Submission No 254

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: Young People in Nursing Homes National Alliance

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Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability service providers in New South Wales

Submission

Young People In Nursing Homes National Alliance

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1. Introduction

The Alliance welcomes the opportunity to contribute to the New South Wales Parliament's *Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability service providers in New South Wales*.

The Alliance has taken a strong interest in the design and implementation of the National Disability Insurance Scheme (NDIS) 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, provides a significant funding stream for the NDIS and delivers lifetime support for injured people. Implementation of the NIIS however is seriously behind schedule. Work on the NIIS must be completed if the benefits to injured people and the financing of the NDIS are to be achieved.

This submission highlights a number of key issues that we believe must be addressed to secure the long term sustainability and effective operation of the NDIS and deliver the supports and services that individuals with disability are looking to the NDIS to deliver in NSW.

These issues include

- The refusal of the NDIS to fund direct care to NDIS participants living in residential aged care nursing homes;
- The adverse impact of the Applied Principles and Table of Services (APTOS) to determine the responsibilities of the NDIS and other service systems on the interactions of the NDIS with programs including health and aged care;
- The failure of the support coordination service type (including Specialist Support Coordination) as part of the NDIS suite of supports;
- The need for a more comprehensive planning and plan implementation methodology that can integrate NDIS services with those from mainstream (non disability) programs
- The impact of a market approach to service provision, and
- Relinquishment of NDIS participants to hospitals and nursing homes.

The Alliance is aware that the *NDIS Act 2013* and associated rules were primarily drafted to launch the scheme and provide a legislative 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.

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.

While 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, a fundamental revision of the design of the operation of the NDIS is required.

2. 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]

The Alliance has extensive experience with individuals needing integrated, multi-program responses through our collaborations with

- Hospitals and health networks around discharge planning and maintaining this cohort in the community post discharge.
- Residential aged care services (RAC), supporting individuals to relocate to community services or, in the absence of other alternatives, remain in RAC with additional supports.
- Individuals seeking to remain in the community in their own homes.

The Alliance regularly provides direct support in the form of advocacy and cross-sector service liaison to people with complex needs across Australia. Most recently, the Alliance has undertaken a statewide project for the Victorian Government that supported individuals with complex health needs to transition to the NDIS.

This direct experience with scheme participants, health services, disability and aged care providers and NDIS processes (including planners and support coordinators) has informed this submission.

3. The NDIS' refusal to fund personal support to NDIS participants living in residential aged care nursing homes

It has long been accepted that the aged care system is neither designed nor resourced to respond to the different needs younger people present with. Indeed, recognition of the shortcomings of the aged care system for younger people resulted in the $244m Younger People In Residential Aged Care (YPIRAC) program that operated nationally from 2006 to 2011.

In the absence of other viable alternatives, however, residential aged care (RAC) continues to be the main hospital discharge destination for younger people with complex health and disability support needs who cannot return home. RAC has also

[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.

become the singular discharge *expectation* that disability providers increasingly have for clients they feel they can no longer support.[2]

Despite an expectation that the NDIS would both recognise the resource shortfall that RAC providers have with regard to their younger residents (as is the case with other state and territory lifetime support schemes, including the NSW Lifetime Care and Support Scheme) and fund their reasonable and necessary supports, this has not been the case. Instead, the NDIS is relying on the Aged Care Funding Instrument to determine the level of support that participants receive; and on the Aged Care Quality Standards to require aged care providers to meet their needs despite having inadequate funding.

Reimbursement of the Aged Care Funding Instrument (ACFI)
Following an agreement with the Department of Social Services (DSS) and the federal Department of Health (DoH), the NDIS agreed to reimburse the Department of Health for the cost of the Aged Care Funding Instrument for eligible NDIS participants in residential aged care. The ACFI is a subsidy paid by the federal Department of Health to each aged care provider to deliver the care a resident requires.

There are four ACFI levels – high, medium, low or nil – that relate to the intensity of assessed care a resident requires in each of three care domains: Activities of Daily Living (ADL), Behaviour (BEH) and Complex Health Care (CHC). The subsidy paid for a resident is made up of the sum of the amounts payable for these care domains. The range of subsidies for high, medium and low levels is presently $216.59 per day or $79,055.35 per annum (high); $147.45 per day or $53,096.55 per annum (medium); and $62.13 per day or $22,677.45 per annum (low).[3]

As well as reimbursing the ACFI, the NDIS also funds the participant's means tested contribution to daily fees. The resident uses these funds to pay RAC providers directly. The NDIS also funds equipment, community access, some therapies and support coordination for YPINH.

Despite funding these 'reasonable and necessary' supports, the NDIS refuses to fund any personal care support for a participant in RAC beyond that provided by the ACFI reimbursement. It maintains this policy position regardless of whether or not the RAC provider can realistically meet the resident's needs comprehensively through provision of additional staffing to meet individual needs for care routines, transfers, meal assistance, exercise routines or behaviour support.

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[2] See Kym Flowers predicament as reported in the *St George and Sutherland Shire Leader* and by Nine News on July 28. See https://www.theleader.com.au/story/5548276/updated-engadine-womans-case-highlights-ndis-failings/ and https://www.9news.com.au/national/2018/07/28/17/59/ndis-kym-flowers-nursing-home-disability-services-struggles

[3] See https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/06_2018/aged_care_subsidies_and_supplements_from_1_july_2018.pdf Accessed 06/08/2018.

The Alliance has supported a significant number of NDIS participants in RAC in their NDIS planning and is aware that NDIS planners have been instructed not to recognise requests for any individual personal support (regardless of the complexity of the participant's needs), or include direct care support in their plans. Yet when the maximum the ACFI provides to support a nursing home resident with the highest level of need is compared with funding that disability providers receive to support residents living in shared supported accommodation settings, the disparity is evident.

As example, the ACFI provides a maximum of $79,055.35 per annum to support an older resident with the highest level need.[4] In contrast, disability providers managing shared supported accommodation services in Victoria commonly have more than double that amount with approximately $140,000 per person per annum to provide the services and supports a resident needs. One specialist ABI service in that state receives some $380,000 per person per year to provide the supports for each resident with complex needs.

This funding gap represents a service gap that impacts directly on the individual, their quality of life and their health and wellbeing. Given that these scheme participants would receive the quantum of personal care they require if they were living in the community, the NDIS is engaging in active discrimination against YPINH because of where they live. Furthermore, the NDIS is determining what is 'reasonable and necessary' for a *cohort* of participants, not looking at each participant as its legislation demands.

Reasons for the NDIS' refusal to fund direct care support in RAC
The NDIS has firmly indicated that, despite being required to fund 'reasonable and necessary supports' under the NDIS Act, the scheme will not fund direct care over and above that provided to a scheme participant in RAC through the ACFI. Regardless of the younger resident's intensity or complexity of need, the NDIS reasons that

- The Aged Care Act obliges providers to meet the full needs of every RAC resident – younger or older. Should the NDIS provide additional funding for direct care for scheme participants in RAC, the scheme argues that it would be 'paying twice' for a service.
- The NDIS views the aged care system as a mainstream service system as defined by the National Disability Strategy and the COAG Applied Principles and Table of Services (APTOS).[5] As such, the NDIS argues the aged care system is required to live up to its 'universal service obligation'.

[4] See https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/06_2018/aged_care_subsidies_and_supplements_from_1_july_2018.pdf
[5] https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdfv

The NDIS thus argues that the Aged Care Act and its stipulation that aged care providers must provide whatever a resident needs once they are accepted into the nursing home, takes precedence over the NDIS Act and that Act's provision of reasonable and necessary supports for all scheme participants, regardless of their domicile.

Yet its reimbursement of the ACFI makes the NDIS *the only funder of a scheme participant living in a nursing home*. In other words, once the NDIS pays the ACFI, the aged care system is no longer involved in funding the care and support of an NDIS participant living in a RAC facility. In other words, the fact that the NDIS is the sole funder of supports for these participants negates any mainstream obligations from the aged care sector.

The NDIS Policy Position

The Alliance asked the NDIS to clarify its policy position regarding the ACFI 'gap'. A response was received from the NDIS via email and stated the following

> The NDIS has a policy expectation that the aged care provider [will] be providing the quantum of personal support a younger person in aged care requires through the Aged Care Funding Instrument (ACFI). Personal support in this case would include personal care (toileting, showering, oral care, grooming etc), meal assistance, transfers where more than one staff member is required, skill development (maintenance of continence and personal hygiene skills etc) et al.
>
> We need to keep in mind that the Productivity Commission 2011 report states that the NDIS is unable to fill the gaps of the service systems as quoted below:
>
> *Access to generic services, such as health and housing, can affect demand for NDIS services, and vice-versa. It will be important for the [NDIS] not to respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would weaken the incentives by government to properly fund mainstream services for people with a disability, shifting the cost to another part of government (such as from a state government to the NDIS, or from one budget "silo" to another). This 'pass the parcel' approach would undermine the sustainability of the scheme and the capacity of people with a disability to access mainstream services.*
>
> Further, COAG's mainstream aged care principal stat's (sic) that:
>
> *The interactions of the NDIS with other service systems will reinforce the obligations of other service delivery systems to improve the lives of people with disability, in line with the National Disability Strategy.*
>
> Lastly, to ensure Scheme sustainably the principals (sic) of reasonable and necessary are critical. We are doing work within this space to support both

> mainstream aged care principals (sic) and the Productivity Commissioner's report.[6]

The Alliance believes this policy position is flawed for the following reasons.

1. Because it does not allow the assessment and funding of reasonable and necessary supports for each scheme participant residing in residential aged care, the NDIS is not complying with S34 its own Act.
2. The NDIS often refers to the need to preserve the scheme's 'sustainability' as a reason for not funding additional personal support. Yet S34 of the NDIS Act contains no reference to scheme sustainability as a factor in making funding decisions for reasonable and necessary supports.
3. By reimbursing the Department of Health for the ACFI, the NDIS becomes the sole funder of supports for YPINH in aged care. Because it is the sole funder, the COAG APTOS to determine the responsibility of the aged care system can no longer apply and cannot be relied upon to inform S34 funding decisions.
4. The inability of the ACFI to meet the different, more intense needs of younger residents has been widely acknowledged and was one of the reasons for development of the $244m national Younger People In Residential Aged Care (YPIRAC) program in 2006.

The NDIS policy position regarding its refusal to fund personal care beyond that the ACFI provides for scheme participants in nursing homes has been confirmed in subsequent meetings with the NDIS' Chief Economist, Mr David Cullen.

RAC provider feedback

The Alliance has received feedback from RAC providers who have had younger residents transition to the NDIS. These residents, their families and their RAC providers have expressed deep concern that the NDIS is not funding all the reasonable and necessary services these younger people require.

Many RAC providers are supporting younger residents with dynamic and fluctuating conditions that can include behaviours of concern. Many younger residents also have intense care routines that require multiple staff and additional time. RAC providers had a clear expectation that the NDIS would resolve the daily challenges in care provision they face for their younger residents through provision of additional care funding, or the creation of suitable alternative services.

In the absence of this additional input from the NDIS, providers are acutely concerned that, following negative feedback from assessors, they may be in breach of their accreditation standards. Others have indicated that accepting younger people into their care may no longer be viable and, in a small number of cases, that residents may have to be relinquished if they leave the RAC to go to hospital.

[6] August 2017 email correspondence with NDIA manager responsible for planners working with YPINH in RAC.

While residential aged care is not a preferred destination for younger people with complex health and disability support needs, nursing homes are going to remain one of the 'options on the spectrum' for this group until accessible housing is developed and a workforce with the higher levels skills is developed to enable this cohort live with confidence in the community. With the support and contribution of the NDIS, residential aged care can deliver a 'hotel service' that provides accommodation, support and meals as an interim option while other, more appropriate accommodation and support models are developed.

Should the NDIS maintain its refusal to fund reasonable and necessary personal care for scheme participants in RAC; should the growing risk for RAC providers failing their accreditation result in these providers refusing to take NDIS participants, then we will see people stay longer in hospital before discharge, or be relinquished by RAC providers to public hospitals. Quite apart from the cost to state health systems that includes reduced capacity to treat sick people in need of these hospital beds, the detrimental impact on the health and well being of scheme participants facing long term hospital placement will deliver increased care costs to the NDIS over the life course.

Kym Flowers, who has spent the last 4 months in Sutherland Hospital after her provider refused to have her return to her group home, is a recent example of this type of relinquishment. After living with cerebral palsy and diabetes all her life, Kym's provider cited her 'health issues' as the reason she is unable to go home. After providing Kym's accommodation for four months, the hospital has indicated Kym may have to be discharged to an aged care nursing home. Yet as this submission has indicated, the NDIS is unlikely to fund the quantum of personal care Kym needs should she be discharged to residential aged care.[7]

> 36 year old Pat suffers from brittle diabetes. A diabetes induced hypoglycaemic episode when he was 20 resulted in a profound Acquired Brain Injury (ABI) that has left Pat vision impaired, unable to communicate or move independently, doubly incontinent, experiencing multiple seizures daily, PEG fed and requiring 1:1 assistance from a support worker for all activities of daily living. He was discharged to a nursing home in a regional centre after several weeks in hospital.
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> The nursing home cannot meet the intensity and complexity of Pat's support needs through the ACFI funding it receives. It has indicated it has staffing difficulties in providing the monitoring and supervision related to Pat's PEG feeds (4 per day x 45 minutes), hydration and medication routine (6 times a day) and half hourly checks related to his brittle diabetes that is in addition to daily personal hygiene, continence changes and repositioning.
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> Prior to transitioning to the NDIS, Pat received additional disability services funding and support to address this gap as well as specialist therapy, therapy support and support worker training through a dedicated community rehabilitation program for younger

[7] See reports in the *St George and Sutherland Shire Leader* and by Nine News on July 28. Available at https://www.theleader.com.au/story/5548276/updated-engadine-womans-case-highlights-ndis-failings/ and https://www.9news.com.au/national/2018/07/28/17/59/ndis-kym-flowers-nursing-home-disability-services-struggles

people with ABI. This augmented the nursing home's efforts by supporting Pat with management of his oral hygiene; delivered a guided exercise routine and massage that minimised his seizure activities and repetitive agitation behaviours; and provided 1:1 support for Pat's social and recreational activities.

With no mandatory staffing levels in aged care, Pat's family worry about the lack of nursing staff available at peak demand periods in the nursing home, such as evening meal times. Out of concern for Pat's safety, one or more family members stay with Pat for several hours each evening to supervise his last PEG feed and settle him for the night.

The nursing home provider has expressed concern about their standards compliance in regard to the intensity of support Pat requires and indicated that without additional resourcing, they may have to relinquish Pat to hospital.

Representations by the YPINH National Alliance

The Alliance has raised this issue with the federal Minister for Aged Care, Hon. Ken Wyatt and the Minister for Social Services, Hon. Dan Tehan. We continue to raise our concerns with the NDIS CEO, senior management, and the scheme's Chief Economist.

In its representations, the Alliance recommended that the NDIS follow the funding policy of the Victorian Transport Accident Commission (TAC) for TAC clients living in RAC. While the TAC reimburses the DoH for the ACFI for its clients, it also funds any additional services TAC clients need over and above those provided through the ACFI. This includes additional direct care, nutrition, therapy, equipment and community access.

Recommendation

That the NSW government work with other States and Territories to demand that the NDIS change its policy on the funding of personal care for participants in RAC to ensure they comply with s34 of the NDIS Act and reduce the negative impact of the current policy on participants and state and territory health systems.

4. Shortcomings of the Applied Principles and Table of Services (APTOS)

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 (non disability) programs, particularly around the contributions these programs would make to NDIS participants requiring their assistance.[8] It was believed that these would both confirm the participation of people with disability in their community and the financial sustainability of the scheme.[9] In practice, nothing could be further from the truth.

The scheme's interpretation of the APTOS' description of the roles of the NDIS and mainstream programs has encouraged the NDIS to adopt a 'siloed approach' to mainstream program interactions that has resulted in the scheme making unilateral

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

[9] *Terms of Reference for the Review of the Applied Principles and Tables of Supports*. 24 October 2014.

decisions about the contributions of other programs without reference to or negotiation with these programs. This behaviour has served to reinforce 'hard' program boundaries, made the mainstream siloes of the human services system more secure than ever and left increasing numbers of NDIS participants worse off as a result.

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 NDIS participants requiring integrated, multi-program service responses.

Health services and the NDIS must, for example, be encouraged to work *with each other* to develop vital outreach services that will help prevent hospital readmissions and support scheme participants to live with confidence in the community. The mutual benefits that come from this type of partnership will not only deliver improved health and well being for NDIS participants. As well as reduced use of hospital services and subsequent and significant savings to health budgets nationally, they can also result in reduced care costs for NDIS participants and reduced costs over the life course for the scheme itself.

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

This has included the scheme deciding whether to continue to fund supports that had previously been funded by jurisdictions via disability support packages, or through programs that are 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, then 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 2017, 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.*[10]

While the COAG APTOS do contain provision for systems to work together where required, these have not been operationalised across all portfolios. Policy

[10]David Bowen in *Hansard*, Senate Community Affairs Committee Additional Estimates 2 March 2017: 112. See http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Festimate%2F9ec8a42b-9637-444c-ae23-1486fa3f9648%2F0003%22

commitment is required from all parts of government to achieve this. In the meantime and in absence of leadership on this issue, it has defaulted to the NDIS to make judgement calls in its own interest on individual planning issues.

Because there is no mechanism for the NDIS to collaborate directly with the various programs described in the COAG APTOS, 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.*
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> *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.*[11]

As much as the NDIS and government agencies want universal certainty and policies with universal application, 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.

Finally, the uncapped nature of the scheme is one of the great design strengths of the NDIS and must be protected at all costs. While it enables individualisation and flexibility, it also requires a significant investment in individual decision making and relationship management by the scheme with participants, providers and other programs. The design of the NDIS drew significantly on that of schemes such as the NSW Lifetime Care and Support Authority and the Victorian Transport Accident Commission. However, NDIS practices and liability management strategies are not yet as sophisticated as those employed by these other schemes.

It is important that the States and Territories who have this no fault social insurance experience (particularly NSW, Victoria and Tasmania) bring this to bear on the

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

operation of the NDIS through the various governance arrangements they are involved in.

Recommendations

- 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.

5. The failure of support coordination (including Specialist Support Coordination) as a service type in the NDIS operation.

The NDIS relies on support coordination to manage plan implementation for participants. Yet 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, but 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, justice, aged care and education. It also requires knowledge of labour market programs and the networks needed to maintain connections with these systems.

Rather than developing a workforce of coordinators who lack connection with the communities in which NDIS participants live, this role should be returned to the community organisations that undertook this work previously. As well as ensuring participants' plans successfully activated, 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.

Indeed, the marketization of what once was a community service has drained the disability sector of voluntarism and goodwill… something that is greatly needed to support community engagement with and for people with disability.

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.
- 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.

6. The need for a more comprehensive planning and plan implementation methodology with capacity to integrate NDIS services with those from mainstream (non disability) programs

The NDIS planning and plan implementation processes continue to remain completely scheme centric. For participants with complex needs requiring multi-program input, the scheme's one-dimensional planning methodology that responds only to their 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 health and disability support needs have not fared well with NDIS plans. In situations where these participants need products, joint health/NDIS 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 that result 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 or negotiation.

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 health and disability support needs. To the enormous frustration of all concerned, the result is delivery of inadequate plans that need immediate review.[12]

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 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."[13]

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.

> Following surgery, Jonathon was left with permanent disability. He breathes with the aid a tracheostomy and relies on a PEG for all his nutrition. Jonathon has no independent movement and requires 24/7 care. Due to lack of funding and the inability of health and disability services to agree on shared funding for him, Jonathon remained in hospital for 16 months.
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> 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.

[12] 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.

[13] Health provider comment, Alliance forum with health and aged care providers, Melbourne, July 2016.

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.

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.

In an effort to improve its acknowledged poor planning performance, the NDIS recently commissioned a series of planning pathways targetted at particular cohorts. These cohorts include

- Participants with complex support needs;
- Children aged zero to six;
- Participants with psychosocial disability;
- Participants from culturally and linguistically diverse backgrounds;
- Aboriginal and Torres Strait Islander communities;
- Remote and very remote communities; and
- LGBTQIA+ communities.

While the NDIS' effort to address its poor planning performance is to be acknowledged, these targetted pathways remain administrative in intent and fail to address the real need for joint planning to be undertaken by the scheme in partnership with the mainstream programs these groups may need to access.

7. The impact of a market approach to service provision.

One of the more confounding aspects of its design and implementation is that the NDIS' social objectives for its participants are at odds with the scheme's reliance on a market approach to achieve these objectives rather than social policy levers.

A glaring example of this contradiction sits firmly within the scheme's approach to the need for accessible housing for scheme participants. Despite its declaration that it is not responsible for housing, the scheme has attempted to stimulate a market response to this accommodation need through its much vaunted Specialist Disability Accommodation fund (SDA). Despite being eagerly anticipated, this fund has capacity to address the needs of only 6% of the scheme's participant population. Policy activity to address the significant lack of accessible accommodation for the other scheme participants is not addressed, either by the scheme's jurisdictional partners or the scheme itself.

Where developers have tried to respond to the SDA incentive, the lack of preparedness and understanding by the NDIS about how this fund could be used, has led either to intense developer frustration and withdrawal from this 'market'; or proposals that are little more than variations on the group home disability accommodation model that has been dominant since the deinstitutionalisation moves of the 1960s and 1970s.

This 'market response' reflects a perception of Australians with disability and their needs that is retrograde and fails to see these individuals as citizens with similar expectations of independent living as other community members. Left to its own devices, the 'market' has done nothing to advance development of the more sophisticated options for independent living that individuals with disability have repeatedly stated that they want. Instead, it has segmented accommodation as a singular solution that takes no account of the critical influence appropriate models of care have on the success of otherwise of a development. Nor has consultation with individuals with a disability about their accommodation preferences been a hallmark of this market approach.

The provider market is another instance where the scheme's presumption that providers will continue delivering the supports clients require is not proving reliable. The Alliance is seeing a disturbing trend of some providers relinquishing clients to hospitals because the client is seen to be too hard, too complex or has challenging behaviours that the provider is either unable or not interested in managing. While Kym Flowers' experience is evidence of this happening in NSW, the Alliance is seeing growing evidence of provider relinquishment to hospitals in other states.

Relying on an undirected 'market' and taking the laissez faire approach that has marked the NDIS activities in these spaces thus far, is simply not good enough. If "the market" is to be a useful tool to achieve the scheme's social and economic objectives, it will require a more strategic approach that combines social policy development with market development in disability services. This necessitates a far better integration of jurisdictional human services policy with the work of the NDIS and the Department of Social Services (DSS).

The NDIS has no separate policy capacity. In its current construct, it is purely an operational agency that relies on DSS and the States and Territories to develop appropriate policy settings. While the scheme does have a clear role in market development, it is not clear if these functions are integrated or whether there is an overall strategy guiding the various governments and agencies. The failure of the National Disability Strategy and its seeming disconnection from the NDIS is further evidence that a better approach is urgently needed.

With regard to people with complex needs, very few of the policy and market gaps that were identified at the inception of the NDIS have been resolved. Some, such as the ACFI, exist because of a deliberate decision. Others, such as those existing

around mainstream interfaces, have arisen largely because of policy inertia and the poor design and negative impact of the COAG APTOS.

The Alliance is willing to provide further information to the inquiry.

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