



**Productivity Commission
Inquiry into the National Disability Insurance Scheme
(NDIS) Costs**

**Submission by the
*Young People In Nursing Homes National Alliance***

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Recommendations

Working with mainstream programs

- The NDIS to become a standing item on all COAG Councils for the remaining years of scheme transition to promote cross-government engagement on the NDIS reform program.
- To improve collaboration and partnership arrangements with the NDIS, the COAG prioritise renewed action on the National Disability Strategy across the six policy action areas.

Collaboration on rehabilitation service delivery

- The COAG establish a cross jurisdictional working party to develop a National Rehabilitation Strategy as part of a comprehensive nation building agenda. This work needs to include an examination of the Victorian *Slow to Recover* program and its application nationally as a companion program to the NDIS.

For scheme participants with complex needs

- For scheme participants with complex health and disability support needs, the NDIS
 - Fund capacity for multidisciplinary teams in local health services to directly undertake integrated planning and plan implementation activity
 - Develop cohort specific planning and funding models for groups of participants needing support from multiple program areas.
- The NDIS legislation be amended to enable alternative funding models including individual funding packaging and funding by request models.

Retaining community programs as discrete entities

- The COAG enact an immediate moratorium on the collapse of community based support programs until a detailed, independent review of the impact of the strategy to collapse the funding of community programs into the NDIS, is assessed.

Support coordination

- To capitalise on existing networks and connections in local communities, the NDIS expand the community partner model for Local Area Coordination to enable multiple community organisations in each NDIS region to provide block funded Local Area Coordination (LAC) as well as coordination of support services in their localities.
- Amend Section 31(k) of the NDIS Act to mandate service coordination to NDIS and mainstream services, not just across different disability supports.

National Injury Insurance Scheme (NIIS)

- The COAG immediately establish a timeframe within which the final two injury categories (medical injury and general injury) are brought into the NIIS.

NDIS Independent policy making capacity

- The NDIS establish its own autonomous policy unit with a clear remit to
 - Progress collaborative working arrangements with non-disability mainstream programs.
 - Develop new service initiatives with disability and mainstream service providers.
 - Target sustainable interventions where systemic service gaps emerge.
 - Engage with policy networks in disability and other sectors at national, state and local levels to maintain active monitoring of policy and funding changes in other sectors that impact the scheme; and have capacity to participate in cross-program policy development as required.

Responsibility for the NDIS to the Council on Federal Financial Relations

- The Council on Federal Financial Relations assume primary responsibility in government for the NDIS and work closely with members of the Disability Reform Council on the remaining NDIS transition processes.

Improved consultation and advisory structure

- The NDIS establish local advisory bodies in each rollout area consisting of people with disability, carers and representatives from local government and mainstream services
- These bodies to be resourced by the NDIS and linked to the Independent Advisory Council. A sustainable national structure should be maintained at full scheme to continue providing local input, resourcing and support for local community engagement with the NDIS.

Devolving scheme functions to the community

- The NDIS block fund NFP community and member organisations to
 - Provide information and assistance to NDIS participants and community members with disability who are not scheme participants.
 - Undertake planning, plan implementation, and monitoring as required
 - Link NDIS participants and other people with disability to community resources and services.
 - Develop improved local collaboration and integrated service delivery options.
- In consultation with a working party of experienced not-for-profit and member organisation representatives, the COAG develop a national approach to community and cross sector engagement to replace the ILC at full scheme.

Introduction

The Alliance welcomes the opportunity to contribute to the Productivity Commission's review of the National Disability Insurance Scheme's (NDIS) costs. The Alliance has taken a strong interest in the design of the NDIS over time and made two detailed submissions to the Productivity Commission's *Disability Care and Support* Inquiry in 2010, as well as submissions to consultations on the NDIS Rules and the independent *Review of the NDIS legislation*.

In addition, we have been active in the work to establish the sister scheme of the NDIS, the National Injury Insurance Scheme (NIIS). The sustainability of the NDIS depends on a complete NIIS that, in providing no fault insurance for catastrophic injury, removes the significant cost drivers of these injuries from the NDIS. Yet delivery of the NIIS is seriously behind schedule. Work on the NIIS must be completed if the benefits to injured people, the NDIS and jurisdictional budgets are to be achieved.

This submission highlights a number of vital design issues that we believe must be addressed to secure the long term sustainability and effective operation of the NDIS.

These design issues include

- The need for a more comprehensive planning methodology that can integrate NDIS services with those from mainstream programs;
- A lack of policy development and negotiation capacity within the agency;
- Gaps in the scheme's risk management capability; and
- Ragged governance arrangements.

Many of these areas covered in this submission overlap and the Alliance apologises for any consequent repetition.

Finally, the Alliance is aware that the *NDIS Act 2013* and associated rules were primarily drafted to launch the scheme and provide a framework for the scheme's operation through the initial three year trial phase. They were not intended to be the definitive design of the scheme, and it important that this review informs its further development.

A comprehensive review of the legislation was to have been undertaken to enable full scheme rollout with incorporation of learnings from trial. But this review has yet to be fully completed and the NDIS continues to function with operational and governance arrangements that do not support some of the significant challenges the scheme is confronting.

Finally the Alliance acknowledges the hard work and commitment of NDIS staff and those in government in implementing the scheme to its current stage of development.

The YPINH National Alliance

The Alliance is a national peak organisation that promotes the rights of young Australians with high and complex health and other support needs living in residential aged care facilities or at risk of placement there (YPINH); and supports these young people to have choice about where they live and how they are supported.

As Australia's first national peak representing YPINH, the Alliance draws its membership from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state peak bodies, government representatives and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue by State and Commonwealth governments; develop policy initiatives at state and federal levels that promote the dignity, well being and independence of YPINH and their active participation in their communities; and 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 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.

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 plight of YPINH;
- Resolve the systemic reforms required to resolve the YPINH issue and the urgent need for community based accommodation and support options that young people with complex needs require;
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver "lives worth living" to young people with high and complex needs;
- Provide on-going support to YPINH, their friends and family members.

Since its inception in 2002, the Alliance has argued for a lifetime care approach to development of supports and services for Australians with disability; and for

collaborative arrangements between programs and portfolio areas including health, disability, aged care and housing. 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

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.

Mainstream program interface arrangements

Following surgery, Jonathon was left with permanent disability. He breathes with the aid of a tracheostomy and relies on a PEG for all his nutrition. Jonathon has no independent movement and requires 24/7 care. Jonathon returned home after spending 16 months in hospital. The NDIS agreed to a package of support for Jonathon, but the planning for his move home was complicated by a number of grey areas of the funding responsibility between the health service and the NDIS. Some essential items for his care were not agreed to by the NDIS, nor were they able to be funded by the health service. Other supports were not included in the plan.

With a young family to support, Jonathon's wife is now the family's sole breadwinner. Following development of an NDIS plan, she took 12 months leave from her work to care for Jonathon following his discharge home from hospital. Jonathon's wife provides substantial informal care to her husband as part of his NDIS package of supports.

Because the NDIS has refused to fund equipment needed for Jonathon's daily care, his family have had to fund these items themselves and are out of pocket to the tune of \$250 per week. The drain on scarce family resources and the need to replace his wife's informal care when she returns to work has left Jonathon in a precarious position regarding his ability to remain with his family.²

Precisely because scheme participants are citizens who need to engage with a range of service systems, the NDIS must have structured mechanisms to work proactively with these systems at policy, service delivery and participant levels. The issue of the scheme's interfaces with mainstream (non-disability) programs has been raised many times since the launch of the NDIS and always in the context of how important the contribution of 'mainstream' programs are to the viability and operation of the scheme.

Unsurprisingly, a mechanism to negotiate these arrangements is yet to materialise, perhaps because the scheme's existing design parameters have not allowed it to be anything other than an operational program. As well as operational decisions, the NDIS needs capacity to make independent policy decisions at the national, state and local levels without having to be subordinate to Commonwealth, state and territory jurisdictions as it currently does.

While this may have been appropriate during the trial phase, there is too much at stake for the NDIS not to have direct capacity to manage its risks and achieve its objectives as it moves to full scheme. Indeed, contemporary thinking on the way governments must work to solve 'wicked' problems, suggests a more networked way of working than traditional rule based programs have allowed.³

² See pages 46-48 of this submission for a detailed outline of this case study.

³ Carey, G. *Grassroots to Government. Creating joined-up working in Australia*, MUP, Melbourne 2016: 8.

The inability of people with disability to participate in the Australian community is certainly the result of multiple wicked social problems. Low rates of labour market participation, poverty, discrimination, poor comparative education and health outcomes, have all helped Australians with disability to have some of the poorest educational and employment outcomes of comparable OECD countries.⁴ Improving these factors is part of the broad change that the NDIS is working to deliver.

To achieve this substantial social reform, the scheme must have the capacity to be part of joined up approaches across government and the community sector. Creating this will help manage instances where joint provision of services for scheme participants may be required; and will also help prevent institutional cost shifting across programmatic boundaries.

This demands the NDIS develop protocols with, for example, local health and hospital services, as well as other mainstream services. It must also develop protocols with statewide programs in government departments and work with community organisations. This type of cross government collaboration and partnership is also at the heart of delivering the National Disability Strategy (NDS) of which the NDIS is one of the Strategy's six components.⁵

The Alliance's work in the NDIS' North East Melbourne Area has shown that where the scheme confronts the extant health needs of a scheme participant in planning, it expects the health system to respond to these needs because the scheme believes them to be outside its remit. Yet in many cases, the health supports required are directly related to the individual's disability and are not available in a form that enables them to be delivered in a complementary way to an NDIS package.

In many situations, required services such as slow stream rehabilitation, individual funding programs for health services, products and non-PBS medications, do not exist in community settings. Health services currently lack the incentives, the mandate or the budget to develop them through their own volition and though the scheme might like to think so, its very existence is not reason enough for mainstream programs to develop new services. If nothing is done, the resulting vacuum becomes a perfect incubator for services and programs to cost shift to the scheme.

In these instances, a partnered approach to resolve these blockages and gaps would deliver mutual benefit to all stakeholders concerned. Yet the NDIS lacks the policy mandate or operational capacity to approach other programs in this way, or to action such collaborative arrangements. The disability portfolios managing the transition to the scheme are not facilitating this joint work either.

⁴ Bennett, C. *Disability Expectations: investing in a better life, a stronger Australia*, PwC, Sydney, 2011.

⁵ https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

The COAG's Principles to determine the responsibilities of the NDIS and other service system

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.⁶ However, the scheme's interpretation of the COAG Principles has seen it make unilateral decisions about the contributions of other programs without reference to or negotiation with those programs.

This conduct is particularly evident where plans are completed for scheme participants with co-morbid health conditions and those transitioning from hospital to the community. The one-sided decision making that has been a hallmark of these plans has not engendered goodwill amongst would be service partners. Nor has it resulted in the collaborative behaviour needed by those requiring integrated, multi-program service responses.

Health services and the NDIS must, for example, be encouraged to work *with each other* to develop these vital outreach services. The mutual benefits that come from this type of partnership will not only deliver improved health and well being for all users. Their availability can ultimately lead to better outcomes for NDIS participants; reduced use of hospital services; and significant savings subsequently for the NDIS as well as jurisdictional health budgets.

While the COAG Principles include scope for joint work, there has been no evidence that this is occurring. Instead, the NDIS has been left to apply the COAG principles and do so from an isolated and defensive position when planning with participants with complex needs.

This has included determining whether to continue funding various supports that had previously been funded by jurisdictions in individual support packages (ISPs); or for participants involved in programs being collapsed into the NDIS, such as the Victorian *Slow to Recover ABI Rehabilitation program*. When asked about where the NDIS sat in regard to rehabilitation and the scheme's interface with health systems, NDIS CEO, Mr David Bowen, spoke of the defensive approach the scheme generally takes to program interface engagements at a Senate Estimates hearing in March this year, saying

*We are reluctant to step into that space because the tendency is, with all of these interfaces, as the agency steps in, the other areas step back from it.*⁷

⁶ See <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

⁷ David Bowen in *Hansard*, Senate Community Affairs Committee Additional Estimates 2 March 2017: 112. See

While the COAG principles do contain provision for systems to work together where required, these have not been operationalised across all portfolios. To achieve this, policy commitment is required from all parts of government. However, in the absence of any leadership on this issue, it has defaulted to the NDIS to make judgement calls in its own interest in individual planning.

Because there is no mechanism for the NDIS to collaborate directly with the various programs described in the COAG Principles, these defensive positions are inevitable. Instead of non-disability programs working in partnership with the NDIS to develop multipart service responses, the Alliance is aware that the current approach to interface arrangements is leading to an intensification of already rigid program silos.

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

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.⁸

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 not sufficient.

Finally, the uncapped nature of the scheme is one of the NDIS' great strengths and must be protected at all costs. While it enables individualisation and flexibility, it also requires a significant investment in decision making and relationship management by the scheme and collegiate other programs, each with the other.

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Festimate%2F9ec8a42b-9637-444c-ae23-1486fa3f9648%2F0003%22>

⁸ 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%2Fcomjnt%2Fb02490da-1f4b-458b-a978-57e36ade0fa5%2F0006%22>

Risk Management and Sustainability

It goes without saying that the NDIS is an ambitious reform. What is often forgotten in this shift from block funded disability programs to a social insurance scheme, is that the NDIS cannot behave like a traditional government program. Most specifically, it cannot rely on the old rule-bound approaches that capped government funding programs use.

Instead, the scheme must prioritise good decision making logic; invest in lifelong relationships with its participants, providers and mainstream programs; and actively build the capacity of participants, their families and the communities they live in. Achieving a reform of this nature requires a significant policy and operational shift to whole of government responses at national, state and local levels of government.

To this point, the conception of the NDIS has been heavily informed by the design of no-fault compensation schemes and in some ways, it has been left with the same limitations these schemes face. Compensation schemes tend, for example, to be boutique funding bodies and don't have capacity to engage with the social issues their clients face; or engage with other programs their clients may use.

However, the feature that sets the NDIS apart from compensation schemes is its objective of achieving greater social and economic participation for its participants. The scheme's focus on these outcomes should be the key driver of cross government collaboration at all levels. Unfortunately, the structures and mechanisms to deliver these outcomes are yet to materialise. In necessarily focusing on its own operation and the establishment of a disability services market, the NDIS cannot address the long standing causes of social exclusion of Australians with disability.

As the *Shut Out Report* so clearly articulated, resolving the poor access to education, employment, healthcare, transport, rights and housing that Australians with disability have historically experienced, requires improved collaboration with mainstream programs and the community.⁹ Unless this happens and the NDIS takes a leadership position here, the scheme's long term costs will be adversely impacted.

A number of the scheme's cost drivers were identified by the NDIS and reproduced in the Productivity Commission's Issues Paper including

- *Access*: the number of participants in the scheme;
- *Scope*: the scope of supports provided to participants in the scheme;
- *Volume*: the quantity of supports received by scheme participants;
- *Price*: the price paid for supports under the scheme;
- *Delivery*: the costs associated with operating the scheme.¹⁰

⁹ National People with Disabilities and Carer Council for the Australian Government, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*, National Disability Strategy Consultation Report, Canberra, 2009.

¹⁰ Productivity Commission, *Review of NDIS Costs*, Issues Paper, March 2017: 8.

While these are important, they are only part of the suite of cost drivers that the NDIS and governments should be concerned about. The evidence that significant cost drivers exist outside no fault schemes such as the NDIS, can be found in compensation scheme research undertaken in Australia and New Zealand.

Prevatt and Gifford (2007) have developed predictive models for identifying long term care cost drivers in compensation schemes.¹¹ According to this research, the quantifiable factors driving cost for compensable individuals are injury type, rehabilitation outcomes and the functional skills of clients.

Despite the detailed clinical and historical claims cost data that is available, Figure 1 shows that more than half the cost drivers remain unexplained and unquantifiable in the narrow terms of the cost drivers listed above. This is a significant concern for schemes whose core business is long term support through effective risk management. Prevatt and Gifford's analysis of anecdotal evidence from scheme managers suggests that family circumstances and claimant community participation activity are important drivers of claim costs.¹²

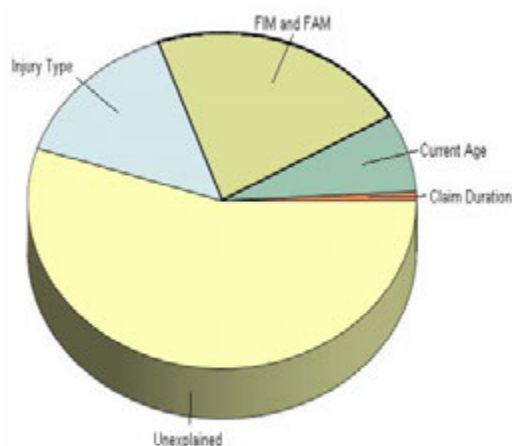


Figure 1: **Key Long Term Care Claims Cost Drivers** (Prevatt and Gifford, 2007)

If this is the case in compensation schemes, the scale of the NDIS and its social and economic participation objectives, makes it imperative that these cost drivers are clearly understood in the context of disability services provision, interfaces with mainstream programs, community connection and participant and family involvement.

¹¹ Prevatt, M. and Gifford, D. "Statistical Case Estimation for Long Term Claimants - Uncovering Drivers of Long Term Claims Cost in Accident Compensation". Presentation to the Institute of Actuaries of Australia, XIth Accident Compensation Seminar, Grand Hyatt Melbourne, Australia, April 2007: 30.

¹² Ibid.

Indeed, the NDIS and the governments that jointly own the scheme must understand and control the scheme's external cost drivers if the NDIS is to become the social insurance scheme that Australians with disability and the broader community are looking for.

From this perspective, there is obviously more to achieving this ambitious reform than simply increasing the quantum of funding and changing the point of disability services purchase from block funding to individual funding as the NDIS is doing. While these are essential ingredients, the scheme needs to be equipped with the capacity to engage directly with mainstream programs and with local communities.

Independent policy making capacity in the NDIS

Successfully implementing the NDIS and achieving its objectives relies on close links with communities and mainstream programs; a flexibility of approach; and capacity for local policy setting, relationship building and designing of local initiatives.

The NDIS cannot simply assume that community connections and cross-sector service collaborations will materialise through the implementation of individually funded disability supports. While the NDIS Act established a funding program for disability supports, the legislation does not give the scheme any mandate to engage in cross-sector collaboration as an independent agency.

As this submission has indicated, relying on Local Area Coordinators and Coordinators of Support to bridge the serious gaps that are emerging, particularly at the scheme's interfaces with mainstream programs, does not address the root cause of this problem. And despite the overwhelmingly positive social objectives in the NDIS legislation, the scheme is not designed to guide effort to achieve these imperatives, either for participants or for itself.

In its current representation, the NDIS is completely vulnerable to the policy and funding decisions of other programs and local mainstream providers, as well as the Department of Social Services.

On their own, packages of disability support are also insufficient to overcome the significant barriers to participation that exist in the Australian community for people with disability. The National Disability Strategy is often cited as the mechanism to deliver the policy level changes that would see mainstream programs and the NDIS become better integrated with each other as part of improved sustainability across the board. But, more than half way through the Strategy's 10 year timeframe, there is little to show for efforts in this area.

Both the NDIS and the governments that jointly own it, must be better equipped to manage the risks to scheme sustainability that exist inside and outside the organisation. As it presently stands, the design of the NDIS only allows the scheme to manage eligibility, pricing and yes or no decisions around requests for support. The scheme has no capacity to negotiate directly with mainstream programs, providers

or sectors at the participant, regional or jurisdictional levels. Nor does it have the ability to develop new and joint service initiatives with other programs; or initiate policy in mainstream portfolios in the interests of participants and the scheme.

As indicated in the mainstream interfaces section of this submission, the Alliance has seen too many instances in which the scheme has refused to fund what it deems “health supports”; and left planners without capacity to negotiate sustainable arrangements with local health services that might avoid review or appeal. The supports being denied by the NDIS for the people the Alliance is working with are essential to their participation in community life. Simply denying liability and refusing to negotiate program sharing arrangements with a mainstream provider or system, is fraught with risk for all parties.

In this transition phase particularly, the scheme needs to establish multi-program arrangements that ensure it has the capacity to negotiate good policy outcomes where its interests are at stake.

The recent cases of *McGarrigle v National Disability Insurance Agency*¹³ as well as *Mulligan and National Disability Insurance Agency*,¹⁴ show the limitations of the scheme’s decision making model.

In both instances, the NDIS made decisions internally concerning what was ‘more appropriate for other service systems’ to provide and decided this without any reference to those mainstream systems or providers concerned. This is a reductive and utterly unsatisfactory way to negotiate the boundaries and interfaces the scheme shares with other systems.

As the cases of McGarrigle and Mulligan show, leaving the scheme’s policy making to an appeals process is not how this critical area of scheme infrastructure should be determined.

Victoria’s Transport Accident Commission (TAC) has experience with the same design vulnerability as that the NDIS faces. The 2003 McRitchie decision in Victoria defined, for example, the TAC’s liability in regard to the living costs for clients in supported accommodation. What began as a decision about the reasonableness of individuals being responsible for their own basic living costs, resulted in a case going to the Victorian Court of Appeal. As a result, additional costs were imposed on the compensation scheme through a decision that required the TAC to fund these basic living costs. This outcome eventually saw a legislative change to the Transport Accident Act to accommodate the ruling on the matter.¹⁵

¹³ See <http://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/single/2017/2017fca0308>

¹⁴ See <http://www.austlii.edu.au/au/cases/cth/AATA/2014/374.html>

¹⁵ See Lombard, M. (Holding Redlich), *Workcover & TAC Amendments in Focus (Victoria)*, Television Education Network, February 2004. Available at

At full scheme, it is unimaginable that a \$22b national program would not have an autonomous policy making function. If it is the intention for the NDIS to have this capacity at full scheme, it is critical that work begins immediately.

Not only would this build capacity in the scheme; it would also provide mechanisms to resolve many of the thorny transition issues now in play and would do so at source. The Alliance believes it is entirely possible to maintain national consistency in delivering the scheme's main functions of eligibility and reasonable and necessary supports, while enabling local variation and discrete protocols with programs and providers to be successfully enacted.

As it is presently designed, the NDIS is too dependant on other structures and market behaviours to effectively manage the range of risks it faces over the long term. Its reliance on the disability services "market" to deliver the social and economic outcomes the scheme requires for its participants is an indirect and ineffective strategy. Without genuine policy collaboration from the NDIS, the performance of mainstream programs will remain a key driver of risk for the scheme.

Currently, the NDIS is dependent on the jurisdictions taking the initiative to address long standing gaps in support, joining up cross government activity and delivering participation opportunities for people with disability. Given other, more direct pressures on State, Territory and federal budgets, it is unlikely that these will be high priorities, particularly when there is an expectation that "the NDIS will fix it".

The NDIS clearly needs its own independent policy making capacity to be able to manage its risks and provide mechanisms to develop agreements and protocols at the scheme's boundaries. Having the policy making function sitting remotely with the Department of Social Services should have been an interim measure only.

However, now that the scheme is at full rollout, the NDIS requires the tools to determine its decision making arrangements at all levels. This is particularly so with regard to the Independence, Linkages and Capacity Building (ILC) framework; the work of Local Area Coordinators and Coordinators of Support; and the scheme's address of mainstream interface imperatives. The NDIS does not exist in a bubble and must negotiate these, engaging directly with sectors, governments and communities far more comprehensively than it has been able to thus far.

Finally, unless the NDIS takes an active role in its own policy arrangements, its policies will be decided in ways that are outside the scheme's control. While utilising the arrangements of the Disability Reform Council may have been necessary in trial, this arrangement is now beyond its use by date.

http://www.tved.net.au/PublicPapers/February_2004,_Sound_Education_in_Law,_Workcover__TA_C_Amendments

Recommendation

The NDIS establish its own autonomous policy unit with a clear remit to

- Progress collaborative working arrangements with non-disability mainstream programs.
- Develop new service initiatives with disability and mainstream service providers.
- Target sustainable interventions where systemic service gaps emerge.
- Engage with policy networks in disability and other sectors at national, state and local levels to remain abreast of policy and funding changes in other sectors that impact the scheme; and have capacity to proactively intervene in these changed policy arrangements as required.
- The NDIS become a standing item on all COAG Councils for the remaining years of scheme transition to promote cross-government engagement on the NDIS reform program.
- To improve collaboration and partnership arrangements with the NDIS, the COAG prioritise renewed action on the National Disability Strategy across the Strategy's six policy action areas.

Mainstream engagement and the need for rehabilitation

With hospital inpatient rehabilitation, Ahmed made a substantial recovery from a stroke. Despite this, doctors refused to allow Ahmed to return home without support services. Disability, health and community aged care services were unable to fund Ahmed's supports and he was discharged to a nursing home.

Required by Centrelink's assets test to sell his home to fund the aged care bond, Ahmed became technically homeless and required an accommodation option as well as funded supports to return to the community. The hospital's limited rehabilitation outreach ceased shortly after admission to the nursing home and Ahmed began to lose the gains he had made.

Two years after entering the nursing home, Ahmed was unable to walk and required a hoist for all transfers. He was incontinent and had arm, hand and foot contractures that required surgery. Ahmed had also lost contact with his friends and was socially isolated. Because his rehabilitation input did not continue and the gains Ahmed made were not consolidated, the NDIS had to fund significantly more support.¹⁶

Rehabilitation is an important area of crossover for health and disability services that requires a structured, collaborative approach. Its interventions facilitate recovery and greater independence for people sustaining serious injuries and those living with neurological conditions. The need for rehabilitation input is indicative of the need for detailed interface arrangements to be developed by the scheme with mainstream programs.

¹⁶ See page 49 of this submission for a detailed outline of this case study.

However, because rehabilitation services are not provided by the NDIS, a crucial service gap exists for NDIS clients with profound acquired brain injuries who need slow stream, community-based rehabilitation to regain their independence; and those with progressive neurological diseases such as Multiple Sclerosis, Parkinson's or Huntington's diseases who rely on rehabilitation services to slow disease progress and maintain their independence.

Rehabilitation therapies to improve capacity have traditionally been seen as the province of health services and been in relatively short supply for those people with specialised rehabilitation need. But the arrival of the NDIS offers a significant opportunity to rethink how rehabilitation services can be developed and made available to NDIS participants. Doing so will enable the NDIS and health portfolios to manage their costs and liabilities more effectively to the mutual advantage of all stakeholders.

The cost benefit in timely provision of rehabilitation services has been evidenced in numerous studies. For an insurance scheme like the NDIS, rehabilitation delivers benefit through greater independence and lower support costs over the life course. For health services, benefits include improved patient health and well being and lower take up of health services including episodes of (re)hospitalisation. A review of Western Australia's Oats Street ABI Rehabilitation service declares the benefits this way

Effective rehabilitation is valuable in its own right, due largely to its ability to reduce the cost of care...If we as a society propose to save the lives of those who acquire a traumatic brain injury, rehabilitation has not only a moral justification but is also a very real way in which costs can be saved within the health system.¹⁷

While the NDIS does not provide rehabilitation services itself, this should not preclude the scheme from collaborating with health services to develop rehabilitation options needed by people with disability. This approach was supported in the *Younger People In Residential Aged Care (YPIRAC) Mid Term Review*, which concluded that supporting those with complex needs

...requires harnessing the interface between health, rehabilitation and disability support services...[and] identified this as a key challenge...[for future programs].¹⁸

At present, slow stream and community based rehabilitation services are not well developed in Australia. This type of rehabilitation requires articulation of medical, allied health and disability services around the person to achieve rehabilitation goals.

¹⁷ Acil Tasman, *Oats Street Facility Redevelopment. A Social Cost Benefit Analysis*, Sydney, 2010: 23.

¹⁸ FaHCSIA, *Mid Term Review, Younger People in Residential Aged Care (YPIRAC) Program*, Canberra, 2009: 43.

Victoria, however, has an excellent community based rehabilitation service, the *Slow To Recover Acquired Brain Injury* rehabilitation program (STR) that is ideally placed to facilitate such collaboration.

STR relies on skilled health practitioners to design rehabilitation programs for individuals with acquired brain injury and train disability support workers to deliver them. The STR program is not facility based and can be delivered anywhere: in an individual's home, in hospital, or in a nursing home. Prior to the arrival of the NDIS, STR provided funding for support worker hours to deliver the program and covered the cost of equipment as well as case management.

A comprehensive review of the program noted that

The STR program is innovative and unique in Australia. The rehabilitation services aim to make a significant difference to the lives of younger Victorians with catastrophic brain injuries, by decreasing their secondary health complications, maximising their independence, increasing their quality of life and subsequently reducing their life time care needs.¹⁹

Over its 20 year existence, the STR program has shown that the coordinated delivery of community-based rehabilitation

- Shortens initial acute hospital stays;
- Prevents rehospitalisation;
- Prevents the physical/cognitive decline of its clients;
- Increases client skills and independence; and
- Provides much-needed support to families who play an integral role in the recovery of their loved ones.

Furthermore, because this service does not require facilities, it comes at a much lower cost than subacute rehabilitation.

STR case managers stress that their clients require therapists who specialise in severe-profound acquired brain injury. Without adequate clinical governance, non-specialised therapists who work with these clients will provide a service that is not evidence-based best practice.

The NDIS therapist credentialing procedure does not require specialist therapists. Nor does it require ABI-specialist case management for scheme participants with ABI.

¹⁹ Sloan S. *Acquired Brain Injury: Slow to Recover Program. Report of the Therapy Review Project*, Melbourne, 2008: 10.

Terry, 48 years, stroke.

Terry had a stroke that has left him with a range of physical and cognitive impairments, and in the absence of disability funding, he was discharged to a nursing home. Three years after entering the nursing home, Terry was able to access the Victorian *Slow to Recover* ABI rehabilitation program. STR began coordinating Terry's transition to live with his two brothers in the community. His rehabilitation goals focused on learning new skills and routines to ensure his transition to live with his brothers is successful.

In transitioning to the NDIS, the STR team and Terry's family strongly recommended that his rehabilitation therapy program be funded by his NDIS plan. Funding for therapy and trained staff to support Terry's rehabilitation goals to move to the community was requested. However, Terry's NDIS plan cuts his therapy from 206 hours previously approved by STR to 30 hours per year. Clinical governance to ensure Terry's rehabilitation goals are met is not available, as the STR clinical governance team do not have a role with the NDIS.

While Terry's NDIS plan substantially increases his attendant care hours from 650 to 2,184 hours per year, his rehabilitation goals have been devolved into more general goals in his plan. While the quantum of his package is larger than before entering the NDIS, the lack of specific focus on rehabilitation and recovery means the attendant care hours are less purposeful and workers are not trained in the health and rehabilitation support that Terry requires. If his rehabilitation goals are not maintained and Terry's greater independence is not achieved, his family and therapists are concerned that he will lose independence. The NDIS faces higher lifetime costs for him as a consequence.²⁰

The NDIS Barwon trial revealed that not only were former STR clients no longer receiving rehabilitation, their NDIS case workers had such little knowledge of acquired brain injury that clients were not adequately informed of processes and workers were not aware that clients may not have been able to make informed decisions or generate ideas in order to make choices.

Cross program collaboration to deliver rehabilitation

The COAG Principles do envisage collaboration between the NDIS, jurisdictional health departments and health services on the delivery of rehabilitation programs. But the scheme does not have the capacity to engage in this joint work at the policy level and its planning methodology precludes it from doing so at the local level.

At an Estimates hearing before the Senate's Community Affairs Committee on March 2, 2017, NDIS CEO, David Bowen, confirmed such an approach. Mr Bowen indicated that while the NDIS cannot pay for the health component of rehabilitation, the scheme will fund the disability services component of these programs

...I have a very strong personal knowledge over many years of the slow-stream recovery that is necessary for people with a brain injury. Generally, we would accept that the nature of the therapies and supports that a person needs once they exit a rehabilitation hospital

²⁰ See pages 52-53 of this submission for a detailed outline of this case study.

would be provided by the NDIS, because, even though it is still progress towards recovery, it is more about maintaining and assisting a person to live in the community. However, there remains a grey area around post-acute rehabilitation in terms of what could be provided by state governments and the hospital systems.

The knowledge of this is very clear that rehabilitation in the community is a better option to assist people, yet often, it is only provided in the hospital setting in a specialist rehabilitation area...So our starting point would be an expectation that state governments, through their hospital funding or hospital system operation, would be providing appropriate rehabilitation. As a person moves to live in the community, we will provide the supports that may be akin to rehab but are about supporting the person in the community.²¹

In stating this, Mr Bowen is reiterating the indicative role of the NDIS in relation to health services that is outlined in the Council of Australian Governments' *Principles to determine the responsibilities of the NDIS and other service systems*.

Section 1 clearly states that Health services will offer

[Jointly with NDIS] Provision of specialist allied health, rehabilitation and other therapy, to facilitate enhanced functioning and community re-integration of people with recently acquired severe conditions such as newly acquired spinal cord and severe acquired brain injury.²²

The Principles further indicate that where a significant component of case coordination is related to the health support

Intensive case coordination [will be] operated by the health system...²³

Applied to the Victorian STR example, this collaborative approach to the provision of rehabilitation would result in the NDIS funding the hours required for disability support workers to deliver rehabilitation program activity, as well as the dedicated training they will need. The NDIS would also resource aids and equipment ...something already funded for scheme participants generally. As the COAG Principles indicate, health services will cover the cost of skilled therapists developing, monitoring and providing clinical governance for the rehabilitation programs they design; and training disability support workers to deliver these programs.

²¹ Parliament of Australia, *Hansard*, Community Affairs Committee Additional Estimates Hearing, 2 March 2017: 111-112. See: <http://bit.ly/2mFmYRo>

²² Council of Australian Governments *Principles to determine the responsibilities of the NDIS and other service systems*, Canberra, 27 November 2015: 4.

²³ Op. Cit.: 5.

These separate goals would be integrated with NDIS plans for participants of both the scheme and of health services...an approach that is entirely consistent with the COAG Principles and something other programs and jurisdictions must implement.

While the *Slow To Recover* program provides slow stream rehabilitation to individuals with acquired brain injury, the program's community based architecture; its use of allied health workers to design and manage rehabilitation programs; and disability support workers to deliver these programs, can be applied to other areas of rehabilitation need, including those of spinal cord injury and progressive neurological disease.

As part of a joint service development exercise, the split of costs between health portfolios and the NDIS to deliver slow stream rehabilitation is something that needs to be negotiated as a matter of priority.

Establishing community-based rehabilitation programs in partnership with the NDIS will not only benefit NDIS participants. A structured joint rehabilitation initiative has the potential to significantly lower care costs over the life course for the scheme and will deliver mutual benefit to health services and the NDIS.

Recommendation

The COAG establish a cross jurisdictional working party to develop a National Rehabilitation Strategy as part of a comprehensive nation building agenda. This work needs to include an examination of the Victorian *Slow to Recover* program and its application nationally as a companion program to the NDIS.

Lessons from the Younger People In Residential Aged Care Program, 2006-2011

The 5 year Younger People In Residential Aged Care initiative (YPIRAC) has been the only national response to the YPINH issue. With \$244m in joint federal and state funding, the Council of Australian Government's (COAG) decision to proceed with the YPIRAC program was directly influenced by the recommendations of the 2005 Senate Inquiry Report, *Quality and Equity in Aged Care*,²⁴ as well as a significant community campaign for action on the YPINH issue.

The YPIRAC experience remains instructive with regard to the successful development of the NDIS. It particularly exemplifies the shortcomings that arise when a multi-program, cross-sector issue is addressed with a single program response.

²⁴ Australian Senate, "Young People in Residential Aged Care Facilities", Chapter 4, *Quality and Equity in Aged Care Inquiry Report*, Canberra, 2005. See http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/aged_care04/report/c04

One of the most obvious learnings YPIRAC delivered is that the YPINH issue is not just one for disability services programs; and it cannot be resolved simply by increasing the supply of traditional disability services.

Maintaining that resolution of the YPINH issue is only the responsibility of disability services, ignores the fact that YPINH commonly need multi-program, integrated service responses that require concurrent access to and contribution from mainstream programs such as health, disability, housing and aged care.

Because the YPINH cohort was poorly understood and disability services programs and selected providers had little experience in this area, many residential services developed under the YPIRAC program were designed as conventional disability responses that lacked the access to health supports required by this group.

While the NDIS is an important contributor to the overall resolution of the YPINH issue, it is naïve to assume that the scheme can resolve this enduring problem on its own. The NDIS can certainly address key issues around the timing and quantum of disability supports needed by a person at risk of aged care placement. It can also offer greater options for YPINH living in aged care, including moving back to the community. But as YPIRAC demonstrated so clearly, the scheme's contribution needs to be part of a coordinated and integrated suite of supports that includes health services, housing and transport, as well as aged care.

Unfortunately, the clinical interventions the YPINH group required were not integrated in the YPIRAC initiative, something highlighted in the program's mid-term review via reference to the particular needs of people with an ABI.

The review stated that

Supporting people with ABI requires harnessing the interface between health, rehabilitation and disability support services [and this is] a key challenge for the YPIRAC Program.²⁵

As standard disability responses, the support and accommodation options developed through the initiative were largely congregate settings staffed by personal care workers not trained to manage the complex needs of their residents. Although YPIRAC residences received additional funding to manage the higher needs of residents, this additional funding did not prevent recurrent health crises occurring.

Indeed, the common response when a health crisis *did* take place was to call an ambulance and admit the individual to hospital via the emergency department. Pressure care issues and mismanagement of PEG feeds leading to aspiration

²⁵ urbis, *Younger People in Residential Aged Care (YPIRAC) Program, Mid-Term Review Report*. Prepared for FaHCSIA by urbis, Sydney, 2009: 43.

pneumonias were all too common causes of recurrent hospital admissions for some young people living in these residences, many of whom had moved out of Residential Aged Care (RAC) to access the life in the community that had been promised.

Then and now, the Alliance is aware of instances where

- Disability service providers refuse to accept the return of a resident on discharge from hospital after several emergencies of this type.
- Medical staff dealing with repeat incidents of aspiration pneumonias refuse to treat the individual on the grounds that he or she lacks a decent quality of life. Families are advised to 'let nature take its course'.
- Young people died as a result of inadequate management of their health needs by the YPIRAC disability supported accommodation service.
- Young people who had moved out of RAC under the program, contacted the Alliance to ask that they be allowed to return to their nursing home because they felt their needs were better understood and more safely supported there.

Health outreach services; improved training of service providers and support staff in the different needs of the YPINH cohort; as well as the provision of nursing overlays in new supported accommodation services, were health interventions that could have provided the health supports YPINH moving out of nursing homes needed. YPIRAC's single program response meant that this was never considered.

Collapsing community programs' funding into the NDIS

The Alliance has long been concerned that the funding and design of the NDIS has required the collapse of community based service programs.

Programs such as *Partners in Recovery*, *Personal Helpers and Mentors (PHaMs)*, the *Victorian Slow to Recover ABI Rehabilitation Program* and the *Young Onset Dementia Key Worker Program*, were all designed to meet the needs of specific cohorts and had a community based service architecture.

Most of these programs are delivered through local service networks; are able to locate formal and informal supports for people; and link to genuine community connection opportunities. Their success relies on their programmatic nature and their networks and peer linkages... all things that do not transfer well to individualisation and cannot be substituted for by individual packages.

The fact that these are being phased out and their funding transferred to the NDIS for the delivery of individual packages will

- Disband hubs of expertise and knowledge.
- Diminish local cross sector networks.
- Increase costs by individualising services.

- Deny access to necessary supports for people ineligible for the NDIS. These individuals may still require community programs to maintain their health and well-being but will have no other option to access their supports than via healthcare or residential aged care once these important programs disappear.

We agree with Professor Patrick McGorry's recent statement about community mental health services reported in the *Australian* on April 6

*The biggest issue here is that the state governments have already dismantled the community mental health system, the clinical system with doctors and support. All that is left now is emergency rooms and acute care, the system is collapsing at a state level.*²⁶

The Alliance is of the view that the same systemic collapse is happening in health and other mainstream programs under this strategy. We recognise that the jurisdictions are challenged by their commitments to contribute to the cost of the NDIS. But "trading in" community programs needed by those inside and outside the scheme, not only reduces capacity for 'tier 2' services; it transfers costs to the NDIS by "marketising" community goodwill and networks.

Most importantly, the loss of these vital community programs leaves major service gaps for people who are ineligible for the NDIS, yet need the specialised support these programs provide. Taking money from one group of people requiring community services to fund another group of people requiring similar services is the same cynical approach to the scheme's funding and sustainability as that represented by the NDIS Special Savings Fund proposal.

An immediate halt to the collapsing of community services funding into the NDIS, in concert with the renegotiation of NDIS bi-lateral agreements as they apply to community services funding, is required.

One question frequently posed about the NDIS, is whether the rollout should be slowed in order to resolve some of the scheme's implementation problems. Rather than the take-up of individual plans for participants being slowed, the Alliance believes the progressive collapse of funding for these community programs into the NDIS must be stopped.

During the period of transition especially, it is important that parallel service streams remain so that the real impact of the transition can be assessed. The impact of the scheme and its processes is important and not only for individuals with disability who enter the NDIS and their families. Assessing its impact is also vital for providers

²⁶ Morton, R. "Mental health in NDIS a 'mistake' says Patrick McGorry", *Australian*, 6 April 2017. See <http://www.theaustralian.com.au/national-affairs/health/mental-health-in-ndis-a-mistake-says-patrick-mcgorry/news-story/7ad228fc1067ff76f0a0c961a6dc1618>

delivering disability and mainstream services, as well as community service programs and the fabric of the community service system itself. These are all imposts that need to be considered when the NDIS' complete complement of funding is required at full scheme.

The cashing out of community programs can be slowed. Other than the ACT, jurisdictions are not required to fully fund their NDIS contribution, so this should not be difficult. In the interim, the Disability Care Australia Fund should be utilised to enable dual-stream transition to be effected.

Lastly, the status of these community programs must become part of an urgently needed revision of how the scheme is being funded and implemented; and include the ILC component of the scheme in this review.

Recommendation

The COAG enact an immediate moratorium on the collapse of community programs until a detailed, independent review of the impact of the strategy to collapse community programs funding into the NDIS, is assessed.

Scheme Design and Legislative Review

Drafted in the context of the scheme's establishment and in a relatively short timeframe, the NDIS legislation was intended to be sufficient to get the scheme underway and through the trial phase. Following trial, the legislation was to have been redrafted to incorporate learnings gained so that a fully fledged scheme based on insurance principles could be delivered.

Unfortunately, the *Independent Review of the NDIS Legislation* that was undertaken in 2015 did not deliver the material needed to do this effectively. The initial scheme design (including the drafting of the rules) was a best guess at a structure and processes that would provide individualised supports to eligible participants.

The scheme's incremental implementation through trial and now at full scheme has generally been supported as a way of delivering such a huge reform. There has been a lot of goodwill towards the scheme during the trial and expansion phases. But as the pressure to meet the bi-lateral targets has increased, the commitment to co-design has diminished in equal measure.

This has made it difficult for stakeholders to engage with the scheme and have the same kind of collaboration and learning that was present initially. While there are forums for national peak bodies to liaise with the NDIS executive, a common complaint the Alliance hears from health service providers particularly, is that it is really hard to work out who to approach in the NDIS concerning things other than price, planning or participants.

Trying to meet the very demanding targets in the bi-lateral agreements has been torturous for both the scheme and for its partners. The NDIS has had to divert

resources away from core commitments to manage these urgent imperatives and must reactivate its co-design activity as a matter of urgency.

Trials are, however, still underway for different scheme functions, including various Local Area Coordination models. In addition, there are a number of legacy and in-kind contributions to the scheme that mean the NDIS is not yet operating as an intact social insurance scheme. The period of trial and progress to full scheme implementation has, however, highlighted some key design gaps in the NDIS.

One of the significant barriers to implementation of the NDIS as a stand-alone scheme is the close and regular involvement of the Australian, state and territory governments. While this may be needed for transition and implementation arrangements, there are many instances where the requirement to obtain agreement from relevant Ministers takes too long and compromises the scheme's ability to run its business. The most recent example of this is the 9 months the Disability Reform Council (DRC) took to agree to a rule for Supported Disability Accommodation payments.

The Alliance believes the following areas are in need of reform.

Governance

The governance of the NDIS has attracted a degree of controversy, largely because of its multi layered nature and overlaps, but also because of the make up of the NDIS Board.

The Alliance supports the selection of a skill based board and welcomes the recent appointments to the NDIS board. However, given the States and Territories ministerial control and transition involvement, questions concerning the board's mandate, role and capacity continue to be raised by stakeholders. While the Board clearly has an important internal governance responsibility, its ability to manage the scheme's external risks is severely constrained by the scheme's design and its continued reliance on governments to make and implement decisions that will be the board's responsibility at full scheme.

The Alliance expects that while COAG needs to remain involved with the NDIS, as the scheme becomes a more independent entity, the Board should be able to take increased responsibility for key financial and risk management activity.

The Council on Federal Financial Relations to take oversight responsibility for the NDIS

Because of the need for the NDIS to be integrated across government and not become an island program, it is important that the scheme be managed by central agencies rather than portfolio agencies.

Instead of oversight by the Disability Reform Council, the Alliance believes the NDIS must become the responsibility of the Council on Federal Financial Relations. Doing so will ensure that treasuries

- Have direct line of sight of all mainstream agencies;
- Can identify efficiencies and cost shifting attempts;
- Quantify the value of joint initiatives; and
- Link the scheme's expenditure to the jurisdictions' funding of the NDIS.

If the economic benefits heralded by the Productivity Commission are to be realised by the scheme, it is essential that the relevant cost offsets, benefits of joint cross program initiatives and awareness of policy and funding decisions in mainstream programs be visible within governments. 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.

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 NIIS...an important strategic imperative in itself.

Although the NDIS is assuming funding responsibility for scheme participants currently funded by the jurisdictions' disability programs, realising efficiencies through the development and maintenance of strong working relationships with other community service portfolios requires the governing portfolio to have direct line of sight into these 'mainstream' areas. Disability ministers and bureaucracies do not have the direct visibility of these programs and certainly little historical influence with them.

One example of line agencies having limited capacity in this way, can be seen in the Commonwealth's response to the Senate's *Inquiry into the adequacy of residential care arrangements* that did not support the Inquiry's recommendation to develop a National Rehabilitation Strategy. As stated earlier, the development of integrated rehabilitation across the NDIS, jurisdictional health programs and the NIIS would generate cost savings and better outcomes for participants. Given its financial remit,

Treasury may have seen this with more clarity than the line agencies who prepared the response.²⁷

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. This role should, however, be time limited and subordinate to the main oversight function of the Council on Federal Financial Relations.

Recommendation

The Council on Federal Financial Relations assume primary responsibility in government for the NDIS and work closely with members of the Disability Reform Council on the remaining NDIS transition processes.

The NDIS Special Savings Account

Recent political debate has seen a great deal of conjecture about whether the NDIS is fully funded and where the money to fund its liabilities will be coming from over the longer term. While much of this commentary is disingenuous and politically driven, the long term security of the NDIS as a permanent institution that can fund the needs of participants and achieve its objectives, is fundamental.

In its model for the NDIS, the Productivity Commission made it clear that, through the NDIS, support for people with disability needs to be a core function of government, saying

*The costs of supporting people with a significant disability from year to year through the NDIS should be viewed as a core funding responsibility of government and met from claims on general government revenue.*²⁸

The Commissioners also recommended that

*...the NDIS would effectively lock in tax revenue to meet its annual liabilities, without a yearly battle through the budget process to secure sufficient funding in competition with other government spending initiatives.*²⁹

The Alliance believes the proposal to establish the NDIS Special Savings Account is seriously flawed. The long-term viability of the NDIS requires guaranteed funding. Yet the Special Savings Account relies either on underspends from other programs and portfolios; or ministerial or cabinet discretion to top up the fund.

²⁷ Commonwealth of Australia, *Government Response to the Senate's Inquiry into the adequacy of residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*. See http://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Government_Response Canberra, February 2017.

²⁸ Productivity Commission, *Disability Care and Support Inquiry Report*, Volume 1, Canberra, 2011: 85.

²⁹ Op. Cit: 573.

The NDIS cannot be sustained by discretionary funding sources. The demands on it will certainly not be discretionary and if the NDIS is to become the social insurance scheme it was designed to be, it needs to have predictable revenue resources. The fact that the NDIS Special Savings Account Bill enables the Minister alone to decide 'deposits' to the fund, as well as allowing the Prime Minister and Cabinet to make discretionary payments to it, makes this a poorly designed and insecure funding mechanism for the scheme.

Lastly, the NDIS Special Savings Account does nothing to engage the States and Territories in guaranteeing long term funding for the scheme; assisting the NDIS with liability management; or integration of the NDIS with mainstream programs in all jurisdictions. These are all core responsibilities of the governments who co-own the NDIS.

To remain viable, the scheme needs to integrate three key strategic elements: scheme viability; participant satisfaction and/or goal attainment; and operational efficiency. These are all complementary elements that cannot be independently leveraged or traded off against each other over the longer term.

The existence of the NDIS Special Savings Account does little to assist in creating the cooperative and integrated structures that are required for the long term sustainability of the scheme.

NDIS Planning and Plan Implementation

The Alliance has seen some positive experiences with planning that have happened because of solid pre-planning preparation and resulted in major benefits for participants and their families. These have generally been where people have had stable need, had services funded for the first time, or where individuals and their families have been extremely pro-active in their preparation.

The Alliance has also been closely involved in planning processes that have delivered adverse outcomes, some of which have taken significant time to resolve.

The types of adverse outcomes for people with complex needs the Alliance has seen include

- Significant delays in plan approvals (more than 12 plus weeks in some cases) where complex questions are referred to a Technical Advisory Team (TAT) within a rollout area. In too many cases, the TAT itself lacks the competence to resolve questions concerning multi-program planning arrangements.
- Reductions in rehabilitation support for participants with Acquired Brain Injury (ABI) moving into the scheme from the Victorian *Slow to Recover* Program.
- NDIS refusal to fund essential supports/products that were funded through ISPs such as tracheostomy tubes, dressings, non-PBS medications such as

Botox (for spasticity relief), saliva control medication, suction and nebuliser equipment.

- Cost shifting to families and participants for the cost of consumable items.
- Services discontinued as a result of not being funded.
- Providers, participants and families left with no avenues for information or advice about how to adapt to changed/reduced support in the NDIS environment that, in its turn, complicates and/or prevents the implementation of completed plans.

For participants with complex needs requiring multi-program input, the NDIS' one-dimensional planning methodology that responds only to disability support needs, is not fit for purpose.

Where health supports are needed to dovetail with disability supports as part of an overall support program, participants with complex needs have not fared well with NDIS plans. In situations where these participants need products, joint assessments, or clinical governance oversight as part of their support, these inputs have been dismissed as the responsibility of a health program and not funded by the NDIS. The plans are therefore incomplete and provide little guidance as to how these different, remaining supports are to be joined up after the plan has been done. Often this task is left to a poorly equipped Coordinator of Supports who, with the participant and their family, is in no position to undertake sophisticated cross sector coordination.

An intentional part of scheme design, this singular focus on disability supports needs revision. Not only has it locked out necessary components of participant support programs, it has also resulted in systemic workforce shortcomings. NDIS planners, Coordinators of Support and Local Area Coordinators (LACs) are recruited, for example, to operate a 'disability services only' model and lack the required working knowledge of mainstream service systems that scheme participants may need to use.

The narrow design of the planning process means that while the scheme is reliant on significant informal contribution from mainstream programs, it has no capacity to fully engage these programs and their providers in developing joint responses for participants with complex needs. To the enormous frustration of all concerned, the result is inadequate plans.³⁰

Although health services do not yet have a meaningful design role in NDIS plans, they are providing substantial information for the planning process at the request of participants and some planners. As well as provision of information, this has

³⁰ The Alliance regularly receives feedback from participants that Coordinators of Support do not understand their plans when they do come back from the planner. This lack of understanding is contributing to significant delays in plan implementation and increasing plan review requests. In some cases, the Alliance is aware that the cost of unfunded supports has been shifted to the participant and their families.

developed to include rewriting clinical assessments in ‘NDIS speak’; and resourcing those private therapists scheme participants have independently approached to obtain information that has been requested by the planner.

For these reasons, some health services have indicated to the Alliance that their workload has increased since the NDIS has come into being and that this additional work is unfunded. The NDIS planning process has not recognised the implications of the NDIS transition on other systems. One health services provider described the NDIS planning experience as a “...‘hit and run’ exercise that came, went and left a trail of debris for us to clean up.”³¹

Hospitals and community health services do not have individualised funding programs that can address the NDIS’ funding approach to items the scheme decides are not its responsibility.

This lack of complementarity between a block funded and an individualised system is problematic. The Alliance is aware of participants and families having to absorb the cost of supports and products that cannot be funded by either system.

This is a significant risk management issue for the NDIS as poorer health outcomes of these participants puts upward pressure on support costs and can prevent the achievement of participant goals over the life course.

As an entity with substantial ‘skin in the game’, the NDIS must be proactive and implement planning regimes that incorporate the realities of local health and other systems; and negotiate with local providers and participants as a first step in the planning process.

Planning for people with complex needs

The Alliance has worked with people with complex health and disability support needs transitioning to the NDIS through a project funded by the Victorian government.

While definitions of what constitutes ‘complexity’ are not settled, the Alliance’s work in this area suggests several factors that are key to a working definition of ‘complex needs’.

Individuals with complex needs are commonly those who require services from multiple service programs such as health, housing and aged care, as well as disability services from the NDIS; and may live with one of more of the following

- Dual disability/co-morbidity.
- Mental health disability requiring hospitalisation.

³¹ Health provider comment, Alliance forum with health providers, Melbourne, February 2017.

- Chronic health conditions requiring regular clinical monitoring (e.g epilepsy, chronic pain, poor skin integrity, diabetes, swallowing difficulties, cardiac function, degenerative neurological condition).
- Requirements for regular hospital admission.
- Behaviour/communication and memory difficulties.
- Financial difficulties that cannot address increases in out-of-pocket costs for supports.
- Living in residential aged care.
- Undergoing a program of slow stream rehabilitation.
- Being a long stay hospital patient needing a comprehensive transition.
- Having a community support program that requires clinical supervision and training of care workers to undertake technical or rehabilitation tasks.

The Alliance is aware that the introduction of the scheme's truncated *My First Plan* planning process has created significant concern. We believe the problems that have arisen are directly related to the time pressures created by the bi-lateral agreements that require set numbers of people to become scheme participants within a designated time; and to the employment of planners, Coordinators of Support and LAC providers without multi-program expertise. Unfortunately, the bi lateral agreements fail to take account of the often complex arrangements that the scheme has to negotiate with other programs, participants and families.

While the scheme is in the midst of a massive growth phase and is trying to make the planning process work as best it can, demonstrating commitment to a sound lifetime support planning methodology must remain a scheme imperative. So too must investing in training to upskill planners, LACs and Coordinators of Support in working collaboratively with non disability programs, as well as enabling more flexibility for some cohorts of participants with complex needs.

The Alliance believes that as long as the *My First Plan* process does not become the scheme's default planning position and cross program capacity is embedded in the planning and plan implementation processes, these concerns may resolve.

Specialist health services

The Alliance is working with a number of teams and clinics within health services that provide a multidisciplinary service to people with complex needs, including coordination of disability services. These include services working with young people transitioning from children's to adult health services and tertiary neurological medical services.

Existing historically because of a gap between disability and health services, these multidisciplinary services play an invaluable role in the management of health issues such as spasticity, nutrition, pain and equipment needs. They also ensure that

disability services are provided to their patients in the context of the clinical imperatives that are an essential component of the support their patients require.

These multidisciplinary services play a critical role in maintaining and managing their patient's health and disability support needs in a seamless way. For some of these patients and families, managing multiple and fragile health conditions is the primary concern, with disability services residual to this. When it enters this space, the NDIS forces these families to turn these priorities on their head.

Feedback from these services is that they have had little engagement from the NDIS. They have had no specific communication about the timing of planning for their patients, or what may be required of them in the planning process. While some patients and families have been pro-active and gathered the necessary clinical information prior to their NDIS planning, the majority have not been aware of what is required.

They have also told the Alliance that their workload and costs have increased since the NDIS has rolled out. They have been asked to provide reports for planning at short notice; and then been asked by planners to re-write them in 'NDIS language'. In some cases, the NDIS has funded private therapists to provide assessments for plans, particularly for equipment. The private therapists seek additional information from the health service to deliver a duplicate of the original assessment. The time and resources this takes has to be drawn from already constrained program budgets and is costing the health system considerable additional money.

Many of the multidisciplinary health services the Alliance has worked with have weighed up whether becoming an NDIS provider would offer them an income stream. However, their team based service model and the workforce constraints they may face, has delivered uncertainty about their capacity to "fit" within an NDIS service environment. One particular concern is that the allocation of services by planners would be done from a disability services perspective and planners would therefore be likely to miss clinical imperatives.

The strong preference from these services is to offer their full multidisciplinary service as part the NDIS planning process and make a planner part of their team. Unfortunately, the NDIS process does not yet allow for this.

Some families have also expressed a desire to have the multidisciplinary team undertake NDIS planning. For them, the management of the multiple and sometimes fragile health conditions of their adult children is the predominant concern. These families have told the Alliance that in many ways, disability services are just a way of delivering support and are subordinate to the health services they receive from these multidisciplinary teams, They expect the health team to be organising and governing the disability service design and delivery and have been nonplussed by the disruption the reversal of these priorities in the NDIS planning process has created.

Alternative planning and funding mechanisms

The Alliance believes that one of the scheme's design weaknesses is the reliance on a single planning and funding model.

As exemplified by the complex needs cohort, the scheme's current model does not work for all participant groups. People with variable and changing needs and those participants needing integrated services from the NDIS and mainstream programs require funding options that can readily adapt to changing circumstances; and respond with funding decisions in real time. This applies to children, people with progressive neurological diseases and individuals with ABI undergoing active rehabilitation.

The Alliance is working with people who have been given plans lacking adequate provision for basic care and support. The capacity to get urgent supports added or corrected immediately when needed, is compromised by the slow and lumbering review process that has left them without vital supports, just as they are to start implementing their plan. This is particularly the case with inadequate provision of therapy hours and equipment. Other models of planning and funding are clearly needed by the scheme.

We would draw the Commission's attention to the funding provisions in the recently delivered Compulsory Third Party motor vehicle schemes that have become part of the NIIS in Western Australia, Queensland and South Australia. Provisions in these most recent no-fault schemes provide options for participants to choose whether they utilise a funding package for an agreed period (similar to the NDIS); or use a 'funding by request' approach where supports can be funded on request in real time.³²

Under the funding by request approach, a participant plan can be dynamic and combine long term (attendant care programs) and short term components (therapy, equipment revisions and training), with the scheme acting as the budget holder and the decision maker.

The establishing legislation for the South Australian Life Time Support Authority describes the packaging option it uses as follows

As an alternative to paying the expenses for which it is liable under this section as and when they are incurred, the Authority may pay those

³² See Explanatory Memorandum, Motor Vehicle (Catastrophic Injuries) Bill 2016, WA Parliament, Clause 18: 4. [http://www.parliament.wa.gov.au/Parliament/Bills.nsf/DA76EC3A2D324DE148257F63000C3A19/\\$File/EM176-1.pdf](http://www.parliament.wa.gov.au/Parliament/Bills.nsf/DA76EC3A2D324DE148257F63000C3A19/$File/EM176-1.pdf); Queensland National Injury Insurance Scheme (Queensland) Act 2016, Queensland Parliament, Section 34. <https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/N/NatInjuryInsSchQA16.pdf>; Motor Accidents (Lifetime Care and Support) Act 2006 No 16, Parliament of South Australia, part 2A (4) <http://www.legislation.nsw.gov.au/#/view/act/2006/16/part2a>

*expenses by the payment to the participant of an amount to cover those expenses over a fixed period pursuant to an agreement between the Authority and the participant for the payment of those expenses by the participant.*³³

The Alliance believes that a choice of funding model should be one of the choices available to participants and families. Funding can still be individualised, but the sometimes unrealistic demand to plan ahead in the face of volatility of need and changing support circumstance, should not be forced on people.

Recommendations

- For scheme participants with complex health and disability support needs, the NDIS
 - Fund capacity for multidisciplinary teams in local health services to directly undertake integrated planning and plan implementation activities.
 - Develop cohort specific planning and funding models for groups of participants needing support from multiple program areas.

- The NDIS legislation be amended to enable alternative funding models including individual funding packaging and funding by request models.

Improved consultation and advisory structures

At maturity, the \$22b NDIS will require diverse consultation and advisory structures that can work across program boundaries at local levels on a range of issues. A strategy to put these in place needs to begin as soon as possible.

The NDIS' Independent Advisory Council is an important feature of the scheme whose members have done excellent work on complex issues such as safeguards, choice and control, self direction and the practicalities of determining reasonable and necessary supports.

As the NDIS continues to expand, however, its consultation and advisory structures must also expand. Relying on one body to advise the board as the scheme expands, fails to address the multitude of local issues the scheme will necessarily confront as it grows. The local nature of issues that will arise in each jurisdiction means that more – and local – advisory bodies must be developed.

The distinctive nature of each rollout area and the diverse range of mainstream and disability service systems there, will require unique, local responses to the scheme's implementation. As well as the NDIS itself, we would recommend a local advisory body be established in each rollout area consisting of people with disability, carers,

³³ Motor Accidents (Lifetime Care and Support) Act 2006 No 16, Parliament of South Australia, part 2A (4). See <http://www.legislation.nsw.gov.au/#/view/act/2006/16/part2a>

representatives from local government and mainstream programs such as health, education, aged care, employment etc. These bodies should be resourced by the NDIS and linked to the Independent Advisory Council.

As local advisory groups, they would also be well placed to remain post full scheme to support individuals not eligible for the NDIS, but who need the full complement of local input and resourcing.

Recommendations

- The NDIS establish local advisory bodies in each rollout area consisting of people with disability, carers and representatives from local government and mainstream services.
- These local advisory bodies be resourced by the NDIS and linked to the Independent Advisory Council. A sustainable national structure should be maintained at full scheme to continue providing local input, resourcing and support for local community engagement with 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 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 has moved beyond trial, it is timely to review the operational model of the scheme. Given that the NDIS is encouraging community engagement for participants, it must create the structures that engage local communities and sectors.

Being a bureaucratic planner and funder (and a Local Area Coordinator as well in some regions) is not the ideal structure through which to develop and sustain community participation. The NDIS cannot expect community connections and cross-sector service collaborations to materialise simply because of its individualised funding model 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.³⁴ In proposing this,

³⁴ Productivity Commission, "The role of the Community and the NDIS", *Disability Care and Support*, Chapter 4, Canberra, 2011: 210-225.

the Alliance referenced the Productivity Commission's Research Report into the *Contributions of the Not-For-Profit Sector*.³⁵

In that report, the Commissioners indicated that not-for-profits utilise processes that are “...participatory, inclusive, quality focused and accessible...”³⁶ 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.*³⁷

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*

³⁵ Productivity Commission, *Contributions of the Not-For-Profit Sector*, Research Report, Australian Government, Canberra, 2010.

³⁶ Op.cit: 16.

³⁷ Ibid.

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.*³⁸

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.*³⁹

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 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.*⁴⁰

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

³⁸ Op.cit: 32.

³⁹ Op.cit: 29.

⁴⁰ Ibid.

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) operated by Alzheimer’s Australia. This program is designed as a cross sector, multi stakeholder initiative that can meet the complex demands created by young onset dementia. The intellectual and social capital of this program makes 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.

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.⁴¹

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 the 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.

Support Co-ordination

While the NDIS relies on support coordination to manage plan implementation for this group of participants, the Alliance's experience would suggest that providers in this part of the market are struggling significantly with the cross program demands this work entails. Rarely a mandated program activity, effective support coordination is also highly personality dependent. While fundamentally different to old style case management, the NDIS workforce that has been employed to undertake this new role is comprised largely of case managers experienced in working with disability programs; and who lack the capacity to work with mainstream programs such as health and aged care.

In the new NDIS world, support coordination requires a working knowledge of other service systems such as health, mental health and education. It also requires knowledge of labour market programs and the networks needed to maintain connections with these 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 same benefits apply to embedding the local area coordinator function in local community organisations.

Recommendations

- The NDIS block fund NFP community and member organisations to
 - Provide information and assistance to NDIS participants and community members with disability who are not scheme participants.

⁴¹ 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/>

- Undertake planning, plan implementation and monitoring as required
 - Link NDIS participants and other people with disability to community resources and services.
 - Develop improved local collaboration and integrated service delivery options.
 - Deliver Coordination of Support services and Local Area Coordination in their localities.
- In consultation with a working party of experienced not-for-profits and member organisation representatives, the COAG develop a national approach to community and cross sector engagement to replace the ILC at full scheme.
 - Amend Section 31(k) of the NDIS Act to mandate service coordination that works across NDIS and mainstream services, not just across different disability supports.

National Injury Insurance Scheme

During a routine day surgery procedure, Georgina sustains a massive brain injury. Her family are informed that 80% of her brain is massively damaged and it is "too late to rescue the situation". As a result, Georgina uses a tracheostomy to breathe, cannot move or speak independently and is denied any rehabilitation. She requires 24 hour nursing and other care.

12 weeks after her injury and despite her family's wishes otherwise, Georgina is discharged to residential aged care. The health service does not provide a health outreach service or additional funding to support Georgina's intensive health needs in the nursing home. Nor does it provide equipment or training to nursing home staff in appropriate management of Georgina's health and other support needs.

Over the six months she resides in the nursing home, Georgina is regularly readmitted to the hospital's emergency department. On two occasions, her condition is considered critical. Four weeks after she was last admitted to hospital, the nursing home informs her family they will not take Georgina back.

Despite remaining in hospital for nearly 12 months, Georgina is yet to obtain the rehabilitation she needs. Her family are investigating suing for compensation. But the time taken to investigate this option, proceed to court if a settlement is likely and reach a settlement, means that Georgina's opportunity to maximise her rehabilitation prospects will have passed before compensation is achieved.⁴²

The Alliance welcomes the inclusion of the National Injury Insurance Scheme (NIIS) in the Issues Paper. The establishment of a national no fault scheme for catastrophic injuries has been a longstanding goal of the Alliance due to the fact that many young people living in aged care are there because of inadequate insurance and compensation arrangements in Australia.

⁴² See pages 54-56 of this submission for a detailed account of this case study.

The Productivity Commission proposed the NIIS in its *Disability Care and Support Inquiry Report* in 2011 as a companion scheme to the NDIS.⁴³ 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.

But despite being before the group, progress on medical injury has stalled following release of a medical injury discussion paper in 2015. Once the medical injury class is agreed and becomes part of the NIIS, work can then begin on the final and perhaps most challenging area, that of general injury.

General injury is a significant area for which there is no existing system of insurance to provide lifetime cover. Nor is there any clear source of premium income to cover the costs of this part of the scheme. It is essential that the NIIS move to cover this gap.

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 four 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.

For example, unlike the NDIS, there is a lack of community awareness of the need for the NIIS. Consequently, there is no public demand for the remaining elements of the catastrophic injury scheme.

The waning interest of COAG and treasury officials, as well as the complexities involved in negotiating the medical and general injury components, are also creating delays and lowering the priority initially given to the NIIS. In discussions with the Alliance, some jurisdictions have privately indicated that creating a general injury scheme may well be a bridge too far in the current political environment. The feeling is that raising a new levy may not be well received; and the NDIS “provides enough of a fall back after all”.

⁴³ Productivity Commission, “Insurance Arrangements for Injury”, Chapter 18, *Disability Care and Support Inquiry Report*, Vol. 2, Canberra, 2011: 851-920.

The Alliance disagrees fundamentally with these views.

The NIIS and the NDIS are critical parts of the COAG'S disability reform. 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 being \$1.8b, and the additional annual cost to be covered by the NIIS to be \$835m.⁴⁴

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.

NDIS as substitute funder for injury

We note that the submission to this inquiry from the NDIA states that the NDIS faces additional cost pressure without the NIIS being fully implemented.⁴⁵

This is because the NIIS funds medical and sub acute rehabilitation services as essential components of lifetime support for people with catastrophic injury and the NDIS doesn't. If the remaining two injury components the NIIS has been designed to insure against are not developed, people with catastrophic injury from medical or general causes will have to obtain their supports from an NDIS that does not provide the comprehensive subacute rehabilitation services they require.

Because subacute rehabilitation services are very limited in public health systems and generally only available to people with compensation, denial of access to rehabilitation will reduce the independence levels of injured people and increase their disability support costs over the life course. Bi lateral agreements state that where jurisdictions do not have full catastrophic injury insurance schemes in place and injured people are supported – and funded – by the NDIS, the latter will be forced to seek full recovery of NDIS package costs from the jurisdictions.

If the two remaining injury components are not activated in the NIIS, this cost recovery arrangement will not only lead to the jurisdictions facing reimbursement of significant costs; it will also result in a range of systemic inefficiencies. For example, without seamless transition to rehabilitation, acute hospital stays will be longer as discharge options become more limited. A high chance of repeated and preventable readmissions of injured people will also become a reality that will place additional demands on already stretched public health resources.

The NDIS support model does not include the management of health needs. Nor does it include development of new or improved health services. In the absence of

⁴⁴ Productivity Commission, Disability Care and Support Inquiry Report Volume 2, Canberra 2011: 906-907

⁴⁵ National Disability Insurance Agency, *Submission to the Productivity Commission Review of NDIS Costs*, April 2017: 113.

the NIIS and the poor integration of their health needs into NDIS plans, injured people in the NDIS who need rehabilitation and health service input will face significant gaps in support, service coordination and clinical oversight that will significantly impede their recovery and increase care costs over their life course for the NDIS.

A fully implemented NIIS offers other advantages to state and territory health systems through development of specialist rehabilitation capacities. Without the demand imperatives of the NIIS, substantial investment in rehabilitation capacity by jurisdictional health systems is unlikely.

The capacity to mobilise specialist resources and service coordination early in a person's recovery, is extremely important. Since our inception in 2002, the Alliance has argued strongly for a comprehensive, no-fault catastrophic injury scheme that delivers long term care and support; and that retains access to common law for heads of damage for economic loss and for pain and suffering. The Productivity Commission comprehensively described the problems with fault based injury schemes in regard to long term care and support in the 2011 *Disability Care and Support Inquiry* report. The inefficiency, high transaction costs, the delays and the injustices remain a reality for those who acquire a disability in circumstances that are outside transport or work circumstances.

As Georgina's example declares, the current situation where too many catastrophically injured young Australians are either unable to be supported or compensated, or need to initiate slow and expensive common law action to access lifetime support, is not only unjust, it delivers unnecessary expense to the health and human services systems as it delays recovery.

That this is still the case for a relatively small number of Australians 6 years after the Productivity Commission's 2011 report and four years after the rollout of the NDIS is shameful indeed.

Recommendation

The COAG immediately establish a timeframe within which the final two injury categories (medical injury and general injury) are brought into the NIIS.

Case Studies

1. Jonathon - Need for cross-program negotiation

Jonathon, 53 years. Married with 2 children. Lives outside an NDIS rollout zone.

- Following surgery to remove an advanced tumour of the jaw, Jonathon developed a critical illness resulting in profound disability.
- He now requires a tracheostomy to breathe, is fed via a PEG tube, has no capacity to move independently and is fully dependent on others to meet all his needs.
- Jonathon's wife and children want him to come home, but a lack of disability and other resourcing means this cannot happen. Jonathon's family refuses to consider nursing home placement and he remains in hospital for 16 months. The hospital then approaches the Alliance to help Jonathon access the NDIS.
- The Alliance worked with Jonathon, his family, the hospital and the NDIS to help Jonathon gain early entry to the scheme.
- Despite being directly related to his care regime and his transition home, the NDIS planning process leaves a number of gaps in Jonathon's support by omitting elements the NDIS planner considers health supports. As example, the NDIS determined that consumable items required for Jonathon's tracheostomy care were not disability supports and refused to fund these costs. A suctioning machine essential to Jonathon's respiratory care was also refused on the grounds that it was a device for health maintenance.
- The NDIS is prepared to fund 97% of Jonathon's support needs. But its refusal to fund the other critical elements of his disability support means his personal care funding cannot be actioned.
- The NDIS does not negotiate with the health service or the family about how these other supports might be funded. Instead, the scheme decides that these supports are not its responsibility and provides no guidance as to how they might be resourced in the plan that is developed.
- Pre-arranged community health outreach therapy to assist with tracheostomy management is initially withdrawn because the NDIS plan nominates 'therapy' as a line item. The community health service wrongly assumes the NDIS is taking responsibility for this therapy when the therapy mentioned in the plan is to provide an occupational therapy assessment for home modifications. No discussion occurs between the NDIS and the community health service to clarify or resolve this misunderstanding.
- The Alliance facilitates pre and post-plan negotiation between the health service and the family involving
 - Early NDIS entry and planning, implementation and transition home arrangements.
 - Resourcing the family and hospital team to prepare a single source of information to support the planning process.
 - Early engagement of NDIS coordinator of supports and support agency.

- Negotiation of plan components with the NDIS, health service and the family.
- Jonathon transitioned home with NDIS funded supports and services as well as health services negotiated by the Alliance. These include
 - Training of primary carer/family and support worker team.
 - Hospital's purchase of suctioning machine.
 - Development of proactive allied health team enabling installation of NDIS funded equipment.
 - Activation of community health program to provide in home support and agreed emergency plans for re-admission to hospital as needed.
 - GP involvement including regular visitation and monitoring.
 - Jonathon's wife providing regular daytime and overnight care.
- Out of pocket consumable items not funded by the NDIS or the health service are costing the family approximately \$250 per week. This does not include higher utility costs that Jonathon's care requires.
- With the negotiated care and support plan working well, Jonathon has avoided readmission to hospital since discharge in February.

Risks to Jonathon remaining at home with his family

The family's financial capacity to fund consumable items.

While the family were made aware of the need to contribute to consumables, the size of this recurrent monthly cost only became clear at discharge. This financial burden on the family is not sustainable and there is no program within health services to fund these items.

Inability to maintain informal support

Jonathon's wife has taken a year off work to establish a care regime at home for Jonathon and is currently providing informal overnight support plus regular assistance with transfers and other tasks during the day.

Meeting the unfunded costs of consumables may force Jonathon's wife back to work earlier than planned. She may also be forced to work more hours than she feels she can reasonably achieve with her care management duties. The informal support she provides will need to be replaced with paid workers and even then the costs will still be challenging with a single income.

Given the risks involved in managing such complex care and support service delivery, as well as the imperative to maintain a healthy family life amidst the support workers, the scheme must fund the informal care Jonathon requires.

However, the NDIS continues to insist on maintaining its 'integrity' by not funding the last 3% of Jonathon's support program. This involves the consumable items that

are intimately related to Jonathon's disability support and cannot be funded by health services.

Given that Jonathon's wife is not in paid work, the family is left to cover these costs and their own living expenses from Jonathon's disability support pension.

Should the family situation change, the NDIS is likely to face higher support costs in the years to come.

2. Ahmed - Lack of rehabilitation input

Ahmed, 43 years. Stroke resulting in cognitive and physical impairment.

- Prior to his stroke, Ahmed had a full time job and lived in his own home with his dog.
- Following hospital inpatient rehabilitation, Ahmed makes a substantial physical recovery, with capacity to walk with an aid and manage his personal care needs.
- Despite his good recovery, doctors will not allow Ahmed to return home without support services.
- Disability services funding is unavailable.
- Funding from health or community aged care cannot be secured and he is discharged to a nursing home.
- Because of the assets test Centrelink applies to all entrants to RAC, Ahmed is required to sell his home to fund the aged care bond.
- Ahmed loses his home and is now technically homeless. To return to the community, Ahmed now requires an accommodation option in addition to funded supports.
- The health service provided time limited outreach rehabilitation to Ahmed in the nursing home. This includes training staff to deliver Ahmed's rehabilitation program. After a short period, the rehabilitation program discharges Ahmed for reasons unknown.
- The nursing home is unable to continue Ahmed's therapy or exercise regime.
- Ahmed's family are not aware that they can ask for rehabilitation input to continue.
- Two years later, Ahmed transitioned to the NDIS. On entry to the scheme Ahmed has lost most of the gains he had made and is
 - Unable to walk and requires a hoist for all transfers.
 - Is incontinent and requires continence aids.
 - Suffers from arm, hand and foot contractures that will require surgical interventions.
 - Is 50kgs heavier than when he had his stroke.
 - Has lost contact with friends, rarely goes into the community and is socially isolated.
 - Is effectively homeless. Ahmed wants to leave the nursing home but has no available housing option.
 - Remains unable to secure rehabilitation services from the health system or the NDIS to progress his recovery.
- At this point, the NDIS will need to provide significantly more support to Ahmed than would have been the case had his rehabilitation input continued and the gains he had made were consolidated.

3. Ava - Loss of rehabilitation

Ava, 51 years. Acquired Brain Injury, owns her own home.

- Ava acquired a brain injury as the result of acute encephalitis. After a period of hospitalisation and in the absence of disability funding for supports, she was discharged to a nursing home. Ava was admitted to the Victorian *Slow To Recover Program (STR)* and made good progress with this slow stream rehabilitation input.
- Ava moved to an aged care funded transitional unit for people with behavioural issues as a consequence of their brain injury. Shortly after moving there, she was notified of her eligibility for the NDIS and planning commenced.
- Ava wants to return to her fully accessible home in the community. Her STR program was focused on her goal of going home and building her independence and safety to complete everyday activities to do so. STR also focussed on developing Ava's communication skills and strategies so that she could be understood at home and in the community.
- Despite provision of comprehensive reports to the NDIS planner and meetings with the NDIA on the importance of maintaining Ava's allied health input, her NDIS plan did not recognise this. As a result, the funding Ava needed to develop the skills and strategies to successfully transition home, was absent.
- As example, Ava's allied health professionals indicated that 157 hours was required in the first six months of Ava's NDIS plan to support a safe and sustainable transition home including
 - Completing a variety of assessments in different environments (including home and various community settings).
 - Establishing and trialling suggested inventions to support Ava returning to her home.
 - Teaching Ava strategies she could rely on to remain living in her own home and community.
 - Reviewing the effectiveness of interventions before establishing an activity program and training workers to support Ava in practicing prescribed activities.
- Once she had returned home, a further 78 hours was requested for the second 6 months of Ava's plan to ensure that, with the assistance of support workers, all skills and strategies were working and risks were minimised.
- A total of 235 hours was requested for speech therapy, physiotherapy and occupational therapy to support Ava's return home.
- Instead and under the 'Improved Daily Living' category, Ava's NDIS plan funded a total of only 45 hours to cover 12 months of speech therapy, physiotherapy and occupational therapy. The plan did not outline what goals these therapy hours were to be used for or how they related to Ava's declared goal of transitioning home.
- The NDIS planner did not approach the STR team to discuss shared funding arrangements that could have enabled Ava to continue with her

rehabilitation program to return home. Under such an arrangement, the NDIS should have funded support workers to be trained and to deliver the program, with either STR or Victorian health services covering the allied health professionals' input.

- Without the funding required to support her transition home, Ava remains in limbo in the aged care service. The NDIS funded therapy hours to support her transition are completely inadequate. In light of these dramatically reduced therapy hours, the number of core support hours for therapy support is also insufficient.
- While a plan review request has been lodged, the significant delays in getting such reviews through the clogged NDIS review system means it could be a number of months before this review is addressed.
- Because the STR program's funding has been included as part of the Victorian government's contribution to its funding of the NDIS, STR funding and therapy input ceased the moment Ava was accepted into the NDIS. As a result, Ava remains in an aged care service without the quantum of therapy hours she needs to continue her goal of returning home; and risks losing the gains she has already made.
- Should this occur, the NDIS will be faced with funding a much larger package of support. Any therapy hours the scheme does decide to fund may be a case of "too little too late" for Ava to successfully recoup the gains she had made.

4. Terry - Lack of clinical governance for rehab goals

Terry, 48 years, stroke.

- Impact of stroke: low immune system function, cognitive impairment and fatigue resulting in a lack of motivation.
- Lived in a nursing home until August 2016 when he moved to live with his two brothers.
- Relocation to the community was coordinated and funded by the ABI *Slow to Recover* program. Terry's rehabilitation goals focus on the transition home and learning new skills and routines to ensure the transition home succeeds.
- During the NDIS planning process, strong recommendations are made by the STR therapy team and Terry's family that his rehabilitation therapy program continue to be funded in Terry's NDIS plan. Funding is requested for therapy and trained staff to support Terry's rehabilitation goals.
- Terry's NDIS plan sees his therapy cut from 206 hours to 30 hours per year.
- Clinical governance to manage Terry's rehabilitation goals is not available because the STR clinical governance team do not have a role with the NDIS.
- While Terry's attendant care hours increase substantially from 650 hours per year to 2,184 hours per year, his rehabilitation goals have been devolved into more general goals in his plan.
- Health issues directly associated with Terry's disability (including epilepsy, fatigue, low immune system response) that impact his everyday life, are now poorly monitored.
- Terry's NDIS goals are now general and his rehabilitation goals have been lost in his NDIS program. While he has a lot of support worker hours, the NDIS package does not provide for workers to be trained or supervised in Terry's rehabilitation goals.
- The Victorian Government is collapsing the STR program funding into the NDIS as part of its contribution to the scheme. However, STR's rehabilitation focus is not being maintained because its therapy hours are not seen as an NDIS responsibility.
- Without the specialised clinical governance that achieving their slow stream rehabilitation goals requires, untrained NDIS planners and LACs will be unable to recognise the rehabilitation imperative. Terry's recovery and independence will be compromised as a result.
- While his attendant care hours have increased and the quantum of his package is larger than before entering the NDIS, the lack of specific focus on rehabilitation and recovery means the attendant care hours are less purposeful and the workers are not being trained in the health and rehabilitation support that Terry requires.
- Terry's family is concerned that his health will deteriorate without the clinical governance and rehabilitation input he requires. They are also concerned that he will not be able to use all his attendant care hours and the gains he has made since returning home will be lost.

- If his rehabilitation goals are not maintained and Terry's greater independence is not achieved, the NDIS faces higher lifetime costs for Terry. The NDIS interpretation of the COAG Principles is that it is the health system's responsibility to provide the rehabilitation program architecture, clinical governance mechanisms and therapy hours for individuals to design and deliver rehabilitation programs.
- The NDIS currently has no means to ensure that any health system can provide this. Should the Victorian STR program collapse, a structural risk will be established for the NDIS with regard to people with ABI.
- The lack of such a cost-effective way of delivering slow stream, community-based rehabilitation for people with acquired brain and other injuries imputes this particular service gap as a national problem for the scheme.

Approved hours comparison, STR and NDIS

Therapy hours per year

Therapy type	ABI STR program	NDIS
Speech Pathology	60	10
Occupational Therapy	103	10
Physiotherapy	43	10
Total therapy hours	206	30

Attendant care hours per year

Rehabilitation support	Core support
650 hrs	2,184 hrs

5. Georgina - Need for a National Injury Insurance Scheme

Georgina, 42 years. Mother of two young children. Acquired brain injury due to medical misadventure.

- In late 2015, Georgina entered a large metropolitan hospital to undergo a routine day surgery procedure.
- During surgery, something went horribly wrong and Georgina sustained a massive brain injury. Georgina was immediately transferred to a major teaching hospital to access a hyperbaric chamber. Following further assessment, doctors informed her family that 80% of Georgina's brain was massively damaged and that it was "too late to rescue the situation".
- Georgina now breathes with the aid of a tracheostomy; cannot swallow and is fed through a PEG tube into her stomach; cannot move or speak independently; is completely reliant on others for every aspect of her health and well-being; and requires 24-hour nursing and other care.
- Over the next six weeks, Georgina's family continually requested that she be provided with rehabilitation to support her recovery. Doctors refused to offer rehabilitation and insisted that nothing further could be done. Six weeks after suffering her brain injury, Georgina's family is informed that the hospital intends discharging her to an aged care nursing home. The family refuse nursing home placement and insist that Georgina access rehabilitation and remain in the hospital to obtain the nursing care she needs.
- In an effort to discharge Georgina, hospital staff pressure the family to agree to nursing home placement and threaten to place Georgina in palliative care if the family doesn't agree. The family refuse initially but finally agree to investigate a nursing home option. 16 nursing homes approached refuse to take Georgina, indicating that her care needs are beyond their capacity to support.
- After serving the family with a discharge notice and informing them that if they don't agree to discharge Georgina to a nursing home, the hospital will ignore their wishes and send Georgina to a nursing home of the hospital's choosing, the hospital finally sources a nursing home willing to take Georgina. Three months after she sustained her injury, Georgina is discharged to a residential aged care service near the family home.
- The hospital does not offer a health outreach service to support Georgina; and does not offer training in managing Georgina's health needs to the nursing home or its staff. No additional funding is available to the nursing home to provide additional staff to manage Georgina's intense needs, provide equipment or train staff in appropriate management of her health needs.
- Two days after her discharge to the nursing home, Georgina is readmitted to hospital with a high fever and pneumonia.
- Over the ensuing six months that she resides in the nursing home, Georgina is readmitted to the hospital's emergency department on at least six separate

occasions. On two of these occasions, her condition is considered critical. In all cases, Georgina's readmission to hospital is due to the nursing home's lack of resourcing and training to care for her appropriately.

- In mid-2016, Georgina is again admitted to hospital in a critical condition. Four weeks later and while Georgina is still an inpatient in hospital, the nursing home advise her family that they are not in a position to take Georgina back. She has remained an inpatient in hospital ever since and has now spent nearly 9 months there. During this time and despite her family's continued requests, Georgina has been denied rehabilitation input. As a result, she has started to develop hand and foot contractures that will eventually require release through surgical intervention.
- Despite the lack of rehabilitation input, Georgina has made significant gains and is able to recognise and respond to her family when they visit.
- The family is once again being pressured by the hospital to discharge Georgina to another nursing home. Given the inability of the residential aged care system to appropriately care for Georgina without significant additional resourcing, Georgina's family will only agree to her discharge to a nursing home if this additional resourcing and training for nursing home staff is available.
- The lack of disability supported accommodation options with capacity to manage Georgina's complex health needs means that, other than continued hospital placement, residential aged care is likely to be the only discharge option for her.
- Georgina's family are presently investigating suing for compensation to obtain the funding Georgina will require to support her needs for the rest of her life. However, the time taken to investigate this option, proceed to court if Georgina's legal team agree that a settlement is likely and then reach a settlement, means that the window of opportunity in which Georgina could maximise her rehabilitation prospects will have passed before the compensation settlement is achieved.
- As it stands, the absence of the National Injury Insurance Scheme and its insurance against medical misadventure for people like Georgina, means that the NDIS is likely to have to fund much higher support costs than it otherwise might have. Because the NDIS will not provide rehabilitation services, it also means that Georgina will not be able to get the rehabilitation she requires if she comes an NDIS participant and her capacity to achieve greater independence will be denied with consequent additional support costs borne by the NDIS.
- The Alliance is currently working with Georgina's family, the hospital and health service, the state health department and a nursing home to develop collaborative working arrangements to ensure that Georgina's discharge option is sustainable and her health, rehabilitation and other support needs can be appropriately met.

- The Alliance is also negotiating with the state health department to trial the Victorian *Slow to Recover* model to provide Georgina with the slow stream, community-based rehabilitation she needs. This will involve a dedicated team of nursing home staff being trained to deliver a rehabilitation program for Georgina that has been designed by the hospital's allied health ABI specialists.
- Should the quantum of resources that Georgina needs be made available; nursing home staff be trained in Georgina's health and support needs; the hospital provide outreach services to support Georgina and the nursing home in managing her health and support needs; and Georgina access the slow stream rehabilitation she has thus far been denied, Georgina's family is happy for her to be discharged to residential aged care.

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