



Insight into Design Issues in the Health and NDIS Systems Interface

SUMMER FOUNDATION SUMMARY REPORT TO
DEPARTMENT OF HEALTH AND HUMAN SERVICES
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The NDIS and the health system will work together at the local level to plan and coordinate streamlined care for individuals requiring both health and disability services recognising that both inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other. (COAG Principles to Determine the Responsibilities of the NDIS and other Service Systems, Nov 2015)

Tom Worsnop, Executive Manager, Practice

Email: tom.worsnop@summerfoundation.org.au

George Taleporos, Policy Manager

Email: george.taleporos@summerfoundation.org.au

Tel: 1300 626 560

Contents

EXECUTIVE SUMMARY	3
Key Issues.....	3
Key Enablers.....	4
Recommendations	4
Recommendations to Improve Interface Capability and Capacity.....	4
Recommendations to Improve Capacity for Discharge to the Community	5
BACKGROUND	6
About the Summer Foundation and Summer Housing.....	6
Setting the Interface Context.....	6
The Project.....	7
Purpose of this Paper.....	8
Methodology.....	9
Health System Issues.....	10
Knowledge of the NDIS and NDIS pathways	10
Gaps in knowledge and expertise of disability	11
NDIS System Issues	12
NDIS delays in pathway and reviews	12
NDIS planners and support coordinators’ lack of clinical expertise.....	12
NDIS resources are activated too late to support participants	13
NDIS systems fail to provide rapid responses when needed	13
Interface Issues:.....	14
Operational guidance for COAG Principles are not in place	14
Communication between health and the NDIS is not streamlined	14
Collaboration between systems is under-resourced	14
People with Disabilities Feel Disempowered.....	14
ENABLERS AND SOLUTIONS	16
Improve Interface Collaboration and Communication	16
Build Interface Capability and Capacity.....	16
Improve Alignment between Health and NDIS Timeframes.....	16
CONCLUSION: A VISION FOR A COORDINATED INTERFACE	18
RECOMMENDATIONS	19
To Improve Interface Capability and Capacity	19
Recommendations to Improve Capacity for Discharge to the Community	20

EXECUTIVE SUMMARY

The implementation of the NDIS requires significant changes to the way state-based health systems operate within the new national system. Recreating an effective interface between them has been difficult as inter-system policies and operational guidelines were not established prior to the NDIS rollout. In recognition of the work needed to develop new policies and practices to ensure that people with high and complex needs using health services are enabled to participate in the NDIS, the Summer Foundation was funded by the Department of Health and Human Services to carry out a project to demonstrate how the NDIS and health can collaborate better to minimise extended hospital stays and increase successful transition to community life for the target group.

This paper is part of the deliverables of the project. It examines the capacity, process and structural barriers that prevent coordination between the two systems and the issues specific to the NDIS/health interface, and provides solutions and recommendations for improving outcomes for NDIS participants with high and complex needs.

Key Issues

- Health systems face barriers to efficient discharge planning because of gaps in health workers' knowledge of the NDIS, and inadequate understanding of the support needs of people with disability and complex needs.
- Lack of escalation and prioritisation processes for people eligible for the NDIS interferes with timely discharge planning decisions by health workers.
- Health practitioners receive inconsistent messages from the NDIA about eligibility and what can be funded as 'reasonable and necessary' in NDIS plans.
- NDIA timeframes for access, plan reviews and planning do not align with rapid health responses to meet changing needs for the target group, causing delays in hospital discharge processes.
- NDIS planners and support coordinators lack necessary clinical expertise leading to failure to incorporate key support recommendations in plans.
- NDIS resources are activated too late for people in hospital who are ready for discharge, extending hospital stays and escalating unnecessary costs.
- Operational guidelines to clarify responsibilities contained in the COAG Principles are not in place.
- There are insufficient resources invested by health and the NDIS to support collaboration across multiple systems, and to coordinate individual planning processes for people with complex support needs.
- Capacity, process and systemic barriers can have negative impacts on the health and well-being of participants.
- Current system design has resulted in gaps in necessary disability and health supports.

Key Enablers

- Improving interface collaboration and communication can be enhanced by re-allocating or increasing staff resources in allied health teams, creating an NDIS contact/specialist role who can oversee and support transition to the community with NDIS support
- Building interface capability and capacity will be enhanced by providing access for all health workers to opportunities to learn about the NDIS and support services for those with complex needs.
- Building capability for NDIS workers will be improved by access to training on the clinical aspects of those with disability and complex needs, on health systems operations, and the use of clinical expertise.
- Health and NDIS timeframes can be better aligned by increasing NDIS support as early as possible, establishing an interim plan, and facilitation of support coordination hours prior to discharge.
- Better inter-system coordination can be achieved by health and NDIS collaborating on the co-design and implementation of a 'fast tracking' procedure with clarification of escalation.

Recommendations

To address the systemic and policy issues we have identified in this paper, and achieve the vision of a coordinated health and NDIS interface where people with disabilities and complex health care needs can more effectively remain in the community, or achieve more efficient discharge, we recommend:

Recommendations to Improve Interface Capability and Capacity

1. NDIA and health providers to recognise the need for staff resources that enable collaborative practices at the local level, to coordinate:
 - Continuity of participant supports pre- and post- discharge
 - Measures to identify and prevent service gaps between systems
 - Advocacy for NDIS access and early planning for people who struggle to navigate systems independently
2. NDIA and health to invest at the policy level to:
 - Monitor, track and understand service gaps created in the transition period
 - Frame escalation pathways for people with disability 'stuck' in health settings
 - Further refine understanding of COAG Principles and health responsibilities
 - Resolve gaps in services in the NDIS transition period, particularly new responsibilities created between health and NDIS and who pays for what
3. Health providers to resource and promote access for staff to training and information resources on:
 - NDIS processes and terminology
 - Disability awareness and supports for people with complex needs
 - Use of Rapid Response tools designed for practitioners¹

¹ Summer Foundation 2018: NDIS and Health Working Together, Getting the Language Right, Getting Ready for NDIS Planning

4. NDIS to:
 - a. Mandate training for NDIS planners and support coordinators on:
 - Health system operations
 - Clinical supports for people with disability who have high and complex needs
 - The use of clinical advice in plan development
 - b. Identify specialist planners from local NDIA offices to:
 - Work with people with complex needs in acute and sub-acute settings
 - Introduce early support coordination, available prior to discharge
5. Health system to assist people with complex needs by:
 - Making education and information materials about the NDIS available to them on admission to hospital
 - Building the expertise of health staff so that they are able to familiarise people with disability to NDIS systems
 - Work on assessment to identify early complex cases or those who may require Rapid Response in their plans
6. Both health and NDIS incorporate escalation design for their own internal systems and processes and share this information with each other so everyone can use it effectively.
7. COAG/NDIA to review operational guidelines to reduce confusion arising from interpretation of the COAG Principles.

Recommendations to Improve Capacity for Discharge to the Community

8. NDIA to incorporate a 'fast tracking' category for people in health settings who have been identified as having permanent and significant disability. Timelines determined in consultation with health system and discharge planners.
9. Health services to identify local champions or NDIS experts within discharge teams, to lead and support patient engagement with the NDIS.
10. In conjunction with health providers, NDIA to increase system flexibility to enable:
 - An early plan to be approved to secure earlier support coordination support for participants
 - Identification and allocation of NDIA planners with expertise in supporting people with complex health and disability support needs, and provide direct telephone numbers and email addresses to streamline access and planning processes
11. In conjunction with health practitioners, NDIA to explore 'step down' accommodation options, such as increasing residential respite, and/or other transition accommodation options to assist with young people at risk of being discharged to RAC.
12. NDIA to promote market growth in SDA for people with complex needs exiting the acute and sub-acute health sector, to address the absence of suitable housing.
13. Governments to develop a national strategy to build the capacity of community and primary health services across the nation to ensure that people with complex health-care and disability support needs are not subject to unnecessary hospital admission

BACKGROUND

About the Summer Foundation and Summer Housing

The Summer Foundation, established in 2006, 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 live where and with whom they choose, with access to high quality housing and support options that enhance health and wellbeing and participation.

Our Mission is to create, lead and demonstrate long-term sustainable systems change that stops young people from being forced to live in RAC because there is nowhere else for them.

Providing the housing and support for people with complex needs, and improving the interface between the disability and health sectors is necessary if we are to stop young people from being forced into RAC.

We are committed to improving policy and practice in the health system and in the NDIS so they work together as smoothly as possible.

Setting the Interface Context

As one of Australia's most significant national reforms of the past half-century, the NDIS represents massive system change. From its early pilots around Australia to the present stage of nearing completion five years later, the NDIS rollout has progressed with great speed through the stages of systems change in the introduction of the new scheme.

Previously, state jurisdictions held the responsibility of disability services provision. Cross-departmental relations made legislation, policies and procedures easier to implement across departments of one jurisdiction. The implementation of the NDIS disrupted this structure. It mandated significant changes in the way state-based health systems (and the people, families and disability services they were accustomed to working with) connect and collaborate with the new national system. New inter-sectoral and inter-governmental relations were required.

Massive change has brought massive challenges. Due to the NDIS-rollout timelines, there was insufficient time to set in place structures to synchronise new interface relations. Part of the challenge is that the structures need now to be developed and refined while the NDIS is being developed, refined and changed through its practice.

With the new role of the Commonwealth new boundaries have been drawn in the disability sector. Health's role in the disability sphere must now meet its own jurisdictional imperatives as well as the tightly drawn boundaries of roles and structures of the NDIS.

Major systems change, new inter-governmental and inter-sectoral relations and imposed timelines set the context of the interface issues discussed here.

The Project

The Summer Foundation was funded by the Department of Health and Human Services

(DHHS) to carry out a practical project to explore and demonstrate how the NDIS and health can improve their collaboration for people with high and complex needs using health services. In the case of people with disabilities and complex support needs in hospital, this means avoiding extended hospital stays and maximising the chances of successful transition to life in the community.

The target group for this report is younger people, aged from 18 to 65, with disability and complex support needs in the health system. By this we mean those whose disability, functional deficits or limitations may involve any combination of physical, sensory, or cognitive elements which impacts on mobility and daily activity, communication and social interaction, decision-making and memory, and/or related functioning. They are likely to experience lifelong impairments as a result. Typical diagnostic examples include acquired brain injury, spinal cord injury, amputation, sensory failure, and neurological disease such as Multiple Sclerosis, Parkinson's or Huntington's. Complex care needs also include situations that require multi-system input and coordination from disability services, community services, allied health, hospital, housing and the NDIS.

The project focuses on people whose changing circumstances will require a rapid and coordinated escalation of supports, because they:

- Acquire a disability through trauma or serious illness requiring hospitalisation; or
- Have an existing disability and their health status has significantly deteriorated; or
- Have an existing disability and their life circumstances change with the reduction or cessation of the sources of support they have had in the past.

We have developed a Rapid Response Model (RRM) and a set of [practical tools](#) to assist health workers and participants to work with health and the NDIS, and disseminated these through a series of workshops and professional development activities (see Attachment for a description of each tool).

The RRM focuses on successful planning, including for the 'what if?' and an effective combined health-NDIS response, specifically:

1. Pre-empting and planning for changing support needs when health conditions and risks associated with a person's disability are likely to result in changes in their health status (e.g. when a person experiences the onset of acute severe infection in their suprapubic catheter site).
2. Anticipating and preparing for significant changes in circumstances, and associated increased support needs, that place a person with disabilities and complex support needs at risk of admission to hospital (e.g. when a person's partner and primary carer leaves the relationship).
3. Developing an early intervention response for sudden onset of disability (e.g. when a person has a fall and sustains acute head trauma requiring admission to hospital).

Points 1 and 2 are about existing NDIS participants. Point 3 concerns people who will be new to the NDIS. By concentrating on all three areas to explore better approaches, the project is seeking to:

- Build the capability of the health system to understand the NDIS, and to support participants to achieve high quality and successful NDIS plans
- Realise the potential of the NDIS to work with people when they come into the health system, and to support them to plan and galvanise necessary supports while they move through that system
- Strengthen NDIS understanding of hospital processes, health-related disabilities, the role NDIS funding can play in preventing hospital admissions, supporting good hospital discharge, and ensuring reasonable and necessary supports are provided
- Improve integration of NDIS and health services and the processes they need to work through to support people
- Refine the RRM (and the tools to go with it) so that it is adaptable to different health settings, and flexible enough to be used in different jurisdictions.

Purpose of this Paper

Many issues prevent health and NDIS systems from meshing smoothly with each other. The purpose of this paper is to highlight design issues across NDIS and health systems that inhibit effective responses when people's circumstances or health status change significantly.

It addresses key enablers of change, and recommends what needs to be done to enhance this complex system interface. Specifically it aims to answer these questions:

- How effectively is the NDIS/health interface currently operating?
- Are there capacity, process or structural issues within the health system and within the NDIS that are preventing them from operating effectively together?
- What are the issues within the NDIS/health interface that are leading to poor outcomes for people with disability?
- What are the solutions that could help overcome these issues?

In conjunction with our practice work, we present this paper on policy development for health and NDIS systems.

Methodology

Evidence used in this report was gathered from a variety of sources, including this project and projects funded through other means, conducted by the Summer Foundation from 2016. Two projects in particular have been drawn on for information for this report: discharge planning forums conducted in 2016, and a current co-design project being undertaken in Barwon and Central Highlands NDIS sites.

Evidence has been gathered within the DHHS Rapid Response project involving consultations, journey mapping and open training sessions with people with disability, family members, health practitioners, support coordinators and NDIS planners. The Summer Foundation held four workshops in Victoria in 2017 with eligible or existing NDIS participants who had been recently discharged from hospital after either a sudden onset of disability, or sudden change in health status requiring changes to support or living situation and hospital admission. Seventeen participant journeys through the health setting were documented illustrating their experiences from crisis point to discharge, and their quotes are included here.

Summer Foundation project workers held a series of workshops on service models and development of tools with 31 Victorian health practitioners from Monash Health, Dandenong, Royal Talbot Rehab Centre (Austin Health), Kew, and Caulfield Hospital (Alfred). Feedback from these workshops and from 220 participants in five discharge-planning forums held by the Summer Foundation around Australia in 2016, also informed this paper.

Finally the paper incorporates strategic advice provided in a workshop with 11 Summer Foundation key informants involved in pilot projects.

CURRENT NDIS AND HEALTH INTERFACE ISSUES

NDIS rollout across Victoria started in the trial site of Barwon in 2013 with new sites continuing to be rolled into the scheme up to 2019. There is now a wide range of practical experience of the scheme across Victoria. However, significant capacity, process and structural issues within the health sector and the NDIS are currently preventing the two systems from operating effectively together. On the ground, they appear to be uncoordinated and disconnected for participants and health workers.

In general, the Summer Foundation's experience in newly rolled regions has been reports of long delays in access and planning, at least partly due to a high volume of applications in the rollout period. Once initial rollout has been completed, some regions have experienced improved and more timely access to NDIS pathways.

Interface issues and gaps in services continue to be problematic with on-going delays in approvals for home modifications, assistive technology and specialist supports. Suitable housing for people with disability continues to be a persistent gap across the state, affecting timely discharge.

With respect to younger people with complex disability and support needs and rapid changes in health or circumstances, evidence from trial sites indicated that the new interface between the NDIS and the health system was not nimble enough to effectively deal with demand. Sudden or rapid changes in health or circumstances often increased the risk of re-admissions into hospital for this cohort, due to the slow response speed in approvals and capacity to access increased supports and services required in these situations.

Health System Issues

Knowledge of the NDIS and NDIS pathways

Clinicians have needed to become familiar with the NDIS, a radically new system, and have detailed knowledge of its operations and procedures, in a very short time frame. Health treating teams continue to lack experienced staff to work with patients through the prescribed stages of the NDIS pathway. Adjustments to the focus and specialisation of hospital discharge practices and staff time have had to be found to assist people to navigate the complexities of the NDIS. *'We're having to work longer hours and de-prioritise other things.'* Hospitals report that they require additional staff resources to meet NDIS system demands. As one clinician said: *'OTs and social workers end up being care coordinators, therapy providers and planners. It's overwhelming, and a huge amount of time for everyone.'*

Health workers' inadequate knowledge of the NDIS system has resulted in the use of 'trial and error' practices, rather than informed and documented procedures, with NDIS pathways continuing to adjust as the scheme matures. Where health workers do not have sufficient competency in NDIS terminology, their recommendations have been less likely to be approved in participant plans. Inadequate knowledge and lack of hospital resources has also lead to health workers unnecessarily completing two different discharge processes, for hospital and the NDIS, constituting an extra burden on staff workload.

Well-defined and clear escalation pathways and processes that address:

- Identifying/assessing those at risk for delayed discharge (i.e. complex cases), and
- Prioritising cases within hospitals that require escalation

are only beginning to emerge now and continue to need work and resources to disseminate knowledge and improve processes. As this is being worked through discharge delays have continued.

Gaps in knowledge and expertise of disability

Health systems have historically lacked adequate staff time and expertise to support people with complex disability in the hospital setting. The introduction of the NDIS with its major paradigm shift to choice and control, and functional compared to clinical and focus on capacity building, has exacerbated this issue. Many health workers have still not accessed information on the support needs of people with disability with complex needs, and how their needs might be met under the NDIS. Many have not been exposed to general disability awareness education, or information on the responsibility mainstream health systems now have to be accessible to people with disability.

Added to this, health clinicians also face difficulties in determining the timing of activating Access Request Forms (ARF) as this 'point in time' step is difficult to synchronise with clinical processes of identifying when a person has permanent and lifelong disability. Advice that early submission of ARFs is an important strategy to allow the NDIA to respond in a timely way, has therefore not been consistently achieved and has contributed to delays.

Historically health has planned for immediate discharge needs after addressing acute and sub-acute needs, but now with the NDIS discharge planners need to incorporate expertise about and planning for life-long disability. Health providers now require capacity building in order to better plan supports in participants' NDIS plans, and cater for rapid response to sudden changes in circumstances or health needs, to avoid re-admission. In the words of a clinician: '*We used to be planning for a period soon after discharge, now we are trying to predict their need 12 months down the track.*'

With State disability protocols disappearing through the transition to the NDIS, another gap this has created is expertise in disability housing and searching for housing options for people with disability and complex care needs. This has meant that increasingly health staff have been required to fill this gap.

One practitioner said: '*Everyone's coming into the NDIS with a degree of blindness.*'

NDIS System Issues

NDIS delays in pathway and reviews

Health processes and NDIS participant pathway processes are mismatched. The time required to complete NDIS participant pathway phases for setting up disability supports has caused delays in meeting hospital discharge targets. Patients with disability can experience long waits of up to 12 weeks or more for the processes of engaging, planning and plan implementation.

Timeframes for access and planning have become a major hurdle; however, there is an expectation that once the scheme reaches full rollout with everyone on-board, delays will reduce. This needs to be monitored carefully, to ensure it does occur.

Having said this, current NDIA timeframes for access (21 days), planning (no timeframes) and reviews (taking up to 9 months) do not align to rapid responses required for the target cohort – those with high and complex support needs.

Health workers have not been able to rely on timelines set by the NDIA being met, and consequently, have been unable to predict how long each NDIS stage will take to be completed. As one health practitioner commented: *'Reasonable wait times are defined differently by the health sector and the NDIS.'* This longer-term planning would be welcome, but for the people with complex support needs it has meant remaining in health settings, where their disability support needs are not being met, and specialist disability supports are not delivered.

NDIS planning processes are slow and difficult for participants to navigate. They are caught in delays when their NDIS plan is activated too late to prevent discharge without supports in place. Participants report being stressed, apprehensive about the future, and less willing to request changes. One said:

'Everything has to go through so many people ...it takes so long.'

Jen*, mother of 13-year-old who sustained spinal cord injury

NDIS planners and support coordinators' lack of clinical expertise

Health worker recommendations for necessary supports are not always translated into participants' plans. NDIS planners lack detailed knowledge of the health system and understanding 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.

Participants were concerned when recommendations for supports that were related to their functional impairment, but required nursing and allied health worker to deliver, were not included in their plans. One commented:

'Why are they (NDIS) questioning the experts like the OTs? Why would we ask for things we don't need?'

Jen*, mother of 13-year-old who sustained spinal cord injury

There is a lack of consistency in messaging and outcomes from the NDIA that creates problems. Health practitioners receive inconsistent messages and information from NDIS planners on eligibility and 'reasonable and necessary' supports. This has eroded their confidence in the understanding the NDIS. Health workers commented: *'You get different answers each time you ring', 'the goal posts keep changing', and 'there is confusion between short and long term goals, and how many goals they want'*.

The NDIS is not well understood yet, and patients and their families need assistance to understand it. Health practitioners are still learning and are not always best placed to provide this information to new participants. Differences in language commonly used by each of the two systems, navigating between case planning and goal setting, understanding clinical prescriptions for support and equipment and how that fits into achieving life goals, require attention. Also, new gaps in services have emerged, in some instances where State disability services have previously provided fill-in options that can no longer be funded under the NDIS framework.

NDIS resources are activated too late to support participants

Many participants require NDIS resources to assist them early in their hospital stay. Where they did not already have a plan in place, support coordination was not available until their plan had been approved. They needed the services of support coordinators early to navigate the interface between hospital and the NDIS if they did not have advocates, and/or had reduced cognitive and physical resources.

There have been increasing delays in NDIS approvals for home modifications, assistive technology and specialist supports, which mean discharge back to prior housing or (where available) to more appropriate stock, cannot occur safely in the timeframes to suit hospital discharge demands. Longer stays in acute and or sub-acute beds have resulted, and are causing increases in pressure from LHNs who cannot release those beds to meet their incoming demand.

NDIS systems fail to provide rapid responses when needed

The NDIS system design does not include a function to deploy resources quickly in response to changing patient needs. Participants with high complex needs can experience unanticipated events, for example for urgent equipment upgrades or repairs. There is no fund for brokerage for additional services or to cover emergencies if not already identified in a participant's plan.

One participant said:

'They should allow a certain amount of dollars to use in a crisis situation. It's very rigid.'

Sarah*, mother of child with autism who was admitted to hospital due to deteriorating health

There is also no effective capacity in the NDIS to prioritise the needs of those waiting for a rapid plan review. 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.

Interface Issues:

Operational guidance for COAG Principles are not in place

Health practitioners are prevented from responding effectively in the NDIS domain by confusion in the application of the COAG Principles². While these principles are detailed in regard to 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”.’*

NDIS planners and regional staff are not clear on the roles and responsibilities of the NDIS for the continuation of funded supports to participants. Although the COAG Principles define the responsibility of NDIS to provide supports in hospital where the participant has complex communication needs or challenging behaviours, these terms require interpretation when applied to particular situations.

Communication between health and the NDIS is not streamlined

Health workers have been unable to consistently access NDIS contact details. They have had difficulty in getting information from the Contact Centre. Health workers have spent considerable amounts of time trying to get information and advice and following up issues on behalf of patients from the right person at the NDIA. In addition health clinicians have been unable to access NDIS planners prior to planning meetings, during plan reviews and in the post plan approval phase. Discontinuity of NDIS planners and support coordinators interferes with health workers’ ability to discuss individual participants effectively and progress positive discharge outcomes for participants.

‘Things were held up because of miscommunication between health service and NDIS.’

Peter*, 60-year-old man with Guillian Barre Syndrome

Collaboration between systems is under-resourced

As a national system the NDIS does not cope well with facilitating NDIS resources for engaging in the specialised space of collaborating with health on local practices. Regional staff resources are stretched and NDIS roles with specialist inter-system negotiation skills are not readily available. While there has been continuing effort to resolve issues between systems, at the coalface there are significant challenges that continue to be reported between health and the NDIS. While expecting that these can be resolved over time, particularly once the scheme is fully rolled out, a major reform of the scale the NDIS represents will require dedicated resources to ensure collaboration issues continue to be identified and addressed.

People with Disabilities Feel Disempowered

Many young people entered the health system knowing nothing of disability. They did not know what to expect, and found the NDIS processes incomprehensible. Some were totally unfamiliar with the ‘world of disability’ services, and needed to grapple with an unknown system while dealing with trauma, grief and uncertainty. Confusion and helplessness was exacerbated if they did not have good family support or advocates, or were not computer literate. One commented:

² Principles to Determine the Responsibilities of the NDIS and other Service Systems COAG 2015

‘Fear of the unknown along the journey has been the hardest part.’

Yvonne*, woman in her 50s, who lost the use of her lower limbs following an infection

Participants and their families found that health and rehabilitation practitioners, who were often their first point of contact, were lacking information about NDIS processes. They found that the hospital and the NDIS did not provide them with information and resources to smooth their progress through the steps of NDIS planning. They were not given information about links to disability groups and networks. There was no designated NDIA contact available in the hospital to meet with staff and participants to assist them to set realistic expectations.

‘The hospital made many promises. They didn’t communicate anything though.’

Jen*, mother of 13-year-old who sustained spinal cord injury

‘I thought there would be two-way communication between myself and the NDIS.’

Yvonne*, woman in her 50s, who lost the use of her lower limbs following an infection

ENABLERS AND SOLUTIONS

Improve Interface Collaboration and Communication

Coordinating health operations with NDIS pathway processes requires ongoing communication to achieve mutually agreed timelines and two-way communication on the progress of participants through connecting and planning.

Health providers can contribute to enhanced communication and collaborative practice by:

- Allocating an NDIS contact/specialist role or team in their setting, or being able to access an NDIS-embedded worker in their organisation, or making sure early support coordination is available
- Allocating resources for collaboration on individual pathway progress and on systemic improvements
- Collaborating on clarification of application of the COAG Principles
- Relationship-building between health and NDIS workers through recognition that they play a joint role in 'negotiating safe passage' through the health and NDIS systems.

Build Interface Capability and Capacity

Practitioners skilled in inter-system operations are needed. It is clear that there are several areas where the design of capacity building measures will improve the coordination of the systems and better participant outcomes. Health systems need to support securing of staff resources to meet increased workload demands. Health teams need to increase capability by accessing skills and knowledge development covering in-depth learning about the NDIS, its terminology, principles and objectives, and training on support services for those with complex needs.

Roles of NDIS regional staff, LAC staff and support coordinators will be enhanced through training in complex needs and disability, in how health systems work, and the use of clinical expertise in the planning process. Planners need to be familiar with the risks for people with complex needs of RAC or unnecessary hospital admissions that can arise from inadequate planning.

Improve Alignment between Health and NDIS Timeframes

From a health system perspective, there is the need to improve processes by supporting people with complex needs to test access as early as possible; facilitating local processes and strategies to support patients with NDIS pre-planning; advocating for an interim plan to enable early allocation of support coordination hours, and; building local relationships to access support coordination resources.

A key enabler would be for participants to be able to receive an interim plan to facilitate early support coordination supports.

There is a need for the NDIA to develop strategies jointly with the health sector to address uncoordinated processes in the health and NDIS interface. The NDIA can pilot system improvements such as enabling an interim plan function to release funds for support coordination early in the participant's hospital stay; setting agreed plan processing timelines to 'fast track' people with complex needs; and building more flexibility into participants' plans.

System improvements need to be made to enable NDIS and LAC planners to implement a 'fast tracking' procedure that includes a series of escalating steps to ensure the participant pathway is effective for people stuck in hospital. Agreed timelines must be set for NDIA roles in pathway steps in recognition of the high priority of people with complex needs in acute and sub-acute health facilities.

During the discharge process, transition for people from hospital or rehabilitation would be more effective if NDIS supports could start earlier in the health setting. This would reduce NDIS costs over time as health practitioners could fine tune their supports and reduce the need for plan reviews.

CONCLUSION: A VISION FOR A COORDINATED INTERFACE

People with disabilities, especially those with high and complex needs, have to connect with the NDIS as early as possible while in hospital and to be supported through their discharge planning with well-coordinated systems. Health staff need to increase their understanding and competence with the NDIS and the new framework and requirements that the scheme has introduced. These will enable the development of effective and responsive individual plans that incorporate clinical support, facilitate timely discharge, and ensure personal goals can be achieved.

Currently there are delays through engagement, planning and plan implementation for those newly entering the NDIS while in hospital and rehabilitation, cause blocking of progress towards discharge, and confusion and frustration for participants.

As concerning is the evidence that these delays, caused by poor system design and operation, can lead to preventable admission to RAC. When the systems fails to function optimally by providing timely and appropriate supports to people with high and complex needs, it results in the escalation of costs for health services, and unnecessary admissions to RAC. These costs can be contained and better outcomes obtained when young people with disability are diverted from RAC into their chosen accommodation option.

For optimal outcomes, both systems must be committed to the interests of the recipients of their services and a shared purpose to work alongside each individual so that both their health and disability needs are met. Evidence indicates that when this is identified as the common driver for all involved, it triggers cooperation and collaboration, even in complex environments.

We need the health system to recognise the importance of framing their interventions based on lifelong functional support, not simply safe discharge.

We need the NDIA to be more responsive and flexible and health providers to understand the language of disability and translate clinical advice into goals in individual plans so that positive outcomes for participants can be achieved. These outcomes include fewer unnecessary admissions to both RAC and acute/ sub-acute hospital settings.

Both systems need to better synchronise their operations, clarify policy barriers and continue procedure development, develop and maintain structures and resources for on-going collaboration, and jointly establish procedures for their shared responsibilities.

It is through joint collaboration and service delivery that young people with complex health and disability support needs will be able to live and meaningfully contribute to their communities. Longer term this will lead to increased opportunities for participants to participate in the workforce or within their community.

RECOMMENDATIONS

To address the systemic and policy issues we have identified in this paper, and achieve the vision of a coordinated health and NDIS interface where people with disabilities and complex health care needs can more effectively remain in the community, or achieve more efficient discharge, we recommend:

To Improve Interface Capability and Capacity

1. NDIA and health providers to recognise the need for staff resources that enable collaborative practices at the local level, to coordinate:
 - Continuity of participant supports pre- and post- discharge
 - Measures to identify and prevent service gaps between systems
 - Advocacy for NDIS access and early planning for people who struggle to navigate systems independently
2. NDIA and health to invest at the policy level to:
 - Monitor, track and understand service gaps created in the transition period
 - Frame escalation pathways for people with disability 'stuck' in health settings
 - Further refine understanding of COAG Principles and health responsibilities
 - Resolve gaps in services in the NDIS transition period, particularly new responsibilities created between health and the NDIS and who pays for what
3. Health providers to resource and promote access for staff to training and information resources on:
 - NDIS processes and terminology
 - Disability awareness and supports for people with complex needs
 - Use of Rapid Response tools designed for practitioners³
4. NDIS to:
 - Mandate training for NDIS planners and support coordinators on:
 - Health system operations
 - Clinical supports for people with disability who have high and complex needs
 - The use of clinical advice in plan development
 - Identify specialist planners from local NDIA offices to:
 - Work with people with complex needs in acute and sub-acute settings
 - Introduce early support coordination, available prior to discharge
5. Health system to assist people with complex needs by:
 - Making education and information materials about the NDIS available to them on admission to hospital
 - Building the expertise of health staff so that they are able to familiarise people with disability to NDIS systems
 - Work on assessment for identifying early complex cases or those who may require Rapid Response in their plans

³ Summer Foundation 2018: NDIS and Health Working Together, Getting the Language Right, Getting Ready for NDIS Planning

6. Both health and NDIS incorporate escalation design for their own internal systems and processes and share this information with each other so everyone can use it effectively.
7. COAG/NDIA to review operational guidelines to reduce confusion arising from interpretation of the COAG Principles.

Recommendations to Improve Capacity for Discharge to the Community

8. NDIA to incorporate a 'fast tracking' category for people in health settings who have been identified as having permanent and significant disability. Timelines determined in consultation with health system and discharge planners.
9. Health services to identify local champions or NDIS experts within discharge teams to lead and support patient engagement with the NDIS.
14. In conjunction with health providers, NDIA to increase system flexibility to enable:
 - An early plan to be approved to secure earlier support coordination support for participants
 - Identification and allocation of NDIA planners with expertise in supporting people with complex health and disability support needs, and provide direct telephone numbers and email addresses to streamline access and planning processes
11. In conjunction with health practitioners, NDIA to explore 'step down' accommodation options, such as increasing residential respite, and/or other transition accommodation options to assist with young people at risk of being discharged to RAC.
12. NDIA to promote market growth in SDA for people with complex needs exiting the acute and sub-acute health sector, to address the absence of suitable housing.
13. Governments to develop a national strategy to build the capacity of community and primary health services across the nation to ensure that people with complex health care and disability support needs are not subject to unnecessary hospital admission.

SUMMER FOUNDATION TOOLKIT PUBLICATIONS

Getting Ready for NDIS Planning: A toolkit for people with disabilities who have complex health and disability support needs

This toolkit is designed to assist people with disabilities and complex health and disability support needs (and their supporters) to be ready for NDIS planning. It is designed for people where the implications of their disability and health status call for specific recognition and tailored support to enable them to:

- Participate more fully in their communities and in life
- Avoid unnecessary admission to hospital if their health condition worsens or home or support circumstances change
- Be as well-prepared as possible if they are admitted to hospital and need to work with health practitioners and NDIS staff to make (or renew) NDIS plans

NDIS and Health Working Together: A guide to assist health and NDIS staff to work with people with disabilities – from hospital admission to discharge

This guide is designed to help health and NDIS staff support people with disabilities and complex health and support needs throughout their time in and transition out of hospital, and to do this in the best possible way. This means:

- All staff collaborating across health and NDIS systems, founded in shared knowledge of NDIS and hospital roles and processes, and shared commitment to individualised, person-centred planning
- People with disabilities and complex health and support needs experiencing smooth and coordinated planning throughout their hospital stay, enabling them to make informed and supported decisions when the time's right for them, and to leave hospital with necessary funding and support in place

Getting the Language Right: a health practitioners' guide to writing assessments, forms, letters and reports for the NDIS

This tool assists practitioners to take the medical language of diagnosis, treatment and rehabilitation to describe a health condition and impairment, and then build on this to write about activity limitation, function and participation. It helps with translating clinical language into the NDIS language of 'participation', and shows health practitioners how to write for the NDIS - how to describe a person's permanent impairment and the related activity limitations which directly affect participation in daily, community and economic life.