

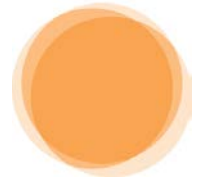
**Submission  
No 204**

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

**Organisation:** Summer Foundation

**Date Received:** 8 August 2018

---



# **Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales**

August 2018

Contact Name: George Taleporos

Contact Title: Policy Manager

Tel: 1300 626 560

Email:

# Table of Contents

<b>Introduction.....</b>	<b>3</b>
About the Summer Foundation.....	3
Young people in aged care in Australia .....	3
Scope of this submission.....	3
<b>The Experience of People With Complex Support Needs In Developing, Enacting And Reviewing Their Plans .....</b>	<b>4</b>
Problems with planning .....	4
Approaches to assessment and the need for specialists in planning for people with complex needs .....	7
Low utilisation rates of funding packages .....	7
<b>The Provision of Housing for People With Disability .....</b>	<b>9</b>
Problems .....	9
Solutions .....	12
<b>The Interface Between Disability Supports and Health Services .....</b>	<b>13</b>
Health systems lack knowledge of the NDIS pathways and processes .....	14
NDIS processes slow down hospital discharge .....	15
NDIS delays in pathway planning and reviews interfere with NDIS navigation.....	15
NDIS plans do not cover needed supports .....	16
New gaps in services have emerged.....	16
The NDIS system fails to provide rapid responses when needed .....	17
Operational guidelines for COAG Principles are not in place.....	17
Conclusion .....	17
<b>Recommendations.....</b>	<b>18</b>
Plan development and Implementation.....	18
Housing.....	18
Health interface .....	19

# Introduction

## About the Summer Foundation

The Summer Foundation works to change human service policies and practices related to young people (18-64 years old) living in, or at risk of entering, Residential Aged Care (RAC) facilities.

Our vision is that young people with disability and complex support needs will have access to services and housing that supports their health and wellbeing and a good life in the community.

We are committed to working with key stakeholders towards achieving accessible and affordable housing for young people with disabilities with complex support needs. We are committed to working to ensure that the NDIS realises its potential to end the forced admission of Young people with disabilities into residential aged care.

## Young people in aged care in Australia

As at June 30 2017, there were 6242 Young People In Residential Aged Care (YPIRAC).<sup>1</sup> According to Senate Estimates, over 2000 have now entered the National Disability Insurance Scheme with most entering in the last 12 months.<sup>2</sup>

Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society. Fifty three per cent of young people in RAC receive a visit from a friend less than once per year and 82% seldom or never visit their friends.<sup>3</sup> They generally lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community<sup>4</sup>.

## Scope of this submission

In the submission, we are responding to the following Terms of Reference that are of interest to the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales:

- (b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,
- (e) the provision of housing for people with disability
- (i) the interface between disability supports and health services,

This submission draws on our experience working closely with NDIS participants with complex needs. The case studies presented are real and the individuals and families have consented to their stories being included in our policy work. We welcome the opportunity to discuss these issues further with NSW parliamentarians.

---

<sup>1</sup> George Taleporos, “Five years on, NDIS is getting young people out of aged care, but all too slowly”, *The Conversation*, Jun 12, 2018, <https://theconversation.com/five-years-on-ndis-is-getting-young-people-out-of-aged-care-but-all-too-slowly-97851>.

<sup>2</sup> Ibid.

<sup>3</sup> Winkler, D., Sloan, S. & Callaway, L. (2007), *Younger people in residential aged care: Support needs, preferences and future direction*, (Melbourne, Victoria: Summer Foundation). PDF

<sup>4</sup> Ibid.

# The Experience of People With Complex Support Needs In Developing, Enacting And Reviewing Their Plans

## Problems with planning

---

*A 17-year-old young man acquired a severe brain injury which resulted in extreme functional impairment as he lost the ability to move independently or speak verbally. His mother campaigned tirelessly for the introduction of the NDIS. Living in the Barwon NDIS trial site meant the young man would be an early NDIS participant. The mother describes their transition into the NDIS as 'bumpy'. She anticipated the transition would involve a light review of her son's state funded plan but... "All that we had learned, all the blood sweat and tears that had gone into my son's plan had fallen by the wayside, it was heartbreaking." They had to begin the process of rebuilding his plan, brick by brick. This process took a long time with many reviews and changes to the plan before it was finalised. "If you do get a plan and you're not happy with it, have the courage to hand it back." Vanda engaged the support of an advocate to help achieve her son's plan. "We are now able to start dreaming and planning as a family again."*

---

Click [here](#) to see the family's digital story which describes this family's experience with the NDIS and planning

The pathway for planning under the roll-out phase has been unclear, inconsistent and inaccessible to many young people in aged care. The split between the access responsibility and the regional planning process makes it difficult for someone with a complex communication or cognitive disability to get any sense of continuity, as they get passed along the system between different people. There has been inconsistency in decision-making with respect to who goes into the different planning streams. Commonly we have seen people with complex needs in the LAC planning stream, when they should be part of the NDIS delivered "complex planning stream".

A lack of preparation support for planning means significant gaps have emerged, because individuals are unable to articulate their complete needs and goals as is required for a good outcome from planning. The important work of supporting people with NDIS preplanning and through the planning process is not being funded in the national roll out, and services such as case management that could have assisted have been de-funded prematurely as the NDIS rolls out.

The Summer Foundation stepped in by providing connections assistance and some preplanning support for young people in aged care in a range of roll-out sites. This work was difficult without the necessary information from government about the location of younger people in RAC. There have also been problems in having pre-planning support maximised with instances of pre-planning documents being completed and provided to NDIS but not read by the allocated planner.

Once in the planning process, wide variation in the skills and experience levels of planners has meant some plans have been seriously underfunded and inadequate to meet the needs of the participant.

Our work in assisting with connections with the NDIS ended when the NDIA undertook a targeted strategy to reach young people in RAC by deploying a team of Facilitated Access Planners in all roll-out regions. This has led to a vast improvement in the number of YPIRAC gaining access to the NDIS. As of April this year, 1958 YPIRAC had entered the NDIS. 1,109 of these YPIRAC entered the NDIS in the six months between September 2017 and April 2018<sup>5</sup>.

We know that with good support, and advocacy, and a planner who understands the person and their condition, people have been able to achieve excellent plans. We have found that the best outcomes occur when the planner is prepared to take the necessary time needed to understand person, as well as seeking out information from family members and practitioners who know the person well.

The following story demonstrates the importance of family involvement with planning, particularly with people who have cognitive and communication impairments:

---

*A mother of an adult daughter who has Multiple Sclerosis is a primary advocate for her daughter. The daughter has lived in a nursing home for over seven years. Even though the nursing home is not conducive to maintaining relationships, the daughter tries her best to stay engaged with her four children and two grandchildren.*

*It was by chance that the mother found out about the NDIS when a visit to see her daughter coincided with the Summer Foundation also visiting the daughter. The mother wasn't even aware that her daughter was living in an NDIS trial site. She often finds herself contemplating that fortuitous meeting, "If we hadn't become connected to the Summer Foundation, we wouldn't have known anything about the NDIS!"*

*The mother immediately registered her daughter with the NDIS and experienced wonderful support from the planner and local area coordinator assigned to her. The planner was a trained occupational therapist and understood the complexity of her daughter's disability. The mother says, "The planner became our personal contact within the department and we could ring at anytime and they would provide any assistance required."*

*Once the NDIS trial period had finished, the daughter's plan became due for review. The mother and daughter were confronted by the reality that the new planner was hopelessly inexperienced, "This planner did not have a disability experience background and had no idea of the philosophy behind the NDIS and how it was meant to work out for*

---

<sup>5</sup> George Taleporos, "Five years on, NDIS is getting young people out of aged care, but all too slowly", *The Conversation*, Jun 12, 2018, <https://theconversation.com/five-years-on-ndis-is-getting-young-people-out-of-aged-care-but-all-too-slowly-97851>.

*the most important person – the client. I had to tell her how this was meant to work and what my daughter’s requirements were and how to actually bring that to being!”*

*The mother’s experience with the NDIS had deteriorated by the third plan review ... “No actual review took place and her daughter received a ‘form’ letter advising that her plan would continue ‘as was’ for the next 12 months and if she required any changes to apply for an internal plan review within 3 months of receiving this letter! This letter was not even signed!”*

*One most significant challenges for the daughter throughout her NDIS experience was when she was initially asked about the goals she would like her NDIS plan to support her to achieve. Having been institutionalised so long, the daughter had lost the capacity to think and plan into the future. Now, with encouragement, she is able consider a more hopeful future and can to actively engage in the process of planning for this future.*

*Regardless of the obstacles, the mother still has high hopes for the NDIS, “This program could be unbelievable if done correctly and it would provide us with a world class initiative.”*

---

Click [here](#) for the full digital story.

At the commencement of the rollout of the NDIS, the first plan approach was adopted as a way of increasing the pace of the rollout. Rather than a thoughtful and in-depth approach to planning, this approach has involved planning over the phone and in most cases the existing state-based funding allocation is rolled over to form the participant’s first NDIS plan. This resulted in particularly poor outcomes for young people in RAC. For example, Enhancement Packages developed under the YPIRAC initiative were capped at around \$15,000. The work of the Summer Foundations NDIS Connections Officers found that around 75% of YPIRAC in the trial sites had no prior relationship with the disability system. We are aware that many of the young people we have assisted to connect to the NDIS have plans with a monetary value of between \$4,000 and \$10,000, much of which may be inflexibly allocated for Support Coordination.

The first NDIS plan for many young people currently in aged care needs to include an Exploring Housing Options Package to give the participant the opportunity to work out their housing goals and identify appropriate housing options. This Exploring Housing Options Package funds a skilled practitioner to work through the questions listed above, as well as purchasing of specialist assessments from professionals such as an Occupational Therapist.

A member of our staff who worked on the ground with young people in Residential Aged Care observed that:

---

*Part of developing people with disabilities’ skills and independence is familiarising them with the market economy and their active role in it. They need to experience being consumers of services and not passive recipients of them. This is about setting*

*expectations. Sadly if people's initial experience of the NDIS is receiving an 'off the shelf' – reference plans – then the promise of the NDIS for an individualised response is severely compromised. The NDIS is a once in a lifetime opportunity to reform the way in which disability services are provided and we have a role in ensuring that the NDIA does not renege on this. The NDIS must invest more time and resources into assisting people to develop their plans from when they enter the scheme so we can deliver something better than the broken system that we want to leave behind.*

---

## **Approaches to assessment and the need for specialists in planning for people with complex needs**

For young people in aged care, who have complex support needs, reference tools that try to average out plan costs are unlikely to be valid. There is a wide variation in the presentation and life circumstances that means tailoring an appropriate plan will require flexibility and creativity as well as expert knowledge and medical expertise. Some of the needs of young people in aged care, particularly the cognitive, communication or behavioural dimensions stretch the bounds of knowledge and skills of regular planners and assessors.

A more appropriate approach is to recognise that the generic pathway to services through planning needs to be replaced by a specialist stream, which can provide the specialised and intensive assessment and planning that is needed by this cohort. This would avoid the need to continually appeal and review plans that are inadequate or do not reflect the complexity and high needs of the individual.

We recommend creating team structures that support planners working with people with complex needs, that can be robust over time, and maintain collective knowledge about assessment processes as team membership changes, as an avenue to retain and refine 'active' assessment processes and tools. We believe that this can be possible through the Facilitated Access Planners that have found it difficult to access detailed information about the skills and training of these plans.

## **Low utilisation rates of funding packages**

The Summer Foundation is concerned but not surprised by the low utilisation rates of funding packages, particularly for new participants and those who are institutionalised, such as people living in aged care. We know that there is a significant amount of planning and capacity building that is needed for a person to fully implement their plan. There is also a severe lack of appropriately trained and skilled support coordinators to assist with planning implementation. People with disabilities and families are reporting that understanding, navigating and getting the most out of the scheme is difficult. This is demonstrated in Jo's experience outlined below:



---

*Jo has been living in residential aged care for over 9 years, and told us that she struggles to understand what to expect from the NDIS. Despite her positive attitude for the scheme's support, she acknowledges there are some large gaps in understanding her rights. This is compounded by the lack of a supportive advocate. Essentially, she is on her own, she says, "I struggle to understand how the NDIS works."*

*She was introduced to the NDIS through the Summer Foundation's Connections Program. Without this proactive initiative, she believes she would still be unaware of her right to access the NDIS in the first place. She has had some success with the NDIS and life has certainly improved, but she would like to understand what is deemed a 'reasonable and necessary request'.*

*One issue that demonstrates her confusion relates to the funding she has received for community access. She is grateful for her community access plan, which funds two recreational outings per week; but sadly, she can't take advantage because only has sufficient funding for transport once a week. This funding omission means once a week she has a funded support worker, but they are unable to go out.*

---

Click [here](#) to see the Jo's digital story where she describes her experience with the NDIS

Jo's story demonstrates the importance of providing people with disabilities support to navigate the NDIS and to solve existing problems in achieving their NDIS goals. For Jo, a major barrier to her achieving her NDIS goals, relates to access to transportation. For others, it may be that there is a lack of suitable and appropriately trained staff or the lack of appropriate housing, among other things.

# The Provision of Housing for People With Disability

People with complex and high-level physical disabilities are forced to live in aged care because they have limited access to necessary support and limited suitable housing options. The introduction of the NDIS should provide the support needed to live independently and for some it should also provide funding through Specialist Disability Accommodation (SDA) payments, to meet the cost of accessible housing.

## Problems

Peter's story shows how many people are stuck in aged care because of the lack of availability of accessible and affordable housing:

---

*Peter who has a neurological condition, registered as a NDIS participant in late 2016. Since then he has been able to secure 50 hours of physical therapy per year, but without a home environment where he can utilise all the new skills he learns, it is unlikely the benefits can be built on in any meaningful way. The process with his planner for the NDIS has not been smooth either. In fact, he believes the planner had little training or experience, and was ill equipped to understand his complex health needs.*

*Having a secure home environment where he can express himself and build a life is paramount for his emotional and physical health. Life in a nursing home is making a bad situation far worse. He is ready and willing to take on the challenge of a more independent life but the longer he continues to have everything done for him in the nursing home, the quicker he will lose the vital skills he needs to pursue a quality life.*

---

We need a range of options to fill the gap in accessible and affordable housing for people with disabilities including models that enable people to live with their partner and/or children. Many (46%) young people in RAC are in partner relationships and 27% are parents of school aged children<sup>6</sup>. Australia desperately needs to create more housing that is both accessible and affordable. Rather than continuing to build segregated specialist housing, the housing needs of people with disability need to be incorporated into mainstream housing strategy.

The life changing impact of access to accessible and affordable housing is demonstrated through David's story, where timely access enabled him to be diverted from entering a nursing home:

---

*In November 2015, David acquired a brain injury that would dramatically and permanently change the direction of his life and that of his family. Devoted and*

---

<sup>6</sup> Winkler, D., Sloan, S. & Callaway, L. (2007), *Younger people in residential aged care: Support needs, preferences and future direction*, (Melbourne, Victoria: Summer Foundation). PDF

persistent advocacy from his wife, combined with fortunate timing has prevented this man from falling through the cracks and ending up in a nursing home. He lived in an NDIS site at the time of his accident and while he was receiving inpatient rehabilitation, a rare supported housing opportunity emerged. The team supporting his rehabilitation worked with the housing provider, support service provider and the NDIS to implement a transition plan. The advocacy required to co-ordinate his move to a new supported home was extensive, and largely driven by his wife. Such a great outcome is rare, and aside from the heavy-duty advocacy required to achieve this, a pathway to a new permanent home from hospital is exactly how it should be in an ideal system. His wife reflects, “It’s such a relief, its such a lovely, lovely outcome for all of us...I know it would have been hard for our children to come and visit David in a nursing home, that was never going to be OK.”

---

The NDIS enables housing options for people with disability to be opened up with the funding of support needed to live in the community. For around 6 per cent of NDIS participants with very high and complex needs, funding for Specialist Disability Accommodation will enable them to live in affordable accessible housing. However, the great majority of NDIS participants will need to find affordable and appropriate housing in mainstream housing systems.

People with disability experience multiple challenges in accessing affordable and appropriate housing - low incomes, additional living costs, the need for dwelling modifications which may preclude private rental options. Low incomes and lack of capital exclude most from home ownership. But to participate in the community, people with disability need stable housing of appropriate design and located where they can access critical supports and services.

Group housing has been the dominant housing option for people with complex support needs over the past 20 years. Recent analysis of demand for SDA by the Summer Foundation indicates that around 84% of current supported accommodation places in NSW are in group homes. The remaining 16% of places are in small and large institutions, to be phased out in coming years. But in the NDIS environment, which supports individual choice and control, many people with disability will be looking for a wider range of housing options, in a variety of locations and which enable diverse living arrangements. People with disability want to decide where and with whom they live with, as any person would.

This means housing options are going to best suit people’s needs where:

- Flexible supports facilitate capacity building and living meaningful and satisfying lives
- Opportunities to build and maintain relationships with family, friends and acquaintances are maximised and new connections and relationships can develop; and
- There is choice in who you live with, whether you live on your own or with family or friends.

These opportunities and choices have not been present in disability housing models that currently dominate the market.

The SDA framework under the NDIS has brought the potential for significant investment in a variety of quality housing types for people with complex disabilities. The Summer Foundation has

done extensive work since the introduction of the SDA framework to promote the potential to invest in new accessible housing and to develop resources and tools to help NDIS participants to understand the path to new housing options, with the support of their NDIS funding.

The SDA Framework is currently being reviewed by the Federal Government in the light of its first two years of operation. At this early stage, the framework has mainly facilitated payments to NDIS participants living in existing supported accommodation (under old models) transitioning to the NDIS.

There is growing interest amongst a range of commercial and not for profit organisations in using the SDA framework to develop quality new housing options. However some early policy and implementation issues with the framework are causing difficulties in this newly developing market. These can be summarised as:

- Problems with inconsistency and uncertainty in the planning process with individual participants, and slow decision-making by the NDIA
- The absence of data from the NDIA about properties being enrolled as SDA (supply) and participants being approved for SDA funding (type and level – demand) to help the market plan for new housing
- NDIA funding decisions about SDA building type and location are undermining choice and control for participants eligible for SDA as they are left with insufficient funding for their preferred home and living arrangement.
- The SDA funding support is being applied by the NDIA on the assumption that only people with SDA funding will share housing with each other. This leaves people with insufficient funding to share their home with anyone who does not have SDA funding - spouses/partners, children, other family and friends.

Summer Foundation's focus is on younger people forced to live in aged care due to lack of alternatives. Only 23 of the 2,000 young people in aged care who have entered the NDIS to date (Australia-wide) have funding for specialist disability accommodation in their NDIS funding plan.<sup>7</sup> Those 2,000 people are a priority group for specialist disability accommodation, so the very low numbers funded for specialist housing is indicative of problems in the way SDA payments are being determined.

The NSW government needs to pay close attention to what is happening in the housing market for NDIS participants, both in relation to SDA as well as mainstream supply. High cost housing markets in Sydney means that even SDA funding support will not enable development of new SDA supply in many Sydney LGAs. The vast majority of NDIS participants will not be eligible for SDA funding but still need to find housing, mainly in the social and private rental markets.

---

<sup>7</sup> George Taleporos, "Five years on, NDIS is getting young people out of aged care, but all too slowly", *The Conversation*, Jun 12, 2018, <https://theconversation.com/five-years-on-ndis-is-getting-young-people-out-of-aged-care-but-all-too-slowly-97851>.

## Solutions

NSW has important measures in place to promote affordable rental housing, through the Affordable Housing State Environmental Planning Policies and initiatives under the *Future Directions for Social Housing in NSW*, particularly the Social and Affordable Housing Fund and Communities Plus. These measures should be positioned to explicitly address the needs of NDIS participants (e.g. by ensuring there are *accessible* housing targets and recognition of people with disability as a target group).

The NSW government should also ensure that mainstream housing supports, such as tenancy advice and private rental market assistance, are accessible to NDIS participants, especially in recognition of those moving into new housing arrangements with NDIS support and becoming direct tenants (with the separation of housing and support in disability housing models) – some participants will need help to access the market and build their capacity to maintain their tenancy obligations.

The NSW government also needs to monitor the provision of “last resort” options for NDIS participants, and issues that arise, should housing arrangements break down - for example a parent carer can no longer support their adult child, a group home tenancy breaks down, a NDIS participant is hospitalised, their support needs change and their current home is no longer suitable. For NDIS participants with high and complex needs in particular, the risk of housing failure is high and the impact of inadequate urgent housing options and providers can have serious consequences.

As NSW has reached full transition to the NDIS, the NSW government needs to be confident that adequate market provision is in place for urgent housing changes for participants, otherwise the only option will be in costly state government services – typically hospitals, but also the judicial system and/or crisis accommodation services. The consequences for individuals will be extreme – unnecessary incarceration, extended hospitalisation, nursing home admission leading to psychological harm, impact on physical wellbeing and loss of community and family bonds. The NSW government needs to pay close attention to risks of service gaps and the consequences of NDIS participants losing their housing.

The NSW government is no longer a funder and provider of disability supports, with the transition to the NDIS. But it needs to maintain an ongoing role in monitoring and understanding how the NDIS is contributing to improved lives for NSW citizens and be proactive about addressing potential risks for NDIS participants. In relation to housing, the NSW government must not abrogate its responsibilities in improving housing options for people with disability. NSW has some positive housing initiatives in place, but there needs to be more explicit recognition of the housing needs of people with disability in the targeting of housing related supports and new affordable housing supply.

# The Interface Between Disability Supports and Health Services

With the roll-out of the NDIS, gaps in disability supports have arisen in the interface of health systems and the NDIS in all jurisdictions. The Summer Foundation's work with key health and NDIS stakeholders around Australia has identified significant problems that prevent the two systems from working effectively together. Inadequate disability supports result in greater pressure on health services to support people with complex needs while they are using health services, and to meet hospital discharge targets.

It is being widely reported that the interface between health and disability is not working as well as it needs to for people with high and complex needs and this is having a serious impact on their health. Add to this a lack of knowledge and understanding amongst planners of the NDIS as well as the changes in mainstream nursing services, the consequences are serious. They include hospitalisations for some (due to urinary tract infections or skin breakdown) and others are experiencing delays in hospital discharge or inappropriately admitted into residential aged care. The impact of a broken interface between disability and health can have serious consequences as is demonstrated in Jarrod's story:

---

*Jarrod had a cerebral hemorrhage in his mid 40's, resulting in an acquired brain injury, complex disability and clinical care needs. Jarrod's needs couldn't be met in the community and he was discharged from hospital to residential aged care (RAC). The facilities Registered Nurse (RN) oversaw Jarrod's catheter management and enteral feeding. Personal Care Assistants (PCAs) monitored Jarrod's, skin integrity, blood pressure and sugars.*

*Jarrod's wife successfully submitted an Access Request Form to the NDIA in early 2016 and Jarrod had a planning meeting in May. During this time his wife located an accessible housing opportunity. The first goal in Jarrod's NDIS plan was to exit RAC and return to live with his wife and children in the community, with appropriate supports from the NDIS.*

*Jarrod's NDIS plan did not provide funding for Jarrod's clinical care. It is likely that the NDIS Planner assumed that Jarrod could access the day-to-day support he needs with feeding and continence, and oversee the management of his skin integrity blood pressure and sugars from health services in the community. Jarrod and his family found that the health system was unable to provide these services. Poor coordination of Jarrod's personal and clinical care resulted in multiple hospital admissions from preventable conditions during his first three months of community living. On discharge from hospital Jarrod was declined HACC funded community nursing on the basis that he was an NDIS participant. Jarrod's NDIS Support Coordinator has been forced to use funding allocated for other support areas to purchase services from a private nursing provider.*

---

Jarrod's situation highlights some of the current problems with the interface between the NDIS and Health.

Individuals with complex disability and clinical care needs generally experience their clinical care needs as part and parcel of their disability. Their ability to exit RAC and live in the community hinges on their access to home based clinical supports.

Jarrod's interim solution is an unsustainable individual response to a systemic issue. Without a systemic solution, many young people may not be able to exit RAC, and those who do, may find that their community living arrangements are precarious, clouded by the constant threat of their readmission to RAC to secure access to clinical care.

Gaps in disability supports cause significant financial strain as well as impacts on staff resources. Queensland has recently calculated that the daily cost of supporting people in hospital due to NDIS-caused delays in discharge, are 23 times greater than the daily cost for NDIS supports for a person living in the community.<sup>8</sup>

NSW committed to a rapid 2-year roll out to full implementation by 2018. Given that NSW has the largest population of any state, the rapidity of the major system change required has given limited time for preparation, learning new procedures and skill sets. Feedback from health sector staff in Summer Foundation consultations, workshops and training indicates that the speed of implementation has compounded many of the problems shared with other states.

### Health systems lack knowledge of the NDIS pathways and processes

Health practitioners are unfamiliar with the NDIS, its principles, operations and procedures. Health treating teams continue to lack experienced staff to work with patients through the prescribed stages of the NDIS pathway. Current hospital discharge teams report that they struggle with the complexities of the NDIS and require additional staff resources to meet NDIS system demands.

In 2018 the Summer Foundation carried out an online survey with 105 health sector staff of Local Health Networks in Liverpool and Wagga to establish their level of knowledge and confidence of cross sector collaboration. A significant number of NSW health sector staff members confirmed that they were not confident in their knowledge of how NDIS supports work for people with complex needs after their hospital admission.

- 48% in Wagga and 37% in Liverpool said their understanding of hospital discharge with NDIS supports was very little
- 80% in Wagga and 61% in Liverpool reported that they were not very confident in discharge planning with NDIS.

In one NSW forum,<sup>9</sup> 150 questions were received from the audience indicating a level of confusion and thirst for information. Feedback was given by participants that the health sector in NSW does not wish to have a role in managing patient engagement with the NDIS. One said: *'NSW Health has told staff to handover clients. You're saying to keep working. Please give guidelines.'*<sup>10</sup>

---

<sup>8</sup> Queensland Audit Office (2018) The National Disability Insurance Scheme Report 14: 2017-2018

<sup>9</sup> Both the online survey and health sector forum were part of a Summer Foundation's ILC-funded project designed to build capacity in hospitals to provide effective discharge planning support to young people (<65years) with complex needs so they can transition to the community with support from the NDIS.

<sup>10</sup> Nous (2018) Evaluation of the Increasing Capacity of the Health and Aged Care systems program – Formative Report. Summer Foundation (unpublished).

Forum participants noted that there have been increasing delays in NDIS approvals for home modifications, assistive technology and specialist supports, which makes it difficult to discharge participants back to their current housing. The result is longer stays in acute and or sub-acute beds, causing increases in pressure from Local Health Networks that cannot release those beds to meet their incoming demand. The delays can also result in young people being admitted into Residential Aged Care.

### **NDIS processes slow down hospital discharge**

NSW hospitals are facing delays in discharge due to lack of timely NDIS access determination, approval of plans and plan activation. This results in unnecessarily long hospital stays sometimes lasting for months.

Health clinicians experience difficulties in determining the timing of activating Access Request Forms (ARF). They are required to synchronise the timing of the ARF submission with their clinical processes of identifying when a person has permanent and lifelong disability. As this process of identification can be a drawn-out, health practitioners can find it difficult to make early submission of ARFs – despite NDIA advice that this is an important strategy to allow the NDIA to respond in a timely way.

During preparation for discharge, long delays in NDIS approval for home modifications prevent patients with complex disability support needs from returning home when ready.

Delays in NDIS approvals for SDA in plans also result in long hospital stays for people who require alternative accommodation, and at worst, ‘forced’ admission to Residential Aged Care.

These problems for health providers in managing delays in discharge for people with complex support needs are experienced in many jurisdictions.<sup>11 12</sup> The QLD government reported delays of up to 351 days, with an average of 172 days for a group of 13 patients.

### **NDIS delays in pathway planning and reviews interfere with NDIS navigation**

Timeframes for NDIS access and planning have become a major hurdle. Patients with disability in hospital or rehabilitation can experience long waits of 12 weeks or more for completion of engagement, planning and plan implementation.

Current NDIA timeframes for access (21 days), planning (no timeframes) and reviews (taking up to 9 months) do not align with rapid responses required.

Patients can wait for a final NDIS access decision for two years if appeals are made.

There have been increasing delays in NDIS approvals for assistive technology and specialist supports, which makes it difficult to discharge participants back to their current housing. The result is longer stays in acute and or sub-acute beds, causing increases in pressure from Local Health Networks that cannot release those beds to meet their incoming demand. The delays can also result in young people being admitted into Residential Aged Care.

---

<sup>11</sup> Ibid

<sup>12</sup> ACT Government (2017), ACT Government Submission to the Productivity Commission Review of the Financial Sustainability of the NDIS.



Processes and pathways that identify patients at risk of delayed discharge (i.e. are likely to have long-term disability needs) are only now beginning to emerge. As this is being worked through discharge delays continue.

### **NDIS plans do not cover needed supports**

Health worker recommendations for necessary supports are not always translated into participants' plans. NDIS planners can lack knowledge of the health system and understanding of participants with complex health and disability support needs. With inadequate training in the use of clinical expertise, planners can fail to incorporate key support recommendations that enable people to live an ordinary life in their community. This can have significant impacts on participants, and increase the workload on health providers involved in requesting urgent plan reviews. This problem is exacerbated when support coordination is not available to facilitate collaborative planning between clinicians and NDIS planners.

Initial plans can contain inadequate levels of supports e.g. support coordination hours only allocated for SIL application not for other aspects of plan implementation support. After reviews, second plans may incorporate cutbacks on supports and cause extra burden on informal supports and health services.

Participants are facing service gaps when recommendations for supports that are related to their functional impairment, but require nursing and allied health worker to deliver, are not included in their plans.

Greater strain has been put on NSW health and housing systems because of lack of approval for SDA funding in plans, and the lack of alternative accommodation.

### **New gaps in services have emerged**

NSW state-based disability services were withdrawn on completion of the full rollout. This resulted in the cessation of services provided by FACS and ADHC leaving gaps in knowledge and expertise in disability housing, support services and specialist programs.

The decommissioning of the FACS vacancy management service in July 2018 has left a major gap in this essential function. People with disability and their families in NSW can no longer access support from this specialist service when tenancies are at risk and there is a potential need for alternative accommodation. As the vacancy management service acted as a provider of last resort, there is no longer anyone available to turn to in crisis situations where tenancies are jeopardised. This can affect health providers as emergency departments can be used as 'last resort' when health issues are involved.

The transfer of NSW funding for Community Care Support Packages (CCSP) has reduced access to supports covered previously by this program both for NDIS participants who have been allocated less in their plans, and for non-eligible people with disability. For North Sydney Local Health District, less than 20% of people who previously accessed CCSP supports, can now access the equivalent NDIS funding.

## The NDIS system fails to provide rapid responses when needed

Health sectors of all states are experiencing greater strain as the NDIS is not structured to deploy resources quickly in response to changing patient needs. Currently there is no prioritisation procedure for people with complex needs that involves a dedicated team response such as that previously included in the Hunter NDIS pilot for people large residential centres. Participants with high and complex needs can experience unanticipated events, for example for urgent equipment upgrades or repairs. There is often no funding to cover emergencies if not already identified in a participant's plan. Health providers can be left to cover emergency costs, particularly if there is no plan in place.

There is also no effective capacity in the NDIS to prioritise the needs of those waiting for a rapid plan review in hospital settings. Requesting an urgent review does not guarantee urgent attention. In a health setting, progress through the pathway may need to be slowed down because of fluctuating health conditions, or sped up when discharge is imminent. A tailored NDIS response is needed to take these factors into account for people with complex needs.

## Operational guidelines for COAG Principles are not in place

Health practitioners in all jurisdictions are prevented from responding effectively in the NDIS domain by confusion in the application of the COAG Principles<sup>13</sup>. While these Principles contain details of the respective roles of NDIS and health, clinicians report that they are being interpreted in different ways. One health worker said: '*COAG Principles are extremely useful, but I have had the NDIA say "they're just principles and we have interpreted them differently to you".*'

## Conclusion

Health systems have experienced demands for rapid skills and knowledge development about the NDIS. They struggle with the pressures of synchronising their key procedures such as hospital discharge imperatives with NDIS pathways. Health clinicians need to manage the impacts of incomplete NDIS planning outcomes and of new gaps arising in disability services as well as system inflexibility in meeting the variable time frames associated with people with complex health needs. Finally, the ongoing lack of clarity in respective responsibilities of the two systems causes confusion and people with complex needs of falling through the gaps.

---

<sup>13</sup> Principles to Determine the Responsibilities of the NDIS and other Service Systems COAG 2015

# Recommendations

## Plan development and Implementation

Plan development and implementation requires significant support and for many YPIRAC their NDIS packages are not being fully utilised until this support can be provided. We recommend that:

- a) Specialist planners are available who are trained and focused on the needs of YPIRAC.
- b) YPIRAC are provided with support coordination to assist them with their Access Request and pre planning. The same support coordinator should be available to support them at their planning meeting, to work with them on plan activation and to identify appropriate alternative housing solutions.
- c) YPIRAC with a goal of leaving aged care should also receive Allied Health Assessment funding for Exploring Housing Options with a plan review after 3 months to consider alternatives to aged care.
- d) All YPIRAC are offered ongoing support coordination.
- e) The New South Wales government prioritise an investment in workforce development of support coordinators including training in working with people who have complex disability and health needs and support to develop expertise in exploring accessible housing options for this cohort.
- f) The New South Wales government fund advocacy services to assist with Access Requests, preplanning support and advocacy through the access and planning process.

## Housing

All levels of government and the NDIA need to work together to improve access to accessible and affordable housing for NDIS participants.

We recommend that COAG amend the National Construction Code to require all new homes to be built to Liveable Housing Australia Guidelines.

We recommend that the NDIA:

- a) Commit to a 28-day turn around for decisions on SDA for YPIRAC where the participant has identified an immediate SDA option and already requested SDA funding in their plan.
- b) Amend the Quarterly Report to include the number of YPIRAC who are receiving Specialist Disability Accommodation funding in their plans.
- c) YPIRAC who wish to reside in SDA should be deemed to meet the SDA Eligibility Requirements. Young people who were assessed by an ACAT for a permanent aged care admission should be deemed to satisfy the SDA Rules requirements for an Extreme Functional Impairment, and also that they have explored all alternative housing options.
- d) Fund interim or 'step down' housing options, when long-term housing options are not available or when a step down option is needed to assist the person to transition out of aged care.

The New South Wales government must actively respond to the unmet and increased need for accessible and affordable housing for NDIS participants with a disability housing strategy that will:

- a) Ensure existing NSW government measures meet the needs of people with disabilities. For example, Affordable Housing State Environmental Planning Policies and initiatives under the Future Directions for Social Housing in NSW, particularly the Social and Affordable Housing Fund and Communities Plus should be positioned to explicitly address the needs of NDIS participants. We recommend a requirement of 95% Gold level and 5% Platinum level (Liveable Housing Australia Guidelines) for all new social housing developments.
- b) Ensure that mainstream housing supports, such as tenancy advice and private rental market assistance, are accessible to NDIS participants.
- c) Include action for the development of “last resort” options for NDIS participants, should housing arrangements break down, and a rapid housing response is required that is not available in the market.
- d) Undertake a detailed stocktake and assessment of the existing houses, including occupancy and tenant satisfaction
- e) Assess the future SDA market in New South Wales under the NDIS, drawing from Summer Foundation’s demand study and consultation with people with disability in the SDA cohort
- f) Consider the potential suppliers in the future SDA market and focus on areas of likely market failure

## Health interface

To achieve a well-coordinated and functional health and NDIS interface for people with complex support needs, we recommend the following actions:

1. Clarify the policy settings for the NDIS-Health interface, by:
  - a) Investigating and track service gaps created in the transition
  - b) Committing funding to resolve the identified gaps in services
  - c) Reviewing and updating the COAG principles based on evidence of the emerging gaps and develop operational guidelines to reduce confusion arising from interpretation of the principles.
  - d) Establishing joint escalation procedures and processes for people with complex support needs.
  - e) Establishing an NDIS-health interface advisory group of community stakeholders to inform the NDIA and Senior Officials about the operation of the interface
2. Create a national data collection and reporting framework to monitor outcomes for people with disability in the health system that would:
  - a) Provide post discharge follow-up to measure outcomes and improve processes
  - b) Reports publicly on the reasons and length of time NDIS participants stay in hospital beyond their discharge date s
3. Build the capacity of health services to support people with disability leave hospital well in the NDIS context
  - a) Fund and mandate training for health providers to ensure competence in NDIS

- (principles, processes and terminology), general disability awareness and supports for people with complex support needs; and the use of Rapid Response tools designed for practitioners.
- b) Fund *discharge planning communities of practice* across the country to share expertise and resources, and support local health champions who are NDIS experts and can support complex discharge processes.
  - a) Developing and implementing assessment protocols to identify early people with complex disability support needs who will face barriers to discharge and develop processes to escalate barriers early.
4. Build NDIA's capacity to support people with complex health support needs, by:
- a) Creating a fast track system for people with disability residing in hospitals to have their access request processed urgently and planning commencing within 2 weeks.
  - b) NDIA and hospitals partnering in developing NDIS plans for participants in hospital where hospitals develop a draft NDIS plan that is reviewed by NDIA specialist planners;
  - c) Identifying NDIA specialist planners to work with people with complex support needs in acute and sub-acute settings who:
    - Undertake training on clinical support requirements of people with complex disability and health needs;
    - Are directly contactable by health services.
5. Develop a set of funded supports to meet the needs of people with disability leaving hospital in a more timely way, by NDIA:
- a) funding Support Coordination and Specialist Support Coordination while participants are in hospital, including through short term plans;
  - a) funding interim or 'step down' housing options, when long-term housing options are not available or when a step down option is needed to assist the person to transition out of hospital.
  - b) fast-tracking Specialist Disability Accommodation decision making for people with complex support needs exiting the acute and sub-acute health sector, to address the absence of suitable housing.
6. Health services to assist people with complex support needs to leave hospital well by:
- a) supporting people with disability to undertake 'pre-planning' while in hospitals, including through education and information materials about the NDIS
  - b) building relationships with other service providers (especially primary care, housing, support coordination and disability support providers) to assist people with disability to seamlessly transition from hospital back to the community.