The Alliance believes that changes are required to the governance and advisory structures of the NDIS.

The first is that instead of being linked to the Disability Reform Council (DRC) of COAG, NDIS must become the responsibility of the Council on Federal Financial Relations. Because of the need for the NDIS to be integrated across government and not become an island disability-only program, it is important that it is managed by central agencies.

Unlike the DRC, Treasuries can:

- have direct line of sight of all mainstream agencies;
- identify efficiencies, waste and duplication across portfolios;
- quantify the economic and value of joint initiatives.

If the economic benefits of the NDIS heralded by the Productivity Commission are to be realised, it is essential that the relevant cost offsets, benefits of joint cross program initiatives and policy and funding decisions in mainstream programs be fully visible. Treasuries are already directly involved in funding the NDIS so it makes sense that they assume an end-to-end governance role.

Disability services have traditionally been residual portfolios within governments that, in many jurisdictions, have been involved with service delivery as well as policy setting and service funding. As a consequence, Disability Ministers have had little capacity to engage with other portfolios or influence across government. Disability agencies are fast disappearing across the jurisdictions so the ability of these ministers to effectively govern the NDIS is becoming more limited.

Should the NDIS remain a one dimensional funding program for disability services with no carry across government, it will be seen as a potential funding source only and not taken seriously by other portfolios.

The potential of the NDIS is, of course, much greater than this. But the scheme needs to assume a totally different identity within government. Because treasuries manage no fault injury schemes around the country, the DRC's oversight of the NDIS is an anomaly. Moving the NDIS into Treasury will enhance the connections between the NDIS and the nascent NIIS, which is an important strategic imperative in itself.

The Alliance recognises that the Disability Reform Council has a key role to play in the transition of people with disability into the NDIS and the reformation of systems in disability services. But because this change is nearing completion, a shift in governance is timely.

The Alliance has recently made a submission and provided evidence to the Senate Community Affairs Committee's Inquiry into the NDIS Streamlined Governance Bill (2019). In this submission, we drew attention to the need to expand the scheme's advisory structures and to find ways of bringing the states and territories into the centre of the governance arrangements of the scheme. We refer the Review to our submission and evidence provided to that inquiry.[9]

National Injury Insurance Scheme

Another failure of governance around the NDIS is the failure to fully implement the National Injury Insurance Scheme (NIIS). This is having cost impacts for the NDIS and negative impacts on individuals with catastrophic injuries who cannot access appropriate services simply by being part of the NDIS.

[9] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/NDISStreamlinedGovernan/Submissions

In its Disability Care and Support Inquiry Report in 2011,the Productivity Commission proposed the NIIS as a companion scheme to the NDIS.[10] It recommended that the NIIS be established ahead of the NDIS to build on existing no-fault schemes and develop a workforce that could be then utilised by the NDIS. For a number of historical reasons, this implementation sequence was reversed, with the NDIS starting first in 2013.

While a NIIS Working Party of treasury representatives from all jurisdictions has been working through the four injury types in sequence, progress to deliver the NIIS across all injury areas has been painfully slow.

However, as a result of this work and from July 2016, all Australian States and Territories now have no-fault motor vehicle schemes for catastrophic injury, with similar arrangements in place for catastrophic workplace accidents.

COAG shelved work on the medical injury stream of the NIIS in 2017. The final and perhaps most challenging stream, that of general injury, has also stalled.

The Alliance is deeply concerned by the lack of progress on these remaining components of the NIIS. Critical to the sustainability of the NDIS, this sister scheme is barely at the half way mark some six years after the establishment of the NDIS. Indeed, a number of factors are combining to make the failure to implement the full NIIS a very real – and very concerning – possibility.

The NIIS and the NDIS are critical parts of the COAG's disability reform program. Because the NIIS raises premium income and doesn't rely on government budgets, it is critical to the financing of the NDIS. In 2011, the Productivity Commission estimated the national per annum cost of catastrophic injury as $1.8b, and the additional annual cost to be covered by the NIIS to be $835m.[11]

In the context of recent speculation about the scheme's financial sustainability and the fact that the NDIS' cost recovery will deliver costs to jurisdiction budgets, implementing the NIIS must be a priority. Failure to do so is simply false economy.

The Alliance recommends that this review investigate a way that the NIIS work can be linked to the governance of the NDIS.

Devolving scheme functions to the community

Despite not being ideal, the Alliance understands that the original design of the NDIS placed key functions inside the scheme. While processes were being designed and

[10] Productivity Commission, "Insurance Arrangements for Injury", Chapter 18, *Disability Care and Support Inquiry Report*, Vol. 2, Canberra, 2011: 851-920.
[11] Productivity Commission, Disability Care and Support Inquiry Report Volume 2, Canberra 2011: 906-907

bedded down, the need for the scheme to have control over planning and local area coordination during establishment made sense from an administrative perspective.

However as the scheme is moving to full implementation, it is timely to review its operational model. Given that the NDIS is encouraging community engagement for participants, it must create the structures that engage local communities and sectors.

Universally centralised planning by NDIS staff and the contracting of tightly controlled Local Area Coordination is not the ideal structure through which the NDIS can enable and sustain community engagement for participants. The scheme cannot expect community and cross-sector networks that are critical to encouraging genuine community connection to materialise simply because of the scheme's existence, or the introduction of individualised funding for disability supports.

In our 2010 submission to the Productivity Commission's Inquiry into Disability Care And Support, the Alliance proposed that not-for-profit member organisations be developed to fulfil this function because of their capacity to make a unique contribution not available in other commercial or for-profit enterprises. Chapter 4 of the Commission's report was devoted to the value of the not-for-profit sector and community organisations to achieving the goals of the scheme.[12] In proposing this, the Alliance referenced the Productivity Commission's Research Report into the Contributions of the Not-For-Profit Sector.[13]

In that report, the Commissioners indicated that not-for-profits utilise processes that are "…participatory, inclusive, quality focused and accessible…"[14] The Report also says that these processes are "central" because they

- Engender trust and confidence in the organisation, enhancing the reach and quality of the activities undertaken.
- Facilitate access to resources from multiple stakeholders including volunteer workers, as well as access to funding and in-kind resources, as NFPs can provide value to those making these contributions.
- Build the capacity and capabilities of staff, volunteers, members and clients for effective engagement over time, including their knowledge and ability to influence the design of future activities.
- These 'quality' processes contribute to achieving the outcomes of the NFP, including what might be incidental outcomes such as improved community connections. In some areas of activity, process, in particular for maintaining trust, can be critical to achieving outcomes.[15]

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[12] Productivity Commission, "The role of the Community and the NDIS", *Disability Care and Support*, Chapter 4, Canberra, 2011: 210-225.
[13] Productivity Commission, *Contributions of the Not-For-Profit Sector,* Research Report, Australian Government, Canberra, 2010.
[14] Op.cit: 16.
[15] Ibid.

The Report also sees NFPs delivering clear value for money, stating

> *The choice by government to involve NFPs as providers involves consideration by government of value for money. Discussed in detail in chapter 12, value for money considerations should include:*
> - *cost-effectiveness of service delivery — and the extent that this depends on the development of relationships with clients.*
> - *complementarity or joint-production with other services — which can enhance client wellbeing beyond that arising from the particular service being funded.*
> - *spillovers (positive and negative) associated with the service delivery — these arise as a by-product that affects others in the community, such as the utilisation of a community centre as a base for services for other groups, and the benefits that flow on from improvements in the lives of individuals as a result of their engagement with NFPs.*
> - *sustainability of the service delivery and/or client relationship, where the longterm effectiveness depends on the continued presence of the provider*.[16]

As we did in 2010, the Alliance concurs with the Productivity Commission's view of not-for-profit organisations as drivers of social innovation who contribute by

- *[providing] service delivery to members or clients.*
- *Exerting influence and initiating change in economic, social, cultural and environmental issues.*
- *Connecting community and expanding people's social networks.*
- *Enhancing community endowment by investing in skills, knowledge and physical, social, cultural and environmental assets for current and future generations.*
- *And that while NFPs may pursue one, some or all of these purposes, their outcomes can interact with others in shaping the eventual impact.*[17]

Furthermore, because social innovation often requires multi-part and collaborative approaches, the Commission's Report identifies NFPs having a unique role to play because they can embrace and take note of responses from different stakeholders.

The Report says

- *Not only multidisciplinary views are required, but views from different stakeholders.*
- *The client, their family, the local community, the school, the youth centre, and the welfare agency for example, all have valid and valuable input required to understand the problem. Second, a solution must be designed that will adequately balance all aspects of the problem, recognising that they interact in complex ways. Success in an experiment*

[16] Op.cit: 32.
[17] Op.cit: 29.

or trial may be the only way to be confident that a proposed solution will be effective.
- *Third, implementation must allow for adjustments to suit the different situations that arise with location, clients and other variations from the model. This will often require action on a number of fronts, requiring collaboration between a range of organisations.*[18]

Then as now, the Alliance believes that not-for-profit member organisations who are not registered NDIS service providers, but who have expertise in supporting individuals with high and complex health and other support needs, are ideally suited to deliver the assessment, planning and monitoring processes that NDIS participants will require. They include organisations supporting people with Huntington's disease, Multiple Sclerosis and Parkinson's disease; those supporting members with quadriplegia, paraplegia and other spinal cord injuries; as well as the acquired brain injury, muscular dystrophy and motor neurone disease associations, amongst many others.

As an example of the high value a member organisation can deliver in these circumstances, the Alliance notes the value and high impact of the Young Onset Dementia Key Worker Program (YODKWP) that until very recently, was operated by Alzheimer's Australia. This program was designed as a cross sector, multi stakeholder initiative that could meet the complex demands created by young onset dementia. The intellectual and social capital of this innovative and successful program made it highly effective and representative of what community organisations can do that a stand alone funder cannot achieve.

Organisations like these have the capacity to deliver key services that for-profit organisations are not well placed to deliver, including (amongst many)
- Volunteers to maintain community involvement and commitment.
- Provision of information to scheme members and the general community.
- Community awareness raising.
- Philanthropic input and in kind support.
- Development and delivery of training modules in the health and other support needs of their members. These organisations have significant expertise in the support needs, expectations and aspirations of their members; and are best placed to develop training modules that can become part of the NDIS' best practice approach to training and service delivery.
- Collaboration with other agencies and service providers on improvements in best practice in service development and delivery.
- Compilation and maintenance of comprehensive information on each claimant they 'manage' through the lifetime support process.
- Host and support NDIS Planners and Coordinators of Support.

[18] Ibid.

In highlighting the significant role that community organisations must play in the operation of the NDIS, the Alliance believes that the current structure, wherein the NDIS contracts a single 'community partner' organisation to deliver planning and LAC services, should only be a short term model. There is little value in investing in only one organisation in a region when there are likely to be many community organisations that have local networks there and relationships with people with disability. The fact that the NDIS has contracted some of these LAC organisations from outside rollout regions and even from other states is both unfortunate and an indication that pressure to deliver on the bi-lateral targets has been prioritised above genuine reform and community connection.[19]

From this point of view, the proposed Independence, Linkages and Capacity building (ILC) segment of the NDIS is also deeply flawed. In trying to operationalise the Productivity Commission's abstract tiered structure of the NDIS, government and the scheme have devised a program that has tried to locate a range of existing community sector functions (information, referral, training, local connection) that, with the transfer to the scheme, will be lost within what is effectively an awareness raising activity.

As it stands, the ILC is a poorly designed and funded concept that fails to address the policy imperatives of he National Disability Strategy. The Strategy's imperatives are at the heart of the NDIS reform and must be taken much more seriously by participating governments than the ILC design suggests.

The Alliance would like to see the ILC project characterised as a trial that is replaced by a national approach to community and cross sector engagement at full scheme. Doing so would directly address the National Disability Strategy's requirements.

[19] See the appointment of aged care provider, Feros Care, as the Local Area Coordinator for the NDIS in the Mackay and Townsville rollout areas. See https://www.feroscare.com.au/feros-care-is-now-delivering-ndis/