



Hospital Discharge of NDIS Participants with High and Complex Needs

Policy Position Statement by the Summer Foundation

July 2021

Executive Summary

Immediate action is needed to improve outcomes for people with complex disability.

Significant reforms of the National Disability Insurance Scheme (NDIS) and health interface systems are needed to reduce unnecessary hospital stays and to prevent younger people with high and complex disabilities from being forced into unsuitable housing and support such as residential aged care (RAC).

Hospital discharge delays have compounding negative consequences for NDIS participants (hereafter referred to as 'participant' or 'participants') and families, NDIS and health systems, and the workers within these systems. Improvements in hospital discharge will reduce costs for both the NDIS and health systems and help fulfil the [Younger People in Residential Aged Care Action Plan](#) of no younger person (under the age of 65) living in RAC unless there are exceptional circumstances.

This report examines the various problems and solutions specific to the NDIS and health interface to minimise extended hospital stays and increase successful returns to community life for people with disabilities.

Problems

- The National Disability Insurance Agency (NDIA) timeframes for access, plan reviews and planning, as well as decision-making for Specialist Disability Accommodation (SDA), Supported Independent Living (SIL), Assistive Technologies (AT) and home modifications, do not align with rapid health responses needed to meet the changing needs of people with complex needs.
- NDIS eligibility is often tested too late in a patient's admission to hospital to activate support. This extends hospital stays and escalates unnecessary costs for patients while stressing hospital staff and resources.
- The capacity of the health system to support people with disabilities is varied. Some staff have specialist skills, yet most need capacity building to adequately assist patients with complex needs.
- Discharge planning for people with disability is problematic, with gaps in supports and services due to:
 - Ambiguity around NDIS and health responsibilities and the retention of knowledge
 - Varying levels of knowledge and specialisation in the health sector regarding the NDIS and understanding of the support needs of people with disability and complex needs
 - Lack of escalation, prioritisation processes and early referral to the NDIS
 - A lack of necessary clinical expertise in NDIS planners and support coordinators, often leading to failure to incorporate key support recommendations in plans
- Resources invested by the NDIS and health are inconsistent and insufficient to support collaboration across multiple systems and to coordinate individual planning processes for people with complex support needs.
- Health Liaison Officers remain largely under-resourced, misunderstood, unknown or inaccessible, particularly outside metropolitan areas.

Solutions

Recommendation 1: Ensure availability of Health Liaison Officers for people with disability and complex needs in hospital to access the NDIS as early as possible.

Recommendation 2: Ensure early access to and approval of plans or interim plans that fund Specialist Support Coordination and other services and supports for participants to leave hospital.

Recommendation 3: Enable planners, support coordinators and clinicians to understand and implement best practice while supporting people with complex needs in hospital.

Recommendation 4: Provide participants with high and complex support needs and their families with information about the NDIS, supports and services as early as possible while in hospital.

Recommendation 5: Develop a national strategy to build the capacity of community and primary health services across the nation.

Recommendation 6: Promote active understanding and knowledge management of NDIS legislation, policy processes and operational approaches.

Recommendation 7: Invest at the policy level to:

- a. Monitor, track and understand ongoing gaps in care and post-discharge needs, adapting good practice and a system of continuous improvement.
- b. NDIS and health systems to incorporate a priority approach around people with disability with high and complex needs for their own internal systems and processes. NDIS and health systems to share this information with each other for effective use and implementation.
- c. Further refine understanding of the Council of Australian Government's Principles and health responsibilities.

A vision for an effective interface between the NDIS and Australia's health systems

As one of Australia's most significant national reforms, the National Disability Insurance Scheme (NDIS) represents generational reform to the way disability services are delivered. Full rollout across Australia required the navigation of a new systems interface between the disability and health sectors. Navigating the new interface required significant changes in the way state-based health systems (and the people, families and disability services they were working with) connect and collaborate with disability support. Interface issues remain prevalent despite significant changes and clarification of responsibilities around disability-related health in the Council of Australian Governments' (COAG) Agreement.

There must be a collaborative relationship between the health system and the NDIS in order to achieve timely hospital discharge. Successful and timely discharge from hospital requires effective and responsive personal plans that incorporate clinical support and ensure personal goals can be achieved.

An effective interface includes:

- Clearly identified roles and responsibilities of NDIS and health to address the needs of participants and those with newly acquired disability
- Health workers having access to, and working knowledge of, the NDIS or access to a subject matter expert to ensure early identification of patients needing access to the NDIS
- Tried and true pathways prioritising the wellbeing of participants. This may include short 'interim' plans (e.g. 3-6 months) as a viable pathway to early hospital discharge
- Good practice, including NDIA and health staff sharing successes and learning from mistakes
- Rapid and coordinated escalation of supports around discharge for those who:
 - Acquire a disability through trauma or serious illness requiring hospitalisation
 - Have an existing disability and their health status has significantly deteriorated
 - 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

The NDIS and health interface and how it affects hospital discharge

Discharge delays are clinically defined as the period of inpatient stay after a patient has been assessed as medically stable and no longer requires acute medical treatment (Rojas-García et al., 2018).

This is different to NDIS eligibility and planning, which requires expert decisions on the permanence of disability and scope of participants' functional capability. This mismatch makes it difficult for health workers, NDIS planners and support coordinators to properly identify and address participants' immediate and long-term needs during transition from hospital to the community.

People with disability face a variety of risks from delays or slow response speeds in NDIS approvals and supports, as well as inadequate planning or funding. People with disability risk contracting infections in hospital, as well as facing emotional stress and frustration, shared by staff from both health and the NDIA, as beds are taken up by people who need to go home (Houston et al., 2019).

"We have a patient who is at 363 days awaiting her SDA to be built. Patients don't deserve to be in hospital for near on a year awaiting suitable accommodation and patients who need therapy don't deserve to be stuck on an acute ward awaiting a bed on rehab to become available."

Eliza – Clinician

Discharge delays take up time and resources, keep participants away from their families and risk admission to RAC or other unsuitable housing options which, in the future, can lead to unnecessary hospital re-admissions.

Additionally, significant changes in people's circumstance or health status hamper effective responses due to uncertainty and delays around advocacy, eligibility decisions and securing needed supports.

Though there is limited research around the experience of people with disabilities and complex support needs in hospital, existing data shows significant challenges related to physical access and provision of care, as well as poor outcomes from extended hospital stays (Houston et al., 2019). It is therefore critical to engage and support people with disability as early as possible in their hospital stay.

Beyond delays in NDIS access requests, planning and support coordination, systemic issues contributing to discharge delays include:

- Extended wait times for necessary funding
- Difficulty navigating housing markets and securing appropriate housing due to lack of accessible and affordable housing
- Lack of community supports and limited support networks (Houston et al., 2019)

Case Study

In December 2019, Tera* had a major brain haemorrhage when having a stent put into her heart. Three days later she had a heart attack, likely due to clotting around the new stent. Tera was unable to move a significant amount of her body and is bed-bound except when she is hoisted into a wheelchair. She had movement in her right upper limb, which she could use to hold and manipulate objects and to indicate yes/no answers to questions.

After being in hospital for 9 months without any further haemorrhage or heart attack, she told everyone ***“All I want is to go back home.”***

Tera's strong wish was to go home to be with her family, with the necessary medical, allied health and nursing support. She had an **interim plan in June 2020** providing funding for a support coordinator, a plan manager, an occupational therapist and quotes for home modifications. While the aim was to enable the gathering together of all needed information for a complete plan, Tera and Edgar had to push for months to get proper reports that the NDIS would accept.

Tera and her partner Edger* had been trying since early August 2020 to gain approval from the NDIA for a variation to Tera's plan providing for all the support she will need. Tera and Edgar felt that the planner and the NDIA were tardy, unresponsive and not transparent.

They had provided all finalised reports and hospital documents, a budget request with further quotes and the support coordinator's own report to the NDIA planner. However, she was at **significant risk of being discharged from hospital into aged care**.

After one year and a longer process than Tera and Edger should have experienced, **Tera was discharged home** and is being successfully supported by a team of nurses on rosters, support workers, night-time support and her partner Edger.

Current gaps and challenges within the NDIS and health interface

NDIS gaps and challenges

NDIS interface issues generally stem from high volume turnover, insufficient or remote staffing, communication issues and stretched resources. This is especially true in regional areas that may have limited access to key personnel, due to arrangements such as sharing a single Health Liaison Officer (HLO) with a wider metropolitan centre.

Insufficient NDIS structures and staff resourcing

In hospitals, people who need disability support may be referred to an NDIS Transition Lead or HLO. The breadth of the NDIS Transition Lead and HLO roles make them critical points of contact for patients and their families, health workers and support coordinators.

When these points break down, it can be incredibly difficult for participants to engage with the NDIS.

Beyond capacity building and patient advocacy, NDIS Transition Leads engage (in most cases¹) directly with HLOs. HLO is a role specifically created by the NDIS as an approach to bridge the gap between the NDIS and state/territory health. The purpose of this role is to “work with hospital and health workers to improve communication between health systems and the NDIS, with the goal of supporting more timely discharge of potential or existing participants from hospital settings”².

HLO roles remain under-resourced and continue to face issues around implementation. With 24 across the country, HLOs have wide geographic areas to cover and because of this patients may experience slower response times if they are hospitalised in a less frequented location.

“There is no review on each hospital stay with a means for additional support. Once my plan used to have contingency hours mapped into the personal support care for an increase in hours when I’m not well but for about 4 years now this strategy of forward planning has been cut from the plan. It would be good if NDIA recognised this again and were open to contingency funding so it’s less of a hassle and we don’t have to initiate a review of the plan.”

Ruby* – Participant

“There was [an HLO] whose job it is to get to make contact with the NDIA. I never had a phone call from that person, I don’t think [our support coordinator] Emily ever had a phone call from that person.”

Edger – Tera’s partner

¹ In South Australia, HLOs are not allowed to be contacted by the NDIS health lead equivalent and must be contacted by individual health staff.

² National Disability Insurance Agency, *Health Liaison Officer Factsheet for Government* (December 2019)

Delays in NDIS pathways

Many people with disability require NDIS resources to assist them early in their hospital stay, such as support coordination or Specialist Support Coordination. Failure to obtain these early enough will often compound delays. However, such supports are not available until a plan has been approved. Delays in referring a person with disability to the NDIS result in critical delays to the provision of and access to adequate supports.

Further delays exist around gaining approval of funding for SDA, SIL, AT or home modifications. Approval does not guarantee interim housing options will be funded or accessible, such as MTA, residential respite, and/or other transition housing options. These options are essential to assist young people with disability and prevent the likely discharge pathway to RAC.

Additionally, eligibility for and funding of SDA, SIL and AT are still being processed with different timeframes. This means a participant can have access to SDA funding while unable to move in due to a lag in funding approval for SIL.

Heightened difficulties for rural and remote operations

Timely delivery of services and supports is made more difficult in rural and remote areas due to limited resources, expertise and staff.

Where HLOs are spread thinly, there is greater difficulty in escalating a person with disability's case and resolving discharge delays that are preventing them from returning home. While a lack of HLOs in rural and remote areas is present, participants in rural areas will continue to experience poorer results.

Health system gaps and challenges

Variability in health systems and staff knowledge and expertise in supporting people with disability impacts health and NDIS integration. These gaps contribute to delays in early identification of the patients requiring NDIS access. It is often up to the family or network of support (including social workers, nurses, coordinators) to gather the required information and progress through the access requirements for the NDIS.

"My sister-in law, a Sydney social worker did a great deal of ringing around trying to gather information re the NDIS."

Dannie* – Participant

Rushed discharge planning

While discharge planning should begin as soon as patients are admitted, this rarely happens. This impact is more evident³ from NDIS trial sites between 2013-2019, which indicated that the interface between the NDIS and health systems was not nimble enough to effectively deal with the demands of younger people with complex support needs.

³ Please see the Summer Foundation's [Insight into Design Issues in the Health and NDIS Systems Interface](#) (2018) paper for more information.

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 in NDIS approvals and limited access to supports and services required in these situations.

While health workers are trained and resourced to provide care for patients, many people with high and complex care needs require dedicated disability supports and services. Delays in NDIS funding have caused patients to remain in hospital beds for several years.

“There was a lot of pressure from hospital executives to get [the participant] discharged. A number of times through the process, I was very heavily questioned about whether I knew what I was doing or whether [the plan] would be funded due to high cost. They questioned me a lot while I pushed for it, saying: ‘Maybe you’ve set this person up to fail, do you know what you’re doing?’”

Emily* – Tera’s support coordinator

There is evidence that dedicated discharge planners improve the likelihood for discharges to be successful, especially for people with high and complex needs (Burke et al., 2014; Houghton et al., 1996; Mennuni et al., 2017). The new disability liaison officer (DLO) role is contributing to positive outcomes, working to bridge gaps in the interface and connect participants and health workers with the NDIS. However, DLOs say that their role remains largely unknown. Greater collaboration between health system DLOs and NDIS HLOs would improve discharge processes and participant experience.

Knowledge and expertise gaps around disability and the NDIS

Health systems as a whole have historically lacked expertise to support complex disability needs in hospital settings. Many healthcare professionals have not been exposed to general disability awareness education or information on the legislative responsibility of mainstream health systems. The exception is often where hospital staff work in sub-acute or community-based specialist health services such as statewide spinal injury or acquired brain injury teams or services that specialise in progressive neurological conditions. These groups have high levels of skill and awareness around disability but continue to request intensive capacity building support related to the NDIS.

“A lot of what we have learnt is from navigating it at ground level. This has meant that senior staff are relied upon heavily to manage the demands leaving small opportunity to upskill staff about the NDIS.”

Eliza* – Clinician

NDIS discharge planners and health workers have struggled to describe and address the life-long disability related needs of a patient in the technical manner required for ARFs and NDIS processes.

Admission to RAC is often seen as the only available option to free up hospital beds.

“In most of my experiences, when people in hospital needed to be discharged, the sub-acute departments were not great with housing, leading participants to aged care.

When I initially started having conversations with [Tera and Edgar], the consultant doctor mentioned RAC as well as a hospital in the home option. Their family was in the hospital every single day they could be, to make sure she had support, advocacy, and company, but hospital executives pushed hard to put Tera in RAC in order to free up her bed as soon as possible.”

Emily – Tera’s support coordinator

“... to be told by professionals along the way and medical experts she’ll never recover, find a nursing home that’s willing to take her as a 29-year-old. I just couldn’t do it. I literally brought my sister home and taught myself how to do it.”

Alex* – Family member of participant

Hospitals and patients are not receiving adequate resources and information regarding housing options. Many are not aware of how to begin navigating the NDIS.

“I don’t remember receiving any information. Maybe a general outline on a piece of foolscap paper. That’s all. I imagine there would be much more information readily available now.”

Dannie – Participant

Requirement to request access to the NDIS was not early

Access request forms (ARFs) are filled out in hospital to support people to commence the NDIS eligibility application process. The early submission of ARFs is an important strategy to allow NDIS planners to assess eligibility in a timely way. Historically, health has planned for immediate discharge needs after addressing acute and sub-acute needs. Health’s focus is to discharge safely and efficiently, and not necessarily anything beyond that goal.

“We used to be planning for a period soon after discharge, now with the NDIS we need to predict their needs 12 months down the track.”

– Healthcare worker

Downstream effects

Delays in NDIS access, supports and services resulting in delayed discharge often have flow-on effects downstream. Local health networks face increased pressure when they cannot release beds to meet their incoming demand as longer stays in acute and/or sub-acute beds require both staff and resources. Disruptions of other hospital services (e.g. elective surgeries) are also likely, as are increases in stress for hospital staff, patients and their families (Houston et al., 2019).

Difficulties for rural and remote hospitals

Rural and regional hospitals are often low on the priority list for NDIS Transition Leads and HLOs. This leads to inadequate support to address eligibility and planning for patients with complex needs.

“We have a HLO who has been assigned to us, however she works across 3 hospitals. She does 1 day a week. Unfortunately, we have not been able to utilise her as an effective resource to assist us with decreasing length of stay and discharging clients from hospital. We have met with other hospitals who report their HLOs are extremely helpful in navigating the system and expediting discharge.”

Eliza – Clinician

Rural clinicians have expressed frustration with their inability to help patients who are stuck in hospital for extended periods of time due to their lack of disability and NDIS knowledge and availability.

“Being in a rural area affects us hugely...Especially if [participants] require SDA and SIL. We just don’t have any, or if we do they have wait lists or are being built. I have a client going to Frankston SDA awaiting her SDA to be built in Gippsland. She has been in hospital over 200 days. Also, we don’t have the support workers to meet the needs of the complex clients. It always feels like the solutions provided to us are not practical in a clinical regional setting.”

Eliza – Clinician

Joint interface issues

Poor communication between NDIS and health

Health workers struggle to get information, advice and adequate responses as they have no clear point of contact at the NDIA.

In many instances, health workers have been unable to access NDIS planners prior to planning meetings, plan reviews and post-plan approval phase. Turnover of staff limits the ability of health and the NDIA to effectively discuss individual participants and achieve positive and timely discharge outcomes.

“Things were held up because of miscommunication between health service and NDIS.”

Peter* – Participant

Determining support needs for individuals continues to pose challenges in relation to establishing NDIS funding. For example, it is often difficult to determine the various supports needed for someone with an acquired brain injury (ABI), especially through a ‘point-in-time’ assessment.

Insufficient and under-resourced collaboration

As a national system, the NDIS has allocated insufficient resources and engagement channels in specialised settings. HLOs are stretched thinly and not readily available. While there has been continuing effort to resolve issues between systems, there are still significant challenges between health and the NDIS. Systems change is required to overcome these barriers and enable efficient approaches to the health/NDIS interface.

The transition from hospital to home comes with additional challenges. Often these are compounded by lack of clarity on responsibilities across systems.

“There was a significant gap [in services] that I was going to be experiencing coming home from hospital.”

Ruby – Participant

“It is a serious gap, that pathway from healthcare over to NDIS needs a lot of work.”

Alex – Family member of participant

Lessons from COVID-19

The COVID-19 pandemic forced the issue as health and local NDIA staff implored the government to fast-track hospital discharges in order to get long-stay patients into appropriate housing as hospitals filled with COVID-19 patients.

This led to close cooperation between NDIS and health staff who shared information, introduced flexibility to Medium Term Accommodation (MTA) criteria and formed effective taskforces. NDIS-funded MTA allowed many participants to move into suitable housing, thereby getting patients out of hospital and freeing up needed beds while:

- Waiting for SDA and SIL decisions to be made, or for community-based therapists to complete functional capacity assessments to be part of SDA and SIL requests
- Waiting for modifications to be completed at home
- Searching for long-term housing

Between 1 March 2020 and 31 December 2021, 2,120 participants were discharged from hospital in order to free up beds in hospitals. This demonstrated effectiveness in housing participants who would otherwise be stuck in hospital for longer periods of time. During 2020, 61 participants (under 65) were recorded as being discharged from hospital into RAC. Of these, fewer than 5 had MTA as a line item in their funding.

In Victoria, the NDIA re-deployed senior planners, forming a 'discharge planners team' that met daily to discuss all the participants stuck in hospital and implement solutions. This ensured that many decisions, such as SDA, were happening very efficiently.

Despite such work, Australians continue to experience delays around hospital discharge, with patients in Queensland, New South Wales, Victoria and Western Australia having to "usually wait two-to-three months to leave hospital and sometimes years"⁴.

The Summer Foundation urges the Federal Government to build on such successes to safely see patients discharged into suitable accommodation in line with their goals. Please see our [position statement on MTA](#) for recommendations of its expansion and improved implementation.

⁴ <https://www.abc.net.au/news/2020-09-02/coronavirus-queensland-rti-documents-disabled-hospitalised-ndis/12607344>

The way forward

Wider implementation of interim plans

Swift access to funding for services and supports is critical to returning to the community. Short 'interim' plans (e.g. 3-6 months) are a viable pathway to early hospital discharge. 1,671 short plans have been recorded between participants' hospital admission and discharge as at December 2020⁵. The average plan composition is summarised as:

| Average Total Plan Budget | Average Core Budget | Average Capacity Building Budget | Average Capital Budget | Average Payments | Average Utilisation (\$) |
|---------------------------|---------------------|----------------------------------|------------------------|------------------|--------------------------|
| \$155,788 | \$119,522 | \$26,381 | \$9,885 | \$42,782 | 28% |

Table of improved collaboration and communication

This table compares the current state of the NDIS/health interface with what the interface needs to look like for people with disability, especially those with high and complex care needs.

| DOMINANT PRACTICE | FUTURE DESIRED STATE |
|---|--|
| <p>Long wait times in hospital; plans are inconsistent</p> <p>Patients' wait-times vary drastically depending upon hospitals and availability of resources and supports.</p> <ul style="list-style-type: none"> Participants are waiting longer for NDIS eligibility in health settings unfamiliar with the NDIS or patients with high and complex needs and months more for receiving a plan. Plans are often ill-suited to needs. Participants often lack access to early support coordination. Many participants who require support coordination or Specialist Support Coordination are not provided with adequate or timely support. Health workers are delayed in contacting DLOs and HLOs due to lack of knowledge, difficulties in communication and/or escalation. | <p>Access is streamlined for patients in acute/sub-acute settings with complex needs</p> <p>Patients able to quickly test access to the NDIS.</p> <ul style="list-style-type: none"> ARFs are filled out in conjunction with HLOs within 3 days of admission and emailed to Health Services. Escalation pathways for priority exist are effectively utilised. Health services are trained in functional language for ARFs. Collaboration occurs between health workers, support coordinators, community, housing and support providers, as demonstrated through the Collaborative Discharge Approach (CDA) aligned with the NDIS' complex pathway. Appendix A. Participants with complex needs receive adequate hours of support coordination or Specialist Support Coordination early on. |

⁵ Australian Senate Estimates. March 2021

HLOs are spread thinly and are often unknown within the health system. The role remains poorly defined

People with disability requiring the assistance of HLOs for eligibility or escalation matters may find themselves waiting for months, especially in rural and remote areas.

- HLOs are contacted for escalating cases around complex disabilities and connecting health workers with the NDIS.

HLOs have a presence in hospitals and authorisation to advise on and draw up ARFs, plans and interim plans

Proximity, technology and physical presence allow HLOs to speak with participants and effectively respond to rapid needs and changes in circumstance.

- HLOs are authorised to determine eligibility, advise on and draw up ARFs, plans and interim plans.

Interim plans are uncommon

Many participants in hospitals have been able to take advantage of short-term plans to access supports and services such as support coordination.

Participants in hospital can arrange interim plans

Participants in hospital have access to supports and services through interim plans that allow rapid response.

- Participants can access support coordinators to assist with discharge while gathering documentation and arranging the full range of supports needed by a participant.

Clinical supports end after participants are discharged from hospital

Hospitals do not adequately engage in post-acute care. This has resulted in sub-optimal results for participants and has contributed to unnecessary rehospitalisations.

Supports begin early and continue after discharge

Health workers assist support coordinators to engage participants early to determine their personal preferences and goals for discharge. Health workers and NDIS supports monitor, track and engage in post-acute care, reducing likelihood for re-admission to hospital.

Health workers have gaps in knowledge regarding NDIS terminology and processes, as well as participants' needs and rights

Health workers spend considerable time following up information or seeking mentoring advice to respond to multiple NDIA requests for further information, leading to issues around:

- NDIS eligibility;
- Escalation and prioritisation
- Accessing and working with planners and support coordinators
- Describing the life-long disability-related needs of a patient in the technical language required for NDIS access forms

Health workers are well-versed on NDIS terminology and processes, as well as knowledgeable of participants' needs and rights

Health workers actively understand and can access knowledge on:

- The terminology, principles and objectives of the NDIS
- NDIS eligibility
- Disability awareness from a human rights-based perspective and support services for those with complex needs
- Use of [Rapid Response tools](#) designed for practitioners
- Early collaboration with local HLO

Lack of standardised training

Support coordinators lack standardised training and skill development in matters of hospital discharge.

- Support coordinators have little time to pursue training and professional development when these are non-billable hours.

Training and good practice is commonplace

The NDIA ensures that support coordinators undertake a certain number of professional development hours every year across key fields of expertise.

- Professional development resources may include [UpSkill](#) and its [Community of Practice](#).

Patients are having their needs and supports identified too slowly, effecting timelines downstream and contributing to discharge delays

Delays in approvals for NDIS and subsequently for SDA, SIL, home modifications and AT are resulting in patient discharge delays or unsuitable housing.

Hospital staff seamlessly connect patients with needed services

Patients are quickly connected with HLOs, planners, support coordination and community partners to arrange supports and services as early as possible.

- Interim housing options such as MTA, residential respite and/or other transitional housing options are sourced prior to discharge while participants are waiting on SDA, home modifications, AT or other appropriate long-term housing.

NDIS and health are under-resourced to achieve meaningful collaboration and to identify and address gaps

Local Health Networks, different health jurisdictions and the NDIS lack standard interface practices.

- Lack of communication around good practice causes preventable poor outcomes for participants, their families and hospitals.

Planned and well-implemented initiatives ensure appropriate resourcing for meaningful collaboration between the NDIS and health

- Gaps are identified and addressed.
 - Lessons from successes are applied to further reduce discharge delays and flow-on effects.
 - Knowledge management and systems are in place to maintain subject matter experts.
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Recommendations

To address the systemic and policy issues identified in this paper, the following are recommended. This will achieve a coordinated health and NDIS interface where people with disability and complex health care needs can more effectively remain in the community and achieve more efficient discharge:

NDIS Recommendations

Recommendation 1: Ensure availability of HLOs for people with disability and complex needs in hospital to access the NDIS as early as possible. Availability of HLOs, streamlining, prioritising of access requests and associated planning is needed to expedite discharge processes.

- a. The number of HLOs must be increased to allow for a continuous and effective presence in hospitals. This will allow for rapid response and escalation of participant needs.
- b. The NDIA must authorise HLOs to draw up and advise on ARFs. ARFs submitted through HLOs are to be given top priority from Access Team.
- c. The NDIA must give HLOs delegation to make access determinations for the NDIS.
- d. The NDIA must ensure that NDIS planners are allocated to people with complex needs who are in hospital.

Recommendation 2: Ensure early access to and approval of plans or interim plans that fund Specialist Support Coordination or other services and supports for participants to leave hospital.

- a. It is critical to fund sufficient hours of support coordination to reduce discharge delays and identify appropriate housing options, preventing the risk of admission to RAC or long stays in hospital.
- b. All participants with high and complex needs should automatically have access to funding for support coordination and Specialist Support Coordination.
- c. The NDIA to issue 3-6 month interim plans to younger people in hospital immediately after NDIS eligibility is determined. This needs to include 60-75 hours of support coordination to assist in discharge planning, capacity building, functional capacity assessment for SDA or SIL and identifying post-discharge options.
- d. The NDIA to better implement funding to ensure participants with complex needs have better access to interim housing options to support efficient discharge, such as MTA and/or other transitional housing options. The ability to have MTA in a participant's plan (without a certain long-term housing option, but with safeguards in place so the participant does not also become 'stuck' in [MTA long-term](#)) is critical to participants waiting for SDA determinations and availability, home modifications, AT or other appropriate long-term housing.

Recommendation 3: Enable planners, support coordinators and clinicians to understand and implement best practice while supporting people with complex needs in hospital. We suggest utilisation of resources such as:

- a. The Summer Foundation's [Housing Hub](#) that provides easy and accessible navigation of housing options.
- b. The [Collaborative Discharge Approach](#) planning resource describes how health clinicians, support coordinators, community and housing providers can work collaboratively with the NDIS.
- c. The Summer Foundation's [Housing Brokerage Service](#) has created a new resource about [housing needs and preferences to support discharge](#) from hospital.

Health recommendations

Recommendation 4: Provide participants with high and complex support needs and their families information about the NDIS, supports and services as early as possible while in hospital.

- a. Making education and information materials about the NDIS available to them. This information should be revisited at various stages throughout hospitalisation to ensure participants are truly informed.

Information provided to participants should be available in a range of formats including plain English, easy English and audio visual (with captions and audio-described). For people with cognitive disability, information should be provided in a way that can be understood, checking understanding of content provided on multiple occasions to gauge retention of information and, where appropriate, including closer others (e.g. family) in these conversations.

- b. Health services identify local champions or NDIS experts within discharge teams to lead and support patient engagement with the NDIS.
- c. DLOs are better resourced and connected within health settings, being responsive to gaps in the interface between participants, health workers, and the NDIA.

NDIS and health recommendations

Recommendation 5: Develop a national strategy to build the capacity of community and primary health services across the nation. The government must ensure that people with complex health care and disability support needs are not subject to unnecessary hospital admissions.

- a. Wider inclusion of hospital-based project leads to support the capacity building of health services.
- b. Wider implementation of the Exceptionally Complex Support Needs Program to work alongside support coordinators, mainstream and community services to support participants with exceptionally complex support needs including referral options for support coordination.

Recommendation 6: Promote active understanding and knowledge management of NDIS legislation, policy processes and operational approaches.

- a. Health workers must have access to resources and training allowing them to work effectively with the NDIS. The [Leaving Hospital Well](#) Community of Practice assists health professionals to understand, navigate and develop best practice collaborative discharge in conjunction with the NDIS. The Leaving Hospital Well [Community of Practice](#) is a national platform for health professionals to share their expertise, identify best practice for working with younger people with disability and complex support needs within the NDIS, and provides a supportive learning environment within the evolving context of health and the NDIS.
- b. NDIS support coordinators and allied health professionals should engage in capacity building programs such as [UpSkill](#) to increase communication and efficacy in health system operations, clinical supports for people with disability who have high and complex needs, and advise in plan development. The UpSkill [Community of Practice](#) provides a platform to resolve complex problems for people working with people with high and complex support needs.

Recommendation 7: Invest at the policy level to:

- a. Monitor, track and understand ongoing gaps in care and post-discharge needs, adapting good practice and a system of continuous improvement.
- b. The NDIA and health systems to incorporate a priority approach around people with disability with high and complex needs for their own internal systems and processes. The NDIA and health systems to share this information with each other for effective use and implementation.
- c. Further improve understanding of COAG Principles and health responsibilities.

About the Summer Foundation

The Summer Foundation, established in 2006, works to change human service policies and practices related to younger people (18-64 years old) living in, or at risk of admission to, aged care.

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, 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 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.

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Appendix A

Summer Foundation resources and demonstration projects related to the NDIS and health interface

Practitioners skilled in inter-system operations are needed to address systemic problems. The Summer Foundation has developed various useful resources, approaches and workshops around capacity building, inter-systems operations, and timely hospital discharges.

There is the need to improve processes and build capacity in NDIS and healthcare professionals 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.

Interim plans

The Summer Foundation's *Hospital Discharge Project: Co-Design Recommendations and Project Summary* (2017) reported the results of NDIS 3-month interim plans piloted by Barwon and Ballarat health services and the Victorian Government. These allowed a support coordinator to work collaboratively with the discharge planning team to gather information that would assist the support coordinator in identifying the reasonable and necessary supports (such as equipment, home modification and support worker requirements).

Interim plans facilitate support coordinators to assist with early navigation of the NDIS/health interface and achieve improved results for many participants without advocates and/or who have reduced cognitive and physical resources.

"[Our support coordinator] had her own frustrations, a lot of which were to do with the unfamiliarity of the hospital with discharge to the home under an NDIS plan. It was really to do with what was required, what would constitute appropriate evidence, and what would the NDIA need for plan approval."

Edger – Tera's partner

The William Buckland Foundation's *Improved Health Program* (2020) has shown that the [Collaborative Discharge Approach](#) (CDA) and availability of interim plans has led to better results for participants, including returning to the community.

Frameworks

Collaborative Discharge Approach

The NDIA must address interface issues through collaborative proven models, such as the [Collaborative Discharge Approach](#) (CDA). CDA is a collaboration between health clinicians, support coordinators, community, housing and support providers. All these groups work together with the NDIA to confirm and activate NDIS supports for a person with a complex disability while they are in hospital. They can then successfully transition from hospital back to their home, or to alternative housing such as SDA.

Training and Resources

UpSkill

The Summer Foundation's [UpSkill](#) program is a national program offering professional development to support coordinators and allied health professionals. UpSkill offers training sessions, resources, and a [Community of Practice](#) for support coordinators and allied health professionals to engage with peers, access information and develop best practice approaches.

Leaving Hospital Well

Training and resources are delivered through the [Leaving Hospital Well](#) project. This capacity building program has shown a 71% increase in the capacity of health workers to interface with the NDIS. As well, the ability of hospital staff to support people to access the NDIS and gain the support they need showed notable improvements across all topics and 98% of participants said they could apply the learning to their work. Key improvements for hospital staff included:

- Implementation of NDIS governance structures, policies, resources, and data collection
- Improved patient discharge outcomes and patient satisfaction with discharge
- Reduced length of stays in hospitals for participants, as well as reductions in re-admissions
- Improved housing outcomes for participants and reductions of discharge to residential aged care

Leaving Hospital Well's [Community of Practice](#) is a national platform for health professionals to share their expertise, identify best practice for working with younger people with disability and complex support needs within the reform of the NDIS, and provide a supportive learning environment within the evolving context of health and the NDIS.

Hospital toolkits

We have also 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.

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 disability 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)

For hospitals, there are a number of [practical toolkits](#) available, including [NDIS and Health: Working together](#), [Getting the Language Right](#) and [Getting ready for NDIS planning](#) which covers:

- [Disability and health supports and how the NDIS defines them](#)
- [My details and preferences](#)
- [What would a great life be for me?](#)
- [About my health – being prepared for NDIS planning](#)
- [If circumstances change](#)
- [About my health – being prepared for hospital admission](#)
- [Sources \(and further information\)](#)

Housing

The Housing Brokerage Service

Locating and securing appropriate housing options based on the person's housing needs and preferences, whether interim or long-term, is critical to being successfully discharged back into the community. The Summer Foundation's [Housing Brokerage Service](#) facilitates a discussion with the patient's health team, their support coordinator, formal Guardian (if appointed), and other relevant stakeholders to create:

- A clear articulation of the person's housing needs and preferences and their support needs
- A Tenant Summary Profile, which can be used in a search for housing
- A greater understanding about SDA eligibility criteria and written evidence
- An evidence base about the gaps in the service system to inform the development of new interim and long-term housing options

Housing Hub

The Summer Foundation's [Housing Hub](#) is an online community of people with disability and housing providers working together to create accessible housing options. It allows the creation of profiles that match people with properties, hosts a library of useful information about housing options and planning a move, and provides news and updates on the housing market.