

# Improving the NDIS Experience:

Establishing a Participant Service Guarantee and removing legislative red tape

## Summer Foundation submission

### 31 October 2019

### INTRODUCTION

The Summer Foundation, a not-for-profit organisation which was established in 2006, works to change human service policies and practices related to younger people (from 18 to 64 years old) living in, or at risk of entering residential aged care (RAC).

Our vision is that young people with disability and complex support needs will have the opportunity to live where and with whom they choose, with access to high quality housing and support options that enhance health, wellbeing and participation.

Providing 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.

The NDIS is critical for the supports people with disabilities need to live an ordinary life. People with complex needs rely on access to effective, timely and well-understood NDIS processes and decisions to achieve high quality outcomes. Currently, NDIS processes and decisions are unreliable, inconsistent and too slow. This is forcing many into aged care and making it difficult for the close to 6000 young Australians in aged care to secure the housing and support that they need to live in the community.

It is the view of the Summer Foundation, that the problem is not the NDIS Act itself, but rather its implementation that is causing young people to be admitted to RAC. In our view, the Act does not require a major overhaul, however, changes to the accompanying rules and organisational procedures are needed.

The Summer Foundation supports the Government's commitment to a Participant Service Guarantee and the introduction of new standards for shorter, realistic timeframes for plan establishment and reviews. Our recommendations will assist in making NDIS decisions more transparent, its processes more understandable and its operations more streamlined.

The Summer Foundation's responses to the discussion paper questions have been informed by the experiences of NDIS participants, families and carers, and in collaboration with health workers and other workers interfacing with the NDIS. The evidence base is provided by formal research, collaborative, practice initiatives in the health/NDIS interface, and from the stories of people in residential aged care, those 'at risk of aged care admission' and those who have moved into independent living housing models.

### What could a Participant Service Guarantee look like?

Principle	Description
Timely	The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.
Engaged	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
Expert	NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.
Connected	The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.
Valued	Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance.
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.
Accessible	All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.

### Key discussion questions

### 1. Which of the above principles do you think are important for the NDIA to adhere to, and why?

All of the principles are necessary but not completely adequate enough, to guide the formulation of service standards for an appropriate and reliable level of service. Young people at risk of admission to RAC, and those already living in RAC, have limited opportunities to achieve their goals without timely NDIS decision-making, NDIS processes which are cognizant of their needs, supports based on a collaborative effort between skilled providers across multiple sectors, and without an understanding of why decisions are made. It is critical that the service standards are clear so that they are well-informed for planning their next steps.

# 2. In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?

The NDIA has failed to deliver on the principles to people with complex disability support needs - young people living in residential aged care (YPIRAC) or those at risk of admission - in the following areas:

### TIMELINESS

The NDIS is not facilitating access to the NDIS for YPIRAC quickly enough. Although the rate of entry has been improving, approximately 16 per cent are not active participants.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> Based on AIHW (3<sup>rd</sup> Release) identifying that there were 5606 people under 65 in permanent residential aged care as at 30 June 2019. https://www.gen-agedcaredata.gov.au/Resources/Access-data/2019/September/Aged-care-data-snapshot—2019

The NDIS is failing to make timely decisions for YPIRAC to access specialist disability accommodation (SDA) funding in order to expedite their exit from RAC to live in the community.

Participants' comments reveal the impact of delayed decisions "The lengthy delays affect not just my son but the people carrying out the work. Quotes expire while we wait for approval. NDIS needs to streamline processes... The date of the approval should be the date the work can start.

(Mother of young man with an acquired brain injury living in family home)

"13 months since the initial plan and Alison\* is still without an appropriate wheelchair." (Power of Attorney of younger woman with multiple sclerosis living in aged care. \*Name changed)

"I'm waiting for a new electric wheelchair - they said I would have it when I arrived at my new facility. I've been in my new accommodation 3 months and I'm still waiting. I was also promised a commode on arrival. I have a right like a normal person to have a shower every day." (Man with cerebral palsy living in supported accommodation)

"NDIS – move quicker! They're like Centrelink but worse. They're dealing with traumatised people and are just giving us more trauma." (Mother of teenage girl with a spinal cord injury living in family home)

#### ENGAGEMENT

NDIS decisions are not informed by adequate consultation with YPIRAC, their family, carers and other support persons. Lack of information and consultation can result in inefficient and unproductive outcomes.

"Little information was provided around the process for ordering equipment with the NDIS, so the nursing home arranged their own assessment .... This request was rejected as it hadn't gone through the right channels."

(Power of Attorney of younger woman with multiple sclerosis living in aged care.)

"I thought there would be two-way communication between myself and the NDIS." (Man with Guillian-Barre Syndrome living at home)

"Everything has to go through so many people it takes so long." (Mother of teenage girl with a spinal cord injury living in family home)

### EXPERT KNOWLEDGE

NDIS staff do not have a high level of disability training and understanding of complex disability support needs. They do not understand how the impairments associated with complex disability support needs impact on participants' lives and what supports they need to live an ordinary life.

"At my first planning meeting, the planner was a 21-year-old with not much life experience. When I asked questions, she didn't know the answers." (Man with cerebral palsy living in supported accommodation)

Support Coordination supports are an integral part of plan supports for YPIRAC. There is a lag in the supply of specialist support coordinators who have expert knowledge and skills in working with participants with complex disability support needs in RAC or other settings.

Currently, decisions made under the NDIS, Aged Care and Health systems are not consistently informed by staff with a high level of disability training and expertise in the impact of the health

conditions that result in complex disability support needs, such as those that can trigger an ACAT assessment for admission to RAC.

### CONNECTIVITY

Young people at risk of admission to RAC frequently engage initially with the health system. For many, hospital is where they first connect with the NDIS. Problems in the interface between health and the NDIS result in uncoordinated systems that prevent a smooth pathway to the best outcome for people with complex disability needs.

NDIS staff are failing to work collaboratively with aged care, health systems and accommodation providers to streamline NDIA approval processes with broader system timelines such as hospital discharge deadlines.

"I have concern going forward there will be a lot of service providers with support workers who are not trained to work with people with high care needs." (Mother of young man with an acquired brain injury living in family home)

Rose\* is in her early 30's, and has been living with a disability since birth. She already had an NDIS plan in place when she was admitted to hospital. Rose believes that the NDIS needs to work with hospitals so that when you leave hospital, any changes in support or equipment needs are updated in the plans, instead of waiting for a plan review. She feels if she had these things in her plan at discharge, she would get better faster. Accessing services would give her hope and reduce her anxiety and depression. She also feels that if she had everything in her plan when she left hospital, it would reduce repeat hospitalisations."

(\*Name changed)

"Nursing home staff need to be better supported. Providing NDIS education and training would mean young people in aged care wouldn't get left behind." (Power of Attorney of younger woman with multiple sclerosis living in aged care.)

### TRANSPARENCY, INFORMATION SHARING AND COLLABORATION

NDIA access decisions for YPIRAC that result in a non-eligible determination (173 people as at 31 Dec 2018), are not reported on in a way that enables appreciation of whether they are transparent, informative, collaborative, and conveyed in a way that ensures participants understand the decision making process.

Further information is needed to clarify why younger people in RAC are assessed as non-eligible if it is deemed that they do not meet the disability criteria. It is not possible to determine if these decisions are made on merit.

NDIS decisions on approved plan supports can cause confusion when they are not clearly explained.

"Unfortunately, when I got my package, I realised it did not meet my needs at all. What the NDIS ended up approving was only half of what I actually originally applied for. It actually looked like somebody else's plan with just my name on it. By cutting my funding it was like cutting my life in half. It didn't even meet my basic needs."

(Man with acquired disability living in aged care)

### ACCESSIBILITY

The NDIS is not operating in a way that enables people with complex disability support needs to understand and use the Scheme.

The following aspects of NDIS performance reduce the Scheme's accessbility to YPIRAC:

- Time frames are still variable with some participants waiting weeks to achieve access to the Scheme
- NDIA planner knowledge of complex disability support needs are variable, which can impact on the development of an effective plan based on the participant's unique needs
- Local Area Coordination (LAC) knowledge is also variable, with some participants and health staff reporting delays in the planning process due to LACs being initially allocated, and then referring the participant to a planner when they feel unable/unskilled to develop a plan for the participant
- NDIS funding is still not effectively allocated or utilised for some YPIRAC, with some people being told they are not eligible for various supports because they live in RAC
- Some participants (endorsed by health staff) report that the documentation they prepare for their planning meeting does not translate into their eventual NDIS plan
- Many participants (endorsed by health staff) report that they do not have clarity about the reasons the NDIA has made decisions to decline access or decline supports in their plans

"They think because I can't read well and I'm losing my eyesight that I won't understand what is written on the page, but that is wrong. The NDIS should mail me a hard copy directly so I can have an understanding of my total plan."

(Man with cerebral palsy living in supported accommodation)

# **3.** What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?

The Participant Service Guarantee will be more effective in achieving evidence-based outcomes and being accountable to participants by adopting the following new principles, and amending the existing principles:

### PROPOSED ADDITIONAL PRINCIPLES

- "Human rights based": This principle will ensure that operations and processes of the NDIS maintain a focus on the protection and promotion of human rights
- "Goal-centred, evidence-based and outcomes focussed": This principle will ensure that
  processes and practices delivered by the NDIS are based on clear, identifiable evidence of
  what is found to achieve the best outcome for people with disabilities. For example, NDIS
  supports should include rehabilitation that leads to outcomes and early intervention. This
  should be coupled with ongoing research to effectively evaluate their service delivery
- "Clear and regular communication": This principle complements the existing "Engage" principle by focussing on the need for the NDIS to ensure staff engage with people with disability, their family, carers and other support persons, and also demonstrate communication that is proactive and understood

### PROPOSED AMENDMENTS TO EXISTING PRINCIPLES

- "Engage": This principle should be re-labelled Collaborative
- "Valued": This principle should be re-defined as "participants and their support persons feel heard and respected, and know where to go if they need further assistance". The reasoning

behind this proposed change stems from some participants reporting that they are clear on what they need, however they find their plans do not reflect what they've expressed

"Decisions are made on merit": This principle should be re-labelled as Transparent, with the following description – "participants and their support persons understand why decisions are made". Support teams for some participants have reported that NDIS communication about decisions has been sent directly to participants who are unable to read/process written information. This has resulted in support teams not being effectively informed of decisions, and consequently being unable to translate this for the participant

Recommendation 1: that the Participant Services Guarantee includes additional principles of 'Human rights-based', 'Goal-centred, evidence-based and outcomes focussed', and 'Clear and regular communication'; and amends the principles of 'Engaged', 'Valued' and Decisions are made on merit' by renaming them.

# 4. One way to measure these principles is through a set of 'Service Standards'. Some ideas for what these Service Standards could be are listed in <u>Attachment A</u>. Do you think these Service Standards are fitting? Are there other standards you believe should be included?

Some service standards are difficult to measure or to determine if they are being met on the basis of evidence. Examples are the principles of "Valued", and "Decisions are made on merit". The Participant Services Guarantee must include measures (quantitative and/or qualitative) for each of the principles so that KPI performance is transparent and participants can determine if they are being met.

### SERVICE STANDARD "TIMELY"

Recommended Service Standards are:

- Access requests should be achieved in 14 days
- Participants are offered a planning meeting date within **10** days of achieving access (however this time frame should have flexibility for a participant in hospital or RAC who may not be effectively prepared for planning)
- New Service Standard: All draft plans are to be made available to participants to view before they are approved
- A draft plan is made available to the participant within **5** days of their planning meeting and within **20** days of their access decisions
- The final plan is approved within **5** days of the final planning meeting for participants in timesensitive living circumstances such as in hospital or in RAC, where delays are causing harm to the person
- Plan amendments are considered within 14 days of the request
- Plans involving SDA or AT requests are made within **14** days of the information being provided.
- New Service Standard: SDA approvals are made within 14 days
- Participants who request an internal review of a decision are contacted within 2-3 days of the request
- New Service Standard: If in hospital ready for discharge, decisions are expedited and made **48** hours of expected discharge date

• Amended Service Standard: Participants who request an internal review of a decision are informed of the outcome by NDIA within **30** days of the request

### SERVICE STANDARD "CONNECTED"

• Add Service Standard: Where it is beneficial to the participant, NDIS systems and personnel communicate and complement other relevant systems and services

### SERVICE STANDARDS FOR YPIRAC

Additional Service standards are needed to track the effectiveness of the NDIS in meeting the 7 participant guarantee principles for YPIRAC and those at risk of admission to residential aged care. The YPIRAC Action Plan identifies the goal to support those in YPIRAC to find alternative appropriate housing and supports if they wish to do so, and to halve the number of younger people (under 65 years) entering aged care by 2025. These additional service standards should be regularly reported on in each quarterly report.

They should cover the following:

The number of YPIRAC that:

- are assessed as eligible for the NDIS (principles 1,2,3)
- have an approved plan (1,3,4,6)
- have activated their plan (1,3,4,)
- have SDA funding (identified as in-kind and non-inkind) in their plan (1,2,3,4,5,6,7)
- have left RAC to live in alternative accommodation and should also include details about where they have gone.

Recommendation 2: That the NDIA sets the Recommended Service standard intervals for measurement of the principle "Timely", as detailed in the response above.

Recommendation 3: That the NDIA adopts a set of measures against each principle that enables the monitoring of progress on the Young People in Residential Aged Care Action Plan.

# 5. Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?

In addition to the measures set out in the recommended service standards (Attachment A), the following qualitative measures are recommended to improve the understanding of NDIS performance against the principles. They require regular surveying of participants, to gather information about their experiences, level of understanding and opinions.

### Engaged:

- People with disability and their support persons report that NDIA processes and operations are clear and reflective of their needs
- People with different abilities and needs understand NDIS processes and operations

**Expert:** People with disability and their support persons report that their interactions with NDIA and their NDIS plans reflect that planners and other staff have a high level of disability training and understanding of how various supports can assist people to achieve their goals.

**Connected:** Evidence is collected from consultation with the broader service system to indicate that the NDIA has worked constructively and collaboratively with stakeholders to ensure there are no gaps.

**Connected:** People with disability and their support persons report that:

- there are no gaps in their needs being met between multiple systems
- they have no confusion regarding which system holds responsibility for what service delivery

Valued: People with disability and their support persons report:

- feeling valued and heard by the NDIA
- their plans reflect and deliver the supports they need to achieve their goals
- the broader community reports an understanding of the purpose of NDIS and where they can go for more information

**Decisions are made on merit:** People with disability and their support persons report:

- an understanding of how NDIA decisions are made
- they know what they can do to gain further understanding of decisions that are not made in their favour

**Accessible:** People with disability and their support persons from CALD, LGBTQIA+ and ATSI backgrounds/communities report:

- they have an understanding of and effective access to the NDIS
- data on increased numbers of people from these backgrounds/communities reflects this

Recommendation 4: That the Participant Services Guarantee adopts a set of additional qualitative measures against each principle to gain participants' views on performance against the principles.

### The NDIS participant experience

### **Participant pathway**

### Key discussion questions

# 6. What are some of the significant challenges faced by NDIS participants in the access process?

Significant challenges for people with complex disability support needs in hospital include:

- Waiting for weeks to achieve access to the NDIS. Coupled with delayed planning processes, this results in long delays to receive the critical supports participants need to avoid entering residential aged care and be successfully discharged to the community.
- Having their access requests rejected due to ineffective documentation about their disability and related functional impairments/needs. This rejection, rather than a request for more information (if NDIA requires more clarity), impacts a potential participant achieving timely access to necessary supports.
- Being directed by the NDIA to gain formal guardianship before being able to access the Scheme, because, according to the agency, they are unable to consent. This results in significant delays to NDIS access, but also to every other subsequent NDIS process.
- LACs are still being allocated for people in hospital this often results in the LAC referring the person to a planner as the LAC doesn't have sufficient knowledge to support the person. Specialist planners are needed for people with complex disability support needs in hospital.

"Navigating the maze of what the NDIS system is, was massive. The phone calls, the paperwork, just documents that were being sent in - like 21 pages worth. We have come to the outcome we have because of our own advocacy rather than the system. It's a scary thought to think of the people that don't have the back-up and support that we were able to give." (Family of young man with an acquired brain injury living independently with supports)

"It is a serious gap - that pathway from healthcare over to NDIS needs a lot of work - it was just this revolving door and there is something missing there." (Sister of young woman with an acquired brain injury who lives with her)

Significant challenges are also faced by YPIRAC. Those who are not yet NDIS participants will be highly likely to require the skilled assistance of support coordinators in the access request process. This includes support in accessing and understanding NDIS information and its relevance to their lives in RAC. YPIRAC may not have access to active family and/or friendship networks or other advocates. It is critical that they are proactively contacted by a NDIS representative to be informed about and introduced to the possibility of NDIS engagement, and to receive any assistance they need to make their access request. Currently, access to specialist support coordinators is not available for all YPIRAC.

YPIRAC need to have timely access to Specialist Planners and support coordinators as early as possible.

### 7. The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?

NDIA access request decisions should be made within 14 days. This particularly applies for people with time-sensitive living circumstances where delays to access can place them at risk and impact their capacity.

# 8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

Written consent should not be required if the person with a disability is not able to provide it (guardianship should not be forced upon them in order to access the NDIS).

People with new, severe disability who are diagnosed with specific AN-SNAP codes, should be granted automatic entry to the NDIS. This will enable timely access to supports necessary to synchronise with hospital discharge and NDIS planning for transition to post-hospital life. This automatic NDIS eligibility could be reviewed at 3 or 6 months. The Victorian TAC model has demonstrated the effectiveness of automatic entry, followed by a review of ongoing eligibility in streamlining access to supports for people in this situation.

Once a person with complex needs in hospital obtains access, it would be beneficial if they would be able to get a short plan, quickly, without a planning meeting to enable flexibility to secure urgent funded supports prior to a planning meeting. This would require a change to the NDIS Act. As part of a Summer Foundation project, the Victorian NDIS Regional Office agreed that once access was granted, they approved some funding for a short-term plan via phone. We believe this should be rolled out nationwide.

An Aged Care Assessment Team (ACAT) assessment for entry to RAC (for a person under 65), should trigger an alert to notify the NDIA that they must commence outreach. Outreach will provide information about advocacy agencies such as the Summer Foundation, Young People in Nursing Homes National Alliance and Youngcare.

The following actions are needed to cut red tape and expedite access decisions.

Recommendation 5: NDIS representatives to initiate proactive contact with young people in RAC to facilitate their connection to the NDIS.

Recommendation 6: An NDIS key contact should be allocated at point of access approval for YPIRAC and people with complex needs in hospital

Recommendation 7: Ensure that people with complex disability support needs in hospital have access to services from a Hospital Liaison Officer (HLO) - either independent or NDIA-appointed - to assist them to navigate inflexible eligibility requirements (palliative care exclusions and residency exclusions).

Recommendation 8: Have an electronic Access Request Form (ARF) available to people in hospital or in RAC, to reduce time delays that result from requesting an ARF.

Recommendation 9: Grant automatic NDIS eligibility status for people with new, severe disability and identified with specific AN-SNAP codes. NDIS to review the participant's ongoing eligibility at 3 and 6 months.

Recommendation 10: ACAT and NDIA should set up an automatic notification to the NDIA when a person under 65 is assessed as eligible for RAC, to act as a trigger for the NDIA to immediately commence outreach to the person.

# 9. Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?

YPIRAC need information prior to making an NDIS access request as they may not have the means or advocacy support to make this contact themselves. Most people with disabilities in hospital or in RAC, report needing support to access the Scheme. Once their living circumstances are known, they should automatically receive support to access the scheme. Typically, they may rely on information being available face to face.

## **10A.** Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

NDIA decisions that result in 'not eligible' status are not effectively communicated. Participants and health staff report that often only the participant receives this notification and not their support persons, and that the notification does not clarify the reason why access was declined.

Recommendation 11: Ensure that the NDIS provides plain English explanations for all decisions, and offers additional assistance for people with communication and cognitive impairments who may need support to understand and/or challenge a decision.

The reasons for a 'not eligible' status for YPIRAC were reported on only in the broadest categories such as: 'did not meet the criteria for disability qualification', or 'age criteria', or 'residence qualification'. No further details were given which prevents further analysis of the health conditions and their impacts that YPIRAC are experiencing at the time of their access determination.

There is no established procedure for YPIRAC to appeal a determination of 'not eligible'.

Recommendation 12: NDIA to amend the NDIS Act to address the issue where people with disability under 65 residing in RAC, have been declined entry to the NDIS on the grounds that their impairment is health-related, not disability-related. They should be able to request an immediate review of the NDIS disability decision by the CEO of the NDIA. The CEO should be required to review the decisions within 14 days. If the CEO upholds the decision, the person should be directed to a disability advocacy service with relevant expertise to assist the person to consider their options.

### Planning processes 1: Creating, your plan

Key discussion questions

## **10.B** What are some of the significant challenges faced by NDIS participants in the planning process?

Despite recent improvements in creating faster access for YPIRAC to NDIS plan approvals, delays in NDIS decision making is still slowing down goal achievements for people wishing to leave RAC.

Jennifer\* suddenly acquired her disability and was discharged from hospital to an aged care facility. Regarding her early access to a skilled NDIS planner, she said: "I've been able to contact him directly and he talks to me as though I am an intelligent human being." Jennifer was supported to move out of the residential aged care facility and into accommodation with her sister. In her words: "Despite how fortunate I've been, it has taken two years to get to where I am now and I'm still not where I need to be."

(\*Name changed)

"It varies enormously - the planner's knowledge, skills, background. It almost starts with an assessment of the planner and what they know." (Allied Health Rehabilitation Clinician)

"My first meeting with the NDIS planner was with people from where I live and my case manager at the time. It didn't go well because people talked over the top of me. I had a second meeting with the same planner, my mum and my 'bestie'. I was heard this time." (Young woman living with a disability since birth who lives in supported accommodation)

"I had no expectation for receiving my plan because I was so overwhelmed by what happened at the meetings." (Young woman living with a disability since birth who lives in supported accommodation)

Challenges for people with complex disability support needs include inappropriate allocation of LACs, leading to delays in planning, lack of access to early pre-plan support coordination and lack of skilled support to explore housing options.

LAC's are often inappropriately allocated to people in hospital or in RAC. Frequently they do not have expertise in complex disability support needs, and subsequently refer the participant onto a planner. This delays the whole process and results in the participant having to telling their story multiple times. Many participants (endorsed by health staff) report that the documents they prepare for their planning meeting regarding their needs and goals are ignored by planners, and their NDIS plan does not match their expressed needs.

Recommendation 13: NDIS to allocate skilled planners, rather than LACs, to people with complex needs in hospital.

It is difficult for YPIRAC to develop goals beyond life in RAC as their lives become constrained and limited, with little opportunity for agency and control over all or most aspects of their lives. The options for alternative accommodation of their choice are likely to be unfamiliar to them as innovative housing models are recent. The possibilities for independent living for people with complex disability support needs are not widely known either by YPIRAC and their families or by staff of RAC facilities.

Recommendation 14: The NDIA should provide YPIRAC, or at risk of RAC admission, with funding for support coordination and plan management to ensure that they have the means to purchase supports from a range of providers.

Once a goal to leave RAC has been identified, YPIRAC require skilled support such as Allied Health to access and understand housing options, including new and emerging housing options.

Recommendation 15: NDIA to provide YPIRAC who have a goal of leaving RAC with funding for Allied Health Assessment for exploring housing options.

# 11. Are there stages of the planning process that don't work well? If so, how could they be better?

When people in hospital and at risk of RAC admission are getting started with accessing the NDIS and the supports needed for discharge, they need a skilled planner who knows the right questions to ask in this transition phase. Once deemed eligible, people in hospital entering the NDIS planning phase would benefit from access to a nominal amount of immediate funding (we would suggest around \$10,000) that can be used for interim supports, including support coordination, while waiting for the plan. This system capacity has worked well for Victorian Transport Accident Commission (TAC) recipients.

An alternative to interim pre-plan support funding, could be an interim plan (i.e. 3 to 6 months). This potentially has value for people in hospital as it can prioritise supports that are recognised as critical to facilitating timely discharge from hospital.

Once YPIRAC get a plan, often they will have difficulty understanding it and do not receive any explanation of roles. This reduces their capacity to make an informed decision and to self-manage. The Summer Foundation's "Journey Mapping" in aged care has revealed that often those profiled had plans in place but no-one to support them. Participants, and carers (e.g. elderly parents), didn't know what to do, for example, how to log into the NDIS portal etc.

Recommendation 16: NDIA to implement interim plan access for people in hospital with complex disability needs, and/or access to immediate funding for interim supports critical to timely hospital discharge.

# 12. How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

As stated in response to Question 4, participants should be offered a planning meeting date within **10** days of achieving access. Acceptance of this offer by a participant in hospital or RAC should have some flexibility where they may not be effectively prepared for planning. NDIS first plan drafts should be provided within **5** days of the final planning meeting and final approval granted within 14 days. This is particularly important for participants in time-sensitive living circumstances such as being in hospital or in RAC, where delays can negatively impact a person's capacity.

# 13. Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

"I gathered quotes and documents from specialists, and then had the documentation questioned by NDIS workers."

(Mother of young man with an acquired brain injury living in family home)

Many participants and health staff have developed their own pre-planning templates for documenting a participant's needs, in the hope of ensuring their NDIS plan effectively reflects these. Many participants and health staff have also commented that some planners don't read or refer to these documents. The NDIA should ensure that planners account for any documentation provided to them by the participant or their support persons for the planning meeting, referring to this and taking the content into account during the planning meeting.

# 14. Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

"Why are they (the NDIS) questioning the experts like the OTs? Why would we ask for things we don't need? (Mother of a teenage girl with a spinal cord injury living in family home)

Participants and health staff report that decisions regarding declining supports that have been advocated for in pre-planning documentation, have not been conveyed in a responsive and transparent manner. NDIS planners have not clarified why these decisions have occurred, and the basis on which the supports were not deemed reasonable and necessary. They have been left unclear on how to advocate for supports that are essential to the participant's timely discharge from hospital - this also has the effect of unnecessarily extending a participant's hospital admission.

# 15. If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?

Participants and hospital staff are still involved in attempts to negotiate and interpret the reasons to NDIS planners why supports are reasonable and necessary.

NDIA has a 'Change of Circumstances' process for people who are current participants, and have experienced a change in their needs. There are similar challenges to those described in responses to questions 10B to 15, regarding the 'ease' of this process. It's very much dependent on whether the participant is supported to advocate for their change in needs, and whether a NDIA planner reviews and references any preparatory documents the participant has completed in their planning meeting.

### Planning processes 2: Using and reviewing plans

### Key discussion questions

16. What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

"I didn't really understand the wording of the plan. I asked a lot of questions before signing off on it. I was assured that everything I specified was covered. A few weeks into the plan. I quickly learnt that was not the case."

(Mother of young man with an acquired brain injury living in family home)

Challenges for participants with complex disability support needs include:

- Not seeing the connection between what they have documented in their pre-plan and their final NDIS plan
- Not understanding the language in the plan and needing support to translate this
- The process of searching for providers how to search, what to look for and availability of providers in remote areas
- Knowing how to choose a provider who has the right skill-set to meet their needs
- Claiming for means tested aged care fees continues to be problematic, and this funding often sits in plans underutilised

# 17. Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?

"Once they wrote it all up it was hard to understand, hard to work it out." (Family member of young person with disability)

Support coordinators (SC) are generally allocated to people with complex disability support needs, however, while this role is still developing, SCs may be unclear themselves on either the person's disability specific needs or how to support them to source providers that will best respond to their needs. NDIA needs to do more in clarifying the requirements of this role and support the development/delivery of training so they can effectively support the application of NDIA processes.

# 18. What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?

All the work by NDIS planners goes into pre-planning and then falls away. There needs to be more work following the pre-planning process. This attention needs to be maintained through to the approvasl stage.

Many participants and providers report that the NDIA's "Find a registered provider" resource does not effectively help them locate what they need. There are a range of search options available online which are reportedly used by providers. The NDIA could review these and either guide participants on how to use them, or consider adapting this search approach themselves. The NDIS should also offer mid-plan check-ins for participants who have not drawn down on their plan, to ensure they (and their support person or support coordinator) effectively understand their plan, step through how to source providers, and support them with these aspects if they are struggling to access what the participant needs.

Recommendation 17: NDIS senior planners should carry out check-ins for participants who have not drawn down on their plan within 3 months, to ensure they have information and resources to access their plan supports.

# 19. What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

"I immediately requested a review. The NDIS' reviewable decision-making process is not easy to understand.....It is very difficult to navigate through the complex appeals process. The whole appeal avenue is inaccessible in many ways for people with disability. It took 4 months for the review process to begin. After the meeting ended, I had no idea what I needed to do to get the package that I needed to support me."

(Man with acquired disability living in aged care)

Beth\* acquired a disability through stroke. Her NDIS plan review overlooked the informal supports provided by her husband who had left her leaving her feeling overwhelmed. Beth had already experienced mental health problems. (\*Name changed)

Challenges for participants with complex disability support needs include:

- Participants may be unable to communicate without support and any NDIA documents sent to them solely may either get missed or their follow up will be delayed
- Participants report feeling very concerned about losing their funding if they haven't accessed some of their plan. Despite there being legitimate reasons for this occurring, these participants are still very worried about losing the support they feel they'll need going into their next plan
- Some participants have had their plan review over the phone, which does not enable effective communication (and subsequent plan updates) between the participant, their support people and the planner
- Timing for plan reviews can vary and some participants and health staff have reported not having sufficient time to prepare

Recommendation 18: The NDIS should offer all face-to face reviews for people with complex disability supports in order to enable effective communication.

### 20. What can the NDIA do to make this process easier or more effective?

Changes to make the review process more effective:

Recommendation 19: The NDIS should:

- Ensure communication regarding the plan review is sent to the participant's nominee or support persons, along with the participant themselves
- Reassure the participant and their support persons that underutilised funding will not result in reduced allocation in subsequent plans, and ensure planners are aware of this messaging
- Ensure that plan reviews for people with complex disability support needs are done in person
- Ensure participants and their support persons have sufficient time to prepare for their plan review meeting (e.g. 2 months prior)

### 21. How long do you think plan reviews should take?

Given that it has been recommended (in question 4 above), that Access Requests should be determined within 14 days, complaints to be resolved within 21 days, and extensions of 28 days granted for plans that are due to expire shortly and that a reasonable time frame for completion of reviews is 28 days.

### Appealing a decision by the NDIA

Key discussion questions

# 22. What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

The challenges for participants with complex disability support needs and/or the providers supporting them, include:

- Lack of awareness that they can seek a review of an NDIS decision, or that they can question a planner who declines a support for a participant when the participant or providers have clearly outlined the reason why the support is important
- Lack of understanding of how to do this, or lack confidence in processing a review request
- Most participants report that they need support to do this
- Those that do seek a review can wait months (at least) for a response from NDIA

# 23. Are there other issues or challenges you have identified with the internal and external review process?

For YPIRAC not already in the NDIS, a further challenge arises when they are deemed ineligible and declined entry to the NDIS on the grounds that their impairment is health-related rather than disability-related. They need to be able to seek a review of this decision by the CEO of the NDIA, and receive a speedy determination.

### 24. How could the NDIA improve the decision review process?

Recommendation 20: Provide simpler guidance as to how to process a review request and encourage participants to seek support in doing this; and provide clear time frames for when and how the NDIA will respond to review requests.

Recommendation 21: People under 65 who are in hospital and at risk of admission to RAC and who have been declined entry to the NDIS on the grounds that their impairment is health-related not disability related should be able to request an immediate review of the NDIS disability decision by the CEO of the NDIA. The review can be triggered by any source (person and/or their carer, advocate, hospital social worker and/or discharge planner). The CEO of the NDIA should be required to review the decision within 14 days. If the CEO upholds the original decision the person should be directed to a disability advocacy service with relevant expertise for assistance to review, rewrite and resubmit their access request form.

### 25. How long do you think reviews of decisions should take?

Refer to the response to Question 4: Participants who request an internal review of a decision should be contacted within 2-3 days of the request, and should be informed of the outcome by the NDIA within 30 days of the request.

### Removing red tape from the NDIS

### Key discussion questions

# 26. Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?

Overall the Act is working well to set the perimeters of the NDIS.

Recent up-dates to SDA Rules have significantly benefited SDA recipients. However, additional changes are needed to enable participants with SDA funding to live with their families. The necessary changes to SDA Rules 6.1 d) and f), 6.10 c), 6.11 f), 6.12 c), 6.18 (vi), 7.9, 7.19, 7.25, 7.26 and 7.3 are set out in Attachment 1.

Recommendation 22: NDIA to amend the SDA Rules to enable participants with SDA supports to live with their families.

The NDIS policy requires that SDA provision and SIL provision must be separated in order to enable participants to have choice over their providers. Currently it is common for these two supports to be covered by the same provider, particularly in group homes. The Rules must be amended to require that these two supports be separated. SIL providers who are also providing housing must be required to register as an SDA provider.<sup>2</sup>

Recommendation 23: The NDIS practice standards, which are part of the Rules, be amended to require all providers to completely separate housing and support by 2022, and that through the audit process, they submit an action plan showing where they are on the separation continuum, and what actions they are taking to achieve full separation by 2022.

### 27. What changes could be made to the legislation (if any) to:

#### a. Improve the way participants and providers interact with the Scheme?

Responses to Question 8 highlight the need for people with complex disability needs in hospital to be able to access a short-term plan to expedite the allocation of funding for support coordination. The Act should be amended to enable approval of a quick short-term plan, in order to expedite the planning process.

#### b. Improve the access request process?

Responses to Question 10A cover the need to amend the NDIS Act in regard to people under 65 years in RAC, who have been denied access on the grounds that their impairment is health-related,

<sup>&</sup>lt;sup>2</sup> <u>https://www.ndiscommission.gov.au/sites/default/files/documents/2018-07/NDIS%20Practice%20Standards.pdf</u>

not disability-related. The amendment should establish the right for the person to request a review of this decision (See Recommendation 12).

### c. Improve the participant planning and assessment process?

The Act should be amended to make it a legal requirement that:

- A participant receives a copy of the plan before it is finalised and has the opportunity to have it discussed with the planner
- Planning decisions must be consistent with the DDA

Currently the wait for Administrative Appeals Tribunal (AAT) means that a subsequent plan is always in place and the right to an external appeal will be closed to everyone. Section103 needs amending to add certainty of a participant's right to take a Section 100 decision to AAT if a subsequent plan is in place. The Section 103 amendment must also ensure that the AAT has jurisdiction to review the s100 decision even if a subsequent plan (or plans) has replaced the plan under the s100 review.

### d. Better define 'reasonable and necessary' supports?

People with complex disability support needs report that they need skills in interpretation of NDIS language and how to use it to translate their needs. Assistance is needed to interpret what is value for money. Value for money can be seen from the perspective of the person and their goals, something maybe more expensive, but still value for money. Understanding this concept can be contested when planners interpret it as the cheapest option.

### e. Improve the plan review process?

No amendments recommended.

### f. Improve the internal merit review process?

No amendments recommended.

### g. Improve the way other government services interact with the Scheme?

YPIRAC at risk of RAC admission commonly interact with multiple service systems such as hospitals and rely on high level system coordination to streamline timelines and processes so that they are not pipelined into RAC as a default. Currently health and NDIA system interfaces are poorly aligned and do not achieve efficient, timely and effective outcomes to prevent RAC admission. Gaps in services available in the community such as primary health and rehabilitation services mean they are not available as needed to prevent hospital and RAC admission.

While the following actions do not require changes to the NDIS Act, they refer to necessary strategies that should be incorporated into the next National Disability Agreement.

Recommendation 24: That the new National Disability Agreement includes the requirement that all jurisdictions commit to policies that:

- a. Increase knowledge and capacity of primary health services to meet complex health care needs in the community
- b. Make slow stream rehabilitation services available in the community
- c. Make preventative health care available in the community and responsive to people with disabilities with high and complex needs

Recommendation 25: That the new National Disability Agreement includes the commitment of the NDIA to lead national action jointly with health services, to identify and address interface problems by:

- a. Investigating and tracking service gaps such as agreement on responsibilities for funding community nursing for people with complex needs
- b. Committing funding to resolve the identified gaps in services

c. Establishing joint escalation procedures and processes for people with complex support needs

### **Plan amendments**

Key discussion questions

### 28. How else could the NDIA improve the process for making changes to a plan?

When requested by a participant, plan reviews should not entail a whole plan review of every item, thereby risking changes in other support items that do not need changing.

The NDIA must assign dedicated planners for people with complex disability support needs as they can develop a greater understanding of the participant's needs, and respond efficiently to changes in their needs and requests for plan updates.

# 29. What are the significant challenges faced by NDIS participants in changing their plan?

The challenges for participants with complex disability support needs and/or the providers supporting them, include:

- Many people report that changing plans takes a lot of time (e.g. some participants in the community are waiting for 6-9 months for a response to their change of circumstances request)
- Additional documentation to outline the request for changing the participant's plan is time consuming and can result in added stress and delays to the participant receiving supports that are essential for their capacity building
- Many participants need support with the process to change their plan

# 30. How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?

Recommendation 26: That the NDIA adopts:

- A more streamlined process for people to request changes to their plan
- The allocation of a dedicated planner for people with complex disability support needs to ensure a more efficient and person-centred process/experience
- A process to enable participants to request changes to each line item in their plan without impacting on the rest of the plan

# 31. How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?

Participants currently have 28 days to provide evidence for their plan change request. If they don't process their evidence in that time, they can ask for an extension. However, many participants and staff are unaware of this option, therefore this needs to be more clearly communicated by the NDIA. If the NDIA is experiencing frequent or significant numbers of requests for extensions, this could indicate the need to extend this initial 28-day time frame.

# 32. Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?

An interim plan for participants in hospital that focuses on hours for specialist assessment and housing exploration should be coupled with a streamlined process for updating this plan closer to the time of the participant's discharge from hospital. This streamlined process will facilitate a timely and effective discharge for the participant into the community, and the updated/longer plan with additional supports will respond to the participant's needs in the community and reduce the necessity for readmission to hospital.

### RECOMMENDATIONS

### Principles

Recommendation 1: That the Participant Services Guarantee includes additional principles of 'Human rights-based', 'Goal-centred, evidence-based and outcomes focused', and 'Clear and regular communication'; and amends the principles of 'Engaged', 'Valued' and Decisions are made on merit' by renaming them.

### **NDIA Service Standards**

Recommendation 2: That the NDIA sets the Recommended Service Standard intervals for measurement of the principle 'Timely' as detailed in the response to Question 4 above.

Recommendation 3: That the NDIA adopts a set of measures against each principle that enables the monitoring of progress on the Young People in Residential Aged Care Action Plan.

### Measurement

Recommendation 4: That the Participant Service Guarantee adopts a set of additional qualitative measures against each principle to gain participants' views on performance against the principles.

### Access to the NDIS

Recommendation 5: NDIS representatives to initiate proactive contact with young people in RAC to facilitate their connection to the NDIS.

Recommendation 6: That the NDIS key contact is allocated at point of access approval for YPIRAC and people with complex needs in hospital to provide details re complex pathway key worker.

Recommendation 7: Ensure that people with complex disability support needs in hospital have access to services from a Hospital Liaison Officer (HLO) (independent or NDIA-appointed) to assist them to navigate inflexible eligibility requirements (palliative care exclusions, residency exclusions).

Recommendation 8: Have an electronic Access Request Form (ARF) available to people in hospital or in RAC, to reduce time delays that result from requesting an ARF.

Recommendation 9: Grant automatic NDIS eligibility status for people with new, severe disability and identified with specific AN-SNAP codes. NDIS to review the participant's ongoing eligibility at 3-6 months.

Recommendation 10: ACAT and the NDIA to set up an automatic notification to the NDIA when a person under 65 is assessed as eligible for RAC, to act as a trigger for the NDIA to immediately commence outreach to the person.

Recommendation 11: That the NDIS provides plain English explanations for all decisions, and offers additional assistance for people with communication and cognitive impairments who may need support to understand and/or challenge a decision.

#### **NDIA Access Decisions**

Recommendation 12: The NDIA to amend the NDIS Act to address the issue where people under 65 residing in RAC, have been declined entry to the NDIS on the grounds that their impairment is health-related, not disability-related. They should be able to request an immediate review of the NDIS disability decision by the CEO of the NDIA. The CEO should be required to review the decisions within 14 days. If the CEO upholds the decision, the person should be directed to a disability advocacy service with relevant expertise to assist the person to consider their options.

#### **NDIS Planning Process**

Recommendation 13: The NDIS to allocate skilled planners, not LACs to people with complex needs in hospital.

Recommendation 14: The NDIA should provide YPIRAC, or at risk of RAC admission, with funding for support coordination and plan management to ensure that they have the means to purchase supports from a range of providers.

Recommendation 15: The NDIA to provide YPIRAC who have a goal of leaving RAC funding for Allied Health Assessment for Exploring Housing Options, and build in a plan review after 3 months to transition towards their preferred alternative to RAC.

Recommendation 16: The NDIA to implement access for people with complex disability needs in hospital, to an interim plan, and/or access to immediate funding for interim supports critical to timely hospital discharge.

### **Plan implementation**

Recommendation 17: That NDIS senior planners carry out check-ins for participants who have not drawn down on their plan within 3 months to ensure they have information and resources to access their plan supports.

### **Plan Reviews**

Recommendation 18: The NDIS to offer face-to face reviews for people with complex disability supports in order to enable effective participant communication.

Recommendation 19: The NDIS to:

- Ensure communication regarding the plan review is sent to the participant's nominee or support persons, along with the participant themselves
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- Ensure that plan reviews for people with complex disability support needs are done in person
- Ensure participants and their support persons have sufficient time to prepare for their plan review meeting (e.g. 2 months prior)

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### Seeking a review of a NDIS decision

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### NDIS Act and Rule amendments

Recommendation 22: The NDIA to amend the SDA Rules to enable participants with SDA supports to live with their families.

Recommendation 23: The NDIS practice standards, which are part of the Rules, be amended to require all providers to completely separate housing and support by 2022, and that through the audit process they submit an action plan showing where they are on the separation continuum and what actions they are taking to achieve full separation by 2022.

Recommendation 24: That the new National Disability Agreement includes the requirement that all jurisdictions commit to policies that:

- a. Increase knowledge and capacity of primary health services to meet complex health care needs in the community
- b. Make slow stream rehabilitation services available in the community
- c. Make preventative health care available in the community and responsive to people with disabilities with high and complex needs

Recommendation 25: That the new National Disability Agreement includes the commitment of the NDIA to lead national action jointly with health services, to identify and address interface problems by:

- a. Investigating and tracking service gaps such as agreement on responsibilities for funding community nursing for people with complex needs
- b. Committing funding to resolve the identified gaps in services
- c. Establishing joint escalation procedures and processes for people with complex support needs

Recommendation 26: That the NDIA adopts:

- A more streamlined process for people to request changes to their plan
- The allocation of a dedicated planner for people with complex disability support needs to ensure a more efficient and person-centred experience
- A process to enable participants to request changes to each line item in their plan without impacting on the rest of the plan



# Summer Foundation Submission to the SDA Limited Cost Assumptions Review:

**Enabling Families and Friends to Live Together in SDA** 

The NDIS SDA Pricing and Payments Framework currently imposes a penalty on SDA providers who house families and friends living together, this penalty can be up to \$60,000.

This submission outlines how this problem can be solved.

The National Disability Insurance Scheme (NDIS) pricing and payments framework for Specialist Disability Accommodation (SDA) has several barriers that stop families and friends from being able to live together in SDA housing.

The 3 current barriers are:

- 1. The SDA Rules require each resident to have their own bedroom this means a participant in a couple relationship needs to have a 2-bedroom dwelling, and a couple with a child can only live in a 3-bedroom property.
- 2. The SDA Rules also require that a majority of bedrooms meet the design category requirement (e.g. a participant in a couple relationship and a child in a High Physical Support Apartment need to have a 3-bedroom apartment; and 2 of those bedrooms must meet Livable Housing Australia Platinum Plus Standard).
- 3. The SDA pricing assumes all residents have SDA. This is evidenced in the SDA Price Guide where 'resident' is defined as any person living in the dwelling. This means a participant's SDA payment drops by 40-60%. This is because the pricing is based on the assumption that they are sharing with another SDA resident. The SDA provider receives less income from housing a participant and their partner and child than if they housed the participant by themselves.

These restrictions make it unlikely for a family to live together in SDA and prevents an SDA resident from living with a friend who does not have SDA. Providers receive less funding from SDA than if they had just accommodated the participant without their family or friend.

For example, the price for a '2 bedroom apartment with 1 resident' is \$109,273 per resident; while the same 2 bedroom apartment with 2 residents will be paid the lower amount of \$49,299 per resident. This means the provider receives \$48,380—a reduction of \$59,974—for housing the same resident when their partner moves into the dwelling.

This is an untenable situation for families where the SDA policy actively disincentivises families living together, to the detriment of participant outcomes and at the expense of long term NDIS costs.

The NDIS benefits substantially where a participant with SDA lives with their family or with a friend. The cost of providing support to the participant can be reduced through informal support. We also know that outcomes are improved when a person can live an ordinary life in the community and can choose where and with whom they live.

The Disability Reform Council (DRC) agreed to change the SDA Rules to address this problem, by:

- Allowing couples and children to share a room where they choose to do so (e.g. enabling a couple to live in a 1-bedroom unit)
- Removing the majority of bedrooms rule (e.g. a couple and child live in a 2bedroom SDA high physical support property, only 1—rather than both bedrooms need to meet LHA Platinum standards).

While these changes are a step in the right direction, more needs to be done to enable families and friends to live together in SDA. Further adjustments to the Rules are needed so that families and friends are able to live together in SDA.

### Real life example – Price impact of accommodating family members

An NDIS participant has a significant acquired brain injury sustained in an accio participant has significant cognitive and self-care needs and has resided in hospi the past 2 years since the accident occurred.

The participant is also a mother, whose accident occurred when her daughter was just a few months old. Her partner and daughter have been supported by the participant's parents throughout this period of recovery in hospital.

The participant leaves hospital and moves into a 2-bedroom SDA High Physical Support apartment. The SDA provider is paid \$109,273 per annum in SDA payments from the National Disability Insurance Agency (NDIA). The participant wants her husband and baby to move in with her. They request permission from the SDA provider to move into the 2bedroom apartments.

As a result of allowing the person's partner and daughter to move in, the SDA provider's payment reduces to \$48,380. This is a reduction of \$59,974 per annum. The SDA market is highly leveraged. This SDA property costs \$900,000, with the cost of interest alone \$49,500. This is before the amortisation of accessibility features, maintenance, property management etc. The SDA provider is unable to accept such a significant drop in SDA income. The SDA provider therefore advises the participant that despite residing in a 2-bedroom property, her husband and young child cannot move in due to the price penalty on families imposed by the NDIS' SDA pricing structure.

The solution proposed would see the payment reduced only by the amount of rent collected from non-SDA tenants. This would enable the family to live together, and have the SDA payment reduced only by the amount of rent charged to the participant's partner. SDA providers would then be able to allow participants to have family and friends reside in their property, providing informal support and reducing costs to the NDIS.

#### **Recommended Solution**

In February 2019, the DRC and the NDIA said they will explore ways to reduce disincentives or barriers for families to live together, noting that SDA funds can only be used to support the provision of housing for eligible SDA participants.

To achieve this, we recommend the following:

- 1. Defining a resident as an NDIS participant with an SDA payment in their plan, enabling a participant's children, partner or friend to move into their home and not counting towards the number of SDA residents;
- 2. Create a new category of people who can live in SDA. This category can be called "non-SDA co-residents".
- 3. An SDA provider would be able to rent the SDA property to non-SDA co-residents when the following conditions are met:
  - the property must only house 1 SDA resident; and
  - the SDA provider must seek their permission to house a co-resident;
- 4. Non-SDA co-residents would be expected to pay market rent for residing in a dwelling. The SDA provider undertakes the following steps when determining market rents for non-SDA co-residents:
  - a. SDA provider determines market rental for a dwelling based on comparable market rentals,
  - b. divides the market rental by total number of residents (including SDA and non-SDA participants, but excluding any dependent children)
  - c. multiplies by number of non-SDA co-residents (excluding any dependent children)
  - d. records this determination of market rent for non-SDA co-residents as evidence to be included in external auditing of SDA provider compliance.
  - e. Any non-SDA co-residents are advised of market rent by the SDA provider and the provider can charge non-SDA co-residents up to market rent;
- 5. Where the SDA tenant and SDA provider agree to co-residents who are non-SDA coresidents:
  - a. the provider advises the NDIA that there are non-SDA co-residents and the provider's determination of market rent for non-SDA co-residents and provides evidence that a non-SDA co-resident has been approved by the SDA resident;
  - b. the NDIA reduces the amount of SDA payments to the SDA provider in the service booking by the potential market rent the SDA provider can charge coresidents (this results in the NDIS recouping the unspent amount of SDA;
- 6. Enrolment of the dwelling there would be no changes to the way dwellings are enrolled, nor any need to re-enrol dwellings if the number of non-SDA co-residents

changes. The SDA Provider would continue to enrol the dwelling for the number of SDA residents will be living in the property;

- 7. Leasing to SDA participants living with non-SDA co-tenants SDA providers should have a single lease with the SDA tenant.
  - The SDA providers' relationship with non-SDA co-residents is through the participant and their lease. As a result, the rent charged by the SDA provider to the SDA participant would include their Reasonable Rental Contribution (RRC) and the market rent for any co-residents the SDA tenant chooses to live with.
  - In the event of a co-resident moving out, the SDA tenants lease would be amended to reduce their rental contribution back to the RRC. This ensures housing stability and security for SDA residents. The SDA provider would advise NDIA of the change, and this would result in an amendment to the service booking to increase the SDA payment as a result of a non-SDA coresident leaving the property.

This solution allows for a person with SDA to live with families and friends. It represents and enables an ordinary life for NDIS participants. It allows the SDA resident to have their SDA determination stay in their plan so they can move between properties and change their living arrangements as they choose without the need for a plan review.

SDA rule	Recommended SDA rule change
6.1 d)	
At least one private bedroom has been made available for the participant or, if the participant is a member of a couple, at least one private bedroom and a second room that may be a bedroom or another similar sized private room has been made available to the couple;	At least one private bedroom has been made available for the resident and if the resident is a member of a couple, they can choose to share the one private bedroom with the non-SDA co-resident;
6.1 f)	
The number of bedrooms and similar sized private rooms in the dwelling is at least equal to the number of residents for which it is enrolled;	No changes required because 'resident' would mean the NDIS participant with SDA in their plan;
6.10 c) & 6.11 f) & 6.12 c)	
All its shared areas and the majority of its bedrooms and similar sized private rooms comply with the Minimum Requirements in the NDIS Price Guide for a design category mentioned in paragraph 4.3 other than Basic design.	All its shared areas and the SDA resident's bedroom comply with the Minimum Requirements in the NDIS Price Guide for a design category mentioned in paragraph 4.3 other than Basic design
6.18 (vi) the number of	The number of participants with SDA in their plan intended to
participants with SDA in their plan	reside in the dwelling

The changes to the SDA rules that would be required are outlined in the table below.

intended to reside in the dwelling	
(which may be lower than the	
number of residents for which the	
dwelling is being enrolled);	
7.9	
The applicant must (if intending to	No changes required because 'resident' would mean SDA
provide SDA) declare that it will	participant;
not house more residents in an	
SDA dwelling than the number for	
which the dwelling is enrolled	
under Part 6.	
7.19 & 7.25	
The registered provider must not	No changes required because 'resident' would mean SDA
enrol a dwelling to house more	participant;
residents than the number of	
bedrooms or similar sized private	
rooms in the dwelling.	
7.26	
In the case of dwellings that are	On the basis that the provider is a participant providing SDA
enrolled to house more than five	to themselves (in accordance with
long-term residents on the basis	paragraph 6.10(b)(ii) or 6.12(b)(ii)), the provider must charge
that the provider is a participant	any non-SDA co-resident market rent or a negotiated rent;
providing SDA to themselves (in	this includes the participant's spouse or de facto partner; the
accordance with	SDA price is reduced by the market rent amount received
paragraph 6.10(b)(ii) or 6.12(b)(ii)),	from non-SDA co-residents.
the provider must not house any	
resident in the dwelling other than	
the participant's spouse or de	
facto partner and children	
7.3	
The registered provider must notify	The registered provider must:
the Agency if the provider	1. Notify the Agency if the provider proposes to charge rent
proposes to charge rent that	that exceeds the SDA amount to be funded by the
exceeds the amount to be funded	Agency plus the reasonable rent contributions payable by
by the Agency plus the reasonable	the participant
rent contributions payable by the	2. Sign an agreement declaring if other rent is going to be
participant	collected from a non-SDA co-residents and provide
· ·	evidence that this has been approved by the SDA
	resident;
	,

# An NDIS participant has a significant acquired brain injury sustained in an accident. See case study description above

The participant is residing in a 2-bedroom SDA High Physical Support apartment. The SDA provider is paid \$109, 737 per annum in SDA payments from the NDIA. The participant and her family decide that her husband and baby will move in.

The SDA provider prepares a market rent estimate for the property. The market rent is determined to be \$600 per week. The provider divides this by the number of adult residents (2), resulting in a contribution of \$300 per week in market rent for any non- SDA co-residents.

The participant's partner is advised that the SDA provider will charge the market rent (\$300 per week) if he chooses to move in. The participant's husband decides to move in. The SDA provider advises the NDIA that a non-SDA co-resident is residing in the dwelling, that market rent is determined to be \$300 per resident and that the service booking for the SDA payment should be reduced by \$300 per week.

As a result of allowing the person's partner to move in the SDA provider's payment reduces by \$15,600 per annum. The SDA provider charges the participant's partner the market rent, and is in the same financial position as if the participant's partner had not moved in.

The NDIA has recouped \$15,600 per annum in SDA payments. It is also highly likely that the NDIA's cost of support will significantly reduce given the person's partner is likely to provide informal support.

The participant achieves significantly better outcomes, being able to remain connected to her infant child and maintain her relationship with her partner.