



**Submission to the Inquiry into the National Disability
Insurance Scheme Amendment (Streamlined
Governance) Bill 2019**

***Young People In Nursing Homes National Alliance
August 2019***

The **Young People In Nursing Homes National Alliance** welcomes the opportunity to make this submission to the Senate Community Affairs Legislation Committee's Inquiry into the National Disability Insurance Scheme Amendment (Streamlined Governance) Bill 2019.

About the Alliance

The Alliance is a national peak organisation dedicated to resolving the issue of younger people with disability living in residential aged care facilities and those at risk of aged care placement (YPINH).

The Alliance undertakes a range of functions including

- Policy analysis and development;
- Research, cross sector collaboration, consultation and service development;
- Individual advocacy;
- Provision of material support for YPINH.

The Alliance routinely works with a range of stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representative bodies, government agencies and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue across jurisdictions and service systems and develop policy initiatives that promote the dignity, well being and community connection of YPINH. We work to ensure that young people living in nursing homes and their families have

- A voice about where they want to live and how they want to be supported;
- The capacity to participate in efforts to achieve this; and
- 'A place of the table', so they can be actively involved in the service responses needed to have "lives worth living" in the community.

The National Alliance's primary objectives are to

- Raise awareness of the realities of YPINH;
- Resolve the systemic causes of younger Australians having to live in aged care
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver "lives worth living" to YPINH;
- Provide on-going support to YPINH, their friends and family members.

From its inception in 2002, the Alliance has argued for an integrated approach to supporting Australians with disability; and for collaborative arrangements between programs and portfolio areas including health, disability, aged care and housing.

Since the conclusion of the Young People In Residential Aged Care Initiative in 2011¹,

¹ See: <https://www.aihw.gov.au/reports/aged-care/younger-people-with-disability-in-residential-aged/contents/summary>

the Alliance has concentrated much of its work on the development of approaches to cross sector service and policy collaboration.²

This work is now being undertaken in the context of the National Disability Insurance Scheme (NDIS) intersection with mainstream service programs. This is an important area of policy work that has highlighted gaps in the design and implementation of the NDIS, as well as the need for cross jurisdictional collaboration.

Over the last two years, the Alliance has undertaken projects that have looked at linking health services with NDIS funded disability services for people with complex needs who require parallel service planning and delivery from both systems. This work has included collaboration with hospitals, sub acute spinal and brain injury rehabilitation services, community health and aged care services, as well as supporting individuals with disability and complex health needs to transition to the NDIS.

The need for a more sophisticated approach to engagement between the NDIS, health systems and health services, and indeed the jurisdictions that deliver these services has been strongly reinforced through this work.

Response to the NDIS Streamlined Governance Bill 2019

The Alliance understands that governance arrangements have been difficult in the rollout phase of the NDIS, and therefore the motivation behind the amendments in this Bill.

However, given the review of the *NDIS Act* that was announced on August 12th this Bill comes at an odd time. Nevertheless, the Alliance congratulates the NDIS Minister for initiating the broader review of the *NDIS Act* and expects that the governance structure of the scheme will be examined in that review, along with other scheme design elements.

The *NDIS Act* and its accompanying rules were written primarily to establish the scheme's trial period. A review and incorporation of learnings from trial was supposed to occur at the end of the trial period but did not. A perfunctory review was commissioned in 2015⁴ but this had little impact.

As the scheme has rolled out since, the governance arrangements that were put in place to manage the trial period have proved to have significant limitations. These have emerged particularly with the NDIS' management of its intersections with other service systems - many of which are administered by the States and Territories and

² See for example: 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.

³ <https://ministers.dss.gov.au/media-releases/5041>

⁴ https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf

whose services are critical to many participants. Given that we are now 3 years past the end of the NDIS trial phase, a review of the *NDIS Act* is long overdue, but still very important.

The lack of appropriate policies and practices for the NDIS intersections with other service systems and the potential for cost pressures that will result, is a key sustainability risk that is not being addressed effectively within the NDIS' current governance arrangements. Some of this is due to scheme design and the lack of an independent policy making capacity within the scheme that prevents the NDIS managing this risk directly. But the absence of a constructive role for the States and Territories in scheme governance makes resolving the mainstream program intersections with the NDIS more difficult.

Considering the Minister's intention to review the *NDIS Act 2013*, we believe this Streamlined Governance Bill is premature and should be deferred until the review of the *NDIS Act* is complete, at which time the legislative provisions for efficient implementation become relevant. As it stands, the Bill will make amendments to a governance structure that may well change after the review.

The goal of the governance framework attending the scheme must be to deliver the scheme efficiently and effectively, reduce service gaps and identify the responsibilities and incentives required to bring about a better structured and integrated service landscape. The NDIS' current governance system cannot do this and the efficiency measures in this Bill bring us no closer to being able achieve this.

It is clear that improving the joint decision making process between the jurisdictions is important if the NDIS is to become the landmark social insurance scheme that has been envisaged. From this viewpoint, the components of this Bill that put timeframes around feedback on decisions appears not to be overly controversial and, according to the explanatory memorandum, will simply codify what happens now on a voluntary basis.

If this is indeed the case and these actions are already occurring, there should be no rush to enshrine this in legislation, particularly if major reform to the NDIS governance regime is likely to emerge from the review of the *NDIS Act*.

The notion of "host jurisdiction"

The Alliance does not support the continued characterisation of the States and Territories as 'host jurisdictions' in the Bill. The proposed amendments to S9 and S10 misrepresent and underestimate the critical role of these jurisdictions in the continuing evolution and ultimate success of the NDIS.

The definition of a host jurisdiction was important in 2013 to establish the NDIS because not all jurisdictions were active during trial. This description of a 'host jurisdiction' was appropriate to the context of the trial phase. However, six years on and now at full scheme, the term is no longer relevant.

Given their funding commitments to the scheme and the important role State and Territory services play in the successful operation of the NDIS, these jurisdictions have a more central role to play in the governance and operation of the scheme than being relegated as hosts or agents for a commonwealth program. If it is to realistically achieve its worthy legislative objectives, the NDIS must become more than just another vertical service program (silo). But it needs the policy and service contributions of its State and Territory partners to do so.

While its bilateral agreements with the jurisdictions make the Commonwealth liable for any cost overruns for the scheme, management of the risks associated with poor integration of the NDIS with State and Territory service programs that may result in cost escalation for the NDIS, must be a priority. This is a shared responsibility of all governments and requires different governance settings than those we have at present to address this comprehensively.

There is more to managing the risks the scheme faces over the long term than just exercising internal scheme processes and the design of the scheme's governance arrangements must enable a more sophisticated approach. As well as ensuring efficient delivery of scheme functions and good intersections with other programs and the National Disability Strategy, they must enable good connections with participants. Minimising cost shifting and duplication across service programs; and delivering benefits for all governments through the organisation of coordinated, concurrent supports to people with disability, is fundamental.

The Alliance is acutely aware of these imperatives through our work with people in hospital trying to access NDIS processes in two different states where the alignment of the NDIS and health service systems remains problematic. Many States are reporting an increase in length of hospital stay as a consequence of poor NDIS process design with a consequent and adverse impact on both the lives of individuals stuck in hospital and state health budgets.⁵

The recent Disability Reform Council's announcement of a hospital discharge delay project, while welcome, is mostly addressing process issues at the intersection of health systems and the NDIS. Projects such as this, and others like the *Young People in Residential Aged Care Action Plan*⁶ are much needed but are not strategically linked. A better integrated governance arrangement could provide a broader strategic context for all the work at the health/NDIS intersection.

While the NDIS must be efficient in its implementation and its administration, it exists in a complex policy and program environment. That complexity cannot be

⁵ See <https://www.premier.vic.gov.au/patients-pay-the-price-for-scott-morrison-batched-ndis/> and <https://www.abc.net.au/news/2019-02-14/federal-government-under-pressure-to-pay-ndis-hospital-bills/10799472>

⁶ <https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative>

ignored or seen only through an administrator's lens. The current governance design has not delivered workable mechanisms to engage with mainstream service systems and enable integrated services to be made available to people needing supports from multiple programs. Simply making decisions faster does not improve outcomes for this group of participants particularly.

The governance systems that are required for the NDIS over the next 10 years of its development are not the ones that were established for trial. Making a poorly designed system work more efficiently is not a substitute for reform.

A key promise of the NDIS was to end the conflict and policy inertia around disability services that had characterised Commonwealth, State and Territory negotiations for decades. The fact that the NDIS hasn't yet resolved these problems must be a question that is addressed in the forthcoming review of the *NDIS Act*, particularly in the design of the scheme's governance arrangements. It is after this that detailed implementation measures can be considered.

The NDIS Board and the Independent Advisory Council (IAC)

The NDIS board, its advisory structures and its relationships with all participating governments must have direct line of sight to the variety of communities and cohorts the NDIS must interact with. The States and Territories knowledge of their communities and their services is critical to the eventual national success of the NDIS and must be retained in the selection process for these bodies.

For this reason, the Alliance does not support the amendment in S127(4D) that provides for the Commonwealth minister to appoint board members without a majority agreement from the states and territories. Rather than tweaking the existing arrangement, it would be more prudent to wait for the outcome of the review of the *NDIS Act* and if a reformed governance arrangement is recommended, then a redesign of the agreement processes to operationalise this can then be undertaken.

The proposed amendment to S147 regarding the IAC appointment process appears to only require consultation about appointments to the IAC, which may not suit the interests of the States and Territories (particularly those with highly diverse regions), and again, does not address the inadequacy of the advisory and consultation facilities of the NDIS as they currently stand.

The IAC has been an important part of the NDIS' governance structure for trial. While a single IAC was reasonable for the trial phase when only 30,000 NDIS participants were involved, a single IAC cannot provide a thorough advisory function for 460,000 NDIS participants residing across Australia's vast and diverse regions. As we approach full scheme, a more comprehensive formal advisory structure is required that enables local connectivity and responsiveness. Critically important to the eventual success of the NDIS, these important connections cannot be delivered through a single body.

In our submission to the Productivity Commission's NDIS Cost Study⁷, we proposed an IAC in every jurisdiction linked directly with the national IAC to provide for a broader structured advisory network.

The Alliance has been a member of the Victorian NDIS Implementation Taskforce (ITF) since its inception in 2016. The Victorian ITF has undertaken an invaluable advisory role in the scheme's implementation in Victoria. This localised response is a viable blueprint for a jurisdictional IAC body that functions as part of a linked advisory network.

Consistent with our views on other parts of this Bill, we believe the review of the *NDIS Act 2013* should take place before any administrative adjustments to the IAC appointment and termination provisions in the original legislation are considered.

For these several reasons, our recommendation is that the Bill not proceed at this time.

Further contact

If required, the Alliance is happy to provide further information for the Committee's analysis of this Bill.

Please contact Dr Bronwyn Morkham, National Director on 0437 178 078

⁷ Young People in Nursing Homes National Alliance Submission to the Productivity Commission Review of NDIS Costs,(Submission 187), p36-37.

https://www.pc.gov.au/_data/assets/pdf_file/0018/216162/sub0187-ndis-costs.pdf