



# National Disability Insurance Scheme (NDIS) Costs

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Summer Foundation Submission to the Issues Paper

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## CONTENTS

Contents.....	2
EXECUTIVE SUMMARY.....	4
INTRODUCTION .....	6
About the Summer Foundation.....	6
Young people in aged care in Australia .....	6
Australia’s human rights obligations .....	6
Australia’s National Disability Strategy and the role of the NDIS.....	7
The context of the Current Submission.....	8
SCHEME COSTS.....	9
Economic benefits from providing reasonable and necessary support .....	9
The critical role of housing.....	10
The impact on the health system and potential long-term savings.....	10
Costs Savings Through Investment In Technology.....	11
Cost Savings Through Investment In Supporting Participants To Self Manage.....	12
Reasons For Low Utilisation Rates Of Funding Packages.....	13
INTERSECTION WITH MAINSTREAM SERVICES: THE HEALTH & DISABILITY INTERFACE AND OTHER SERVICE GAPS.....	14
Gaps in Rehabilitation , Housing and Transport.....	16
Slow stream rehabilitation .....	16
Housing .....	17
Transport.....	18
Information Linkages and Capacity (ILC) and Local Area Coordination (LAC).....	18
National Injury Insurance Scheme (NIIS).....	19
PLANNING PROCESSES .....	20
The first plan approach.....	22
Approaches to assessment and the need for specialists in planning for people with complex needs	23
NDIA’s budget-based approach to planning .....	24
Avenues for resolving disagreements about participant supports.....	24
MARKET READINESS.....	25

Will Participants Be Ready .....	25
Will Providers Be Ready .....	26
<b>RECOMMENDATIONS .....</b>	<b>28</b>
Remove the bureaucratic hurdles people preventing young from accessing the NDIS.....	28
Bring young people in aged care into the NDIS faster and with a higher priority.....	28
Bring forward support for young people in aged care who live in the last rollout sites .....	29
Build the capacity of aged care providers to be ready for the NDIS.....	29
Stop the pipeline of entry into aged care from the health system.....	29
Build the capacity of people with disabilities in aged care to effectively participate in the NDIS	30
Build the capacity of people with disabilities to use technology .....	31
Take action to address the broken interface between health and disability.....	31
Develop an effective national approach to quality and safeguarding for SDA.....	32
Support SDA market readiness .....	32
Invest in building the capacity of people with disabilities to self manage their supports .....	33
<b>REFERENCES .....</b>	<b>34</b>

## EXECUTIVE SUMMARY

The National Disability Insurance Scheme (NDIS), when designed correctly and implemented effectively will transform the lives of people with disabilities and assist Australia to meet its human rights obligations. By increasing socio economic participation, the scheme will also provide significant improvements to Australia's economy, raise the shamefully low employment levels of people with disabilities and carers and increase our nation's GDP. By providing individualised funding and shifting control from service providers to people with disabilities, economic efficiencies will follow, as consumers chase value for money and achieve greater outcomes.

However, young people in aged care are facing significant barriers accessing the scheme as well as problems developing and implementing their NDIS plans. The bureaucratic processes in the NDIS as well as a lack of service expertise and appropriate housing are preventing hospitals from discharging people with disabilities with complex health needs back into the community.

Preventing new entries to Residential Aged Care (RAC) requires information and education at the coalface of discharge planning, and liaison roles that can oversee smooth transition of supports between sub-acute health and the community. People with complex support needs leaving sub-acute services require flexible and responsive supports that can respond to changes in a timely way, and their needs may change rapidly, requiring input from both health and disability providers, especially in the period immediately after discharge.

The lack of suitable housing is a significant barrier to moving young people out of RAC and a major reason why they are remaining in hospital unnecessarily or moving into inappropriate institutionalised settings. The delay in introducing SDA payments, the hold-up in these payments being issued and market uncertainty around quality safeguards has meant that very few housing options have been made available. This has meant that funding packages cannot be effectively utilised as the person remains in a nursing home or hospital bed with nowhere else to go.

Young people in aged care and those at risk of entry require a coordinated effort across sectors to meet their needs. It is not always clear which sector should be delivering a particular service. For people in rehabilitation after trauma or injury, the split of responsibilities between systems result in delays in service delivery and an inefficient service response. For younger people in aged care to have good outcomes, a jointly resourced approach across health and disability sectors is more efficient and effective than the current cross referral pathways.

For young people in aged care, who have complex support needs, planning is a difficult process. This is not a group, generally, who can navigate the NDIS pathway independently. There are significant inequities emerging because of the varied skill levels of planners, the amount of advocacy or supports an individual can access to prepare for planning, and the hasty haphazard manner in which plans are being developed.

*We need to remember that being forced into aged care is a terrible outcome for young people, their families and friends and for our country. These young people's emotional, physical and mental health all decline while they live in aged care. As aged care compounds a person's disability, they are likely to have higher health and support costs when access to the NDIS is delayed. It is a terrible waste of human potential and resources.*

We need to take action to ensure that the NDIS delivers on its potential to stop young people being forced into aged care.

We need young people in aged care and those at risk of entering, to have an easy pathway into the NDIS, by making this group a designated "program" and bringing forward support for young people in aged care who live in the last rollout sites.

We need to stop the pipeline of entry into aged care with a strategic plan for discharge from hospital to the community through an effective NDIS plan, facilitated by expert designated staff who are responsible to prevent transfers of young people from hospital into aged care.

We need to fix the broken interface between health and disability so people can live healthy lives in the community and to prevent costly hospital admissions. This will require health outreach services that provide 24 hour on call nursing with staff trained to work effectively with people with complex disability and health needs. It will also require nationwide access to slow stream rehabilitation, transitional health services and ongoing support coordination for complex clients with changing needs.

We need to build housing that is accessible, affordable and adaptable to the specific needs of people with complex disabilities. We need to improve accessibility in the mainstream housing market and develop Specialist Disability Accommodation (SDA) that leads to positive outcomes associated with an active and full life in the community. There is a danger that the market will not provide this and unless we have an effective national approach to quality and safeguards and clarity with respect to the roles and responsibilities of SDA providers.

We need to build the capacity of people with disabilities with complex needs to make the most of the NDIS. It is critical to develop understanding about how to prepare for planning and how to make informed choices about housing and support.

*Building capacity of individuals and their families to self manage is essential for the NDIS to maximise value and participant satisfaction.*

## INTRODUCTION

### About the Summer Foundation

The Summer Foundation, established in 2006, is an organisation that works to change human service policies and practices related to young people (18-64 years old) living in, or at risk of, entering residential aged care (RAC) facilities.

OUR VISION is that young people with disability and complex support needs will have inherent value as members of our society, with access to services and housing that supports their health and wellbeing.

OUR MISSION is to stop young people from being forced to live in aged care because there is nowhere else for them.

### Young people in aged care in Australia

According to recent Senate Estimates there were 6225 young people in Residential Aged Care (RAC) (Parliament of Australia, Senate Community Affairs Committee, March 2, 2017). Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society. Fifty three per cent of young people in RAC receive a visit from a friend less than once per year and 82% seldom or never visit their friends (Winkler, Sloan, Callaway, 2007). They generally lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community (Winkler, Sloan, Callaway, 2007).

Senate Estimates also tell us that on 31 December 2016, there were 374 young people in residential aged care in the National Disability Insurance Scheme with a plan . A total of 2,058 young people in aged care were scheduled to transition into the National Disability Insurance Scheme in the 2016-17 financial year.. (Parliament of Australia. Social Service Portfolio, December 2, 2016). Therefore, the NDIS is not meeting its own targets with respect to transitioning young people in aged care into the NDIS.

### Australia's human rights obligations

These statistics demonstrate that Australia is failing to meet its obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the United Nations CRPD says that all people with a disability have a right to live in the community. The convention stipulates that people with a disability should have the “opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements” 9, p. 13 (United Nations Convention on the Rights of Persons with Disabilities, 2007). This convention also states that people with disability should have a “range of in-home, residential and other community support services including personal assistance...to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

## Australia's National Disability Strategy and the role of the NDIS

Australia's National Disability Strategy 2010-2020 provides a ten-year national policy framework for improving life for Australians with disability, their families and carers (Parliament of Australia. Social Service Portfolio, May, 2012). It represents a commitment by all levels of government, to address the challenges faced by people with disability, and in doing so, should stop young people being forced to live in aged care. In this strategy, Australia has committed to a range of outcomes including:

- People with disability to live in accessible and well designed communities with opportunities for full inclusion in social, economic, sporting and cultural life.
- People with disability, their families and carers to have access to a range of supports to assist them to live independently and actively engage in their communities.

In order to achieve these outcomes, a major overhaul of the disability service system is required. This was evidenced by the Productivity Commission's report into disability care and support who recommended that a National Disability Insurance Scheme (NDIS) (Australian Productivity Commission. Disability Care and Support, 2011):

*“Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed... a coherent and certain system for people with a disability is required — with much more and better-directed resourcing, a national approach, and a shift in decision-making to people with a disability and their carers”*

Reference: Productivity Commission, 2011, p.5

The implementation of a NDIS holds the promise to enable the full socio-economic participation of people with disabilities and a future where people with disabilities have the necessary housing and support to where, how and with whom they want to live. Thereby having their human rights upheld and stopping young people being forced into aged care.

Without access to housing, people with disability may have the personal care support to move out of home but they will not have the access to housing that is critical to leaving the family home.

Without access to well-located, secure and affordable housing, the NDIS' predicted GDP gains are unlikely to be achieved.

## The context of the Current Submission

The Summer Foundation is pleased to have the opportunity to contribute to the Productivity Commission's study into NDIS Costs. Our organisation is well positioned to comment, as we have been heavily involved in working to ensure that the scheme meets the needs of people at risk or currently living in aged care. This work ranges from high-level policy work in relation to the NDIS, sector development in the field of neurological disability, market and technical development in Specialist Disability Accommodation, as well as in-depth research through our partnerships with leading academic institutions including Monash and Latrobe University. We are also active members of the Australian Housing and Urban Research Institute (AHURI).

This submission also brings together expertise from our Ambassador Program and NDIS Connections projects. The case studies and examples outlined are real people who have had their stories deidentified, unless they were featured in our digital stories where participants have provided their consent to have their stories publicly available on YouTube.

Our Ambassador program provides us with insights that are only possible through our ambassadors' first-hand experience of living in a nursing home, or being at risk of entering RAC. Our Ambassadors work in a variety of ways to advocate for young people with disability who are at risk of entering aged care. Some of our ambassadors' stories have been included here to demonstrate the human impact and explain the difference that the NDIS is making to people's lives, as well as its shortcomings. Our ambassadors have also worked with us to create digital stories that are available on YouTube and some of these have been linked in our current submission

The NDIS Connections Project works to link eligible Young People in Residential Aged Care (YPIRAC), and to support them to register, prepare and implement their plan. The project commenced in the Hunter and Barwon NDIS trial sites, later expanding into the ACT and Perth Hills (WA) trial sites and now operates in the various rollout areas. Through our connections work, we have developed an in-depth understanding of the NDIS and what is needed to make the scheme work for young people living in or at risk of being admitted into a nursing home. The work of the NDIS Connections team informs our policy advocacy and the recommendations contained in this report.

In this submission we have addressed the questions put forward in the Productivity Commission NDIS Costs Issues Paper that are related to our mission of stopping young people with disabilities being forced to live in aged care. The sections reflect the topic areas in a thematic format, with emphasis on sections that relate specifically to NDIS costs. A question and answer format would have resulted in unnecessary repetition.



## SCHEME COSTS

*Our understanding of NDIS costs must occur within the context of what happens to people and our society when reasonable and necessary supports are not provided. We know what that looks like, and the fact that there are over 6000 younger people with disabilities living in aged care demonstrates that we have a long way to go to support all Australians to be active participants in the community. Any analysis of scheme costs must consider the economic benefits of providing reasonable and necessary supports. There are significant economic benefits to be had by providing people with disabilities with access to appropriate housing, support, and technology. There are also economic benefits in building the capacity of people with disabilities to exercise choice and control under the NDIS.*

### **Economic benefits from providing reasonable and necessary support**

The Productivity Commission's study examined both the costs of the NDIS as well as the benefits of the NDIS. It was found that, as a result of increases in the employment of people with disabilities and their carers, the NDIS will lead to significantly higher benefits to the economy than the cost of the NDIS (Australian Productivity Commission. Disability Care and Support, 2011).

It was estimated that increasing the number of Australians with disability in employment by around 100,000, through the provision of reasonable and necessary supports would add around \$8 billion per annum to Australia's GDP. There would also be a further savings to government of around \$2.7 billion per annum in reduced Disability Support Pension (DSP) payments.

In relation to carers, the Productivity Commission estimated that around 220,000 carers were supporting people with disability within their homes. Of these, 120,000 carers were not employed. Over 10% of these unemployed carers (15,000) cite the lack of disability support for the person they care for as the reason they cannot work. If half of these unemployed carers return to work, Australia's GDP benefit would increase by \$750 million.

In fact, the Productivity Commission suggests that this is an underestimate of the benefit of assisting carers return to work, as it does not count the benefit of employed carers increasing their hours or employment benefits to non-resident carers. This larger benefit could increase GDP by around \$1.5 billion per annum.

## **The critical role of housing**

Securing employment for both people with disability and carers will depend on a range of supports, including access to well located, secure and affordable housing. Housing is a critical enabler of employment for people with disability. Without access to housing located near employment, people with disability are unlikely to achieve the employment gains modeled by the Productivity commission. Many people with disability are unable to use private transportation, making access to public transport a critical enabler of employment. The inability to find affordable housing that provides access to employment will be an ongoing barrier to increasing employment rates.

Access to housing is an even more critical enabler of carers returning to work. Access to housing enables carers to return to work because adult children with disabilities are able to leave home and be supported to live in the community. Without access to housing, people with disability may have the personal care support to move out of home but they will not have the access to housing that is critical to leaving the family home.

*Without access to well located, secure and affordable housing, the NDIS' predicted GDP gains are unlikely to be achieved.*

## **The impact on the health system and potential long-term savings**

*Reasonable and necessary support and diverting young people with disabilities away from aged care and into appropriate housing with the right supports in place will also result in cost savings for the health system.*

Once in RAC, young people experience deterioration in their health, a loss of skills and their social networks diminish. Preventing new admissions is a much more efficient use of resources than letting young people be admitted to RAC and then moving them out. Most (59%) young people are admitted to an acute or rehabilitation hospital before their first admission to RAC (Winkler, Holgate, Sloan & Callaway, 2012). Preventing new admissions requires investment and involvement from both the health and disability sectors.

Young people in RAC are often highly susceptible to secondary conditions. These secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Periodic admissions to acute health services are common – 42% of young people in RAC are admitted to an acute hospital each year, with some people experiencing multiple admissions (Winkler, Holgate, Sloan & Callaway, 2012).

Peter's story demonstrates the serious impact that being forced into a nursing home can have on an individual's health:

Peter has a degenerative neurological condition. His life in a nursing home compounds the effects of his disease and corrodes any hope he has of regaining a more normal life. In the 5 years he has lived in the nursing home his health has deteriorated leaving him in pain and bedridden

Recently he was admitted to hospital with health problems exacerbated by inactivity resulting in an extended stay. Nursing homes rarely have active therapy programs or rehabilitation and his well-being has suffered the affects of little movement and poor quality health support. He came to the conclusion that he was actually more content in a clinical hospital environment than returning to his life in the nursing home. At least in the hospital there was an effort to keep health a priority. His emotional health is deteriorating each day as he considers his long-term prospects after he gets discharged and sent back to the nursing home.

### Costs Savings Through Investment In Technology

There is significant evidence that assistive technologies are effective in increasing independence, decreasing functional decline and reducing hospital and nursing home admission rates and reliance on support workers and on unpaid carers (Cook, A., & Polgar, J., 2015; Heywood, F., & Turner, L, 2007). It has also been shown that technology can enable community participation, maintain health and improve quality of life (AAATE, October, 2012; ARATA, 2012).

Our experience in developing housing and support models also demonstrates the benefits and the longer-term cost saving potential in technology. An evaluation of our Abbotsford housing project found that technology could:

- Reinforce each tenant's sense of, and capacity for, independence, privacy and personal control (through control of, for example, light, blinds, temperature, door access)
- Reinforce each tenant's confidence and sense of security when they were alone
- Create reliable communication, safety and security arrangements for emergencies and contingencies
- Simultaneously reduce the need for ever-present support staff by increasing each tenant's independence.

In our housing demonstration projects each tenant can alert staff at any time in the event of an emergency or need for urgent unplanned assistance using a range of devices (such as pendant, alert on the wall, alert button on an ipad or smart phone). In response to the alert, staff can make two-way voice contact with the tenant in their unit through hands free speakers and microphones located in all major rooms in their unit. Via an ipad or smartphone, tenants can operate the lighting, blinds, heating and cooling in their units as well as open the door to their unit and open the door to the apartment building to let visitors in.

In our housing demonstration projects, the user interface is a mainstream product, and is able to be adapted or customised to suit the ability and choice of the tenant at any given time. In fact, we are at a point now where assistive technology most commonly involves finding a mainstream product and making some adaptations made to fit the needs of the individual. The mainstreaming of adaptive technology provides significant cost savings due to the much larger size of the market.

*From an insurance perspective, it is important to note that these technologies, if implemented correctly, pay for themselves in the longer term and thereby provides cost savings to the NDIS. It is in the interests of the NDIS to invest in technology, including technology that is increasingly mainstream.*

### **Cost Savings Through Investment In Supporting Participants To Self Manage**

The Productivity Commission's study into Disability Care and Support demonstrated that cost benefits of a scheme that supports people to self-direct or self manage their funding (Australian Productivity Commission. Disability Care and Support, 2010). Research into the benefits of self-direction for participants and the Scheme are clear.

*An individual's ability to make decisions about how to use their funding leads to greater self-efficacy and resilience, better outcomes and a reduced need for paid support. It enables them to spend their budget on what provides them with the most value rather than a prescribed option that may not best suit their needs. It also results in cost savings for the NDIS by reducing spending on administrative fees and overheads, and allows more funding to be spent on what the individual decides will meet their goals.*

*The current practice of the NDIS of recouping any savings only serves to increase ineffective and unnecessary spending. Providing the individual with the freedom to use any cost savings towards the achievement of their goals over a longer timeframe is an important incentive to motivate participants to choose to self manage and to take on the administrative tasks involved in self-management.*

## Reasons For Low Utilisation Rates Of Funding Packages

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

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

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

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

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

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

*We know that plan development and implementation requires significant support and for many young people in aged care, their NDIS packages are sitting idle or are not being fully utilised until this support can be provided.*

## **INTERSECTION WITH MAINSTREAM SERVICES: THE HEALTH & DISABILITY INTERFACE AND OTHER SERVICE GAPS**

Young people in aged care and those at risk of entry require access to high levels of both disability and health supports. Currently, while there is still not enough housing to provide an alternative to RAC, access to quality health and disability supports needs to also include that provision in cooperation with the age care sector.

Experience so far for our cohort of entering the NDIS, indicates that the quality of access to supports and services from the NDIS and health systems varies greatly from individual to individual. The reason for this variation is not simply a lack of clarity about whose responsibility it is to provide a particular service, but the lack of real cooperation in jointly addressing a need for someone whose services sits across multiple sectors.

*Scarce resources are being wasted chasing the appropriate funder for a particular need, leading to a deterioration in health, unnecessary hospital admissions and costs to the economy.*

Young people living inappropriately in residential aged care facilities inherently have complex disability needs and complex health support needs. Although the NDIS Operational Guideline for Supports in the Plan outlines that nursing care, training and supervision is a reasonable and necessary support, our experience is that this vital service has not been included in people's Plans. This may be for a variety of reasons, including:

- the incorrect assumption from the NDIS Planner that community nursing will address these needs;
  - Community nursing was previously HACC funded and we know that this funding for people under 65 with disability was transferred to the NDIS, resulting in many community nursing ceasing services for people under 65.
- the incorrect assumption from the GP/family/therapy team that the NDIS does not fund this type of service;

Understandably there is confusion regarding what are reasonable and necessary high care needs given that people's health support needs range from monitoring blood pressure, blood sugars and weight, which may be deemed the responsibility of mainstream services; compared to skin integrity checks, tracheostomy tube changes and catheter changes, which are accepted as disability related and therefore reasonable and necessary under the NDIS.

The interface between health and disability is not working. The NDIS' effort at cost shifting is having a serious impact on the health of participants in the scheme. Add to this a lack of knowledge and understanding amongst planners of the NDIS and its Guidelines as well as the changes in mainstream nursing services has resulted in increased hospitalisations for people (due to urinary tract infections or skin breakdown) and others being at risk of remaining in residential aged care facilities. The impact of a broken interface between disability and health can have serious consequences as is demonstrated in Jarrod's story:

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

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

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

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

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

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

*Outcomes in the NDIS and health interface can be improved by funding arrangements that ensure all necessary sectors are contributing to service types that bridge systems, and are jointly responsible for achieving outcomes. In the compensable system, where insurance companies are liable for lifetime care costs across all sectors (Health and Disability in particular), then bridging services such as case management do not have artificial splits between systems that create barriers to efficient outcomes.*



Health services such as the Austin network in Victoria, have dedicated some of their staff resources to NDIS readiness, and have done internal education and support to their discharge planning teams, so that the NDIS is understood and access requests forms are being submitted in a timely way. However the responsiveness by the NDIA has been poor, with significant delays in getting planning underway, and implementation mostly is still not being achieved within reasonable timeframes.

A member of our connections team observed that, in some areas, not one person has been discharged from hospital to the community because the NDIS has been slow in processing their paperwork. When the NDIS is slow in processing a young person's forms, there are unnecessary financial costs on the health system, hospital beds are not available for the critically ill and the hospital has no choice but to move the person into aged care.

*The interface between health and disability is dysfunctional and needs significant investment to bring it back to health. Entry to the NDIS and effective planning requires an effective interface across these two sectors as well as one-on-one support and strong advocacy. Additional investment is required to make long-term and nationwide repairs.*

## **Gaps in Rehabilitation , Housing and Transport**

### **Slow stream rehabilitation**

*Slow stream rehabilitation is a critical determinant of NDIS scheme costs. More NDIS participants regaining functional capacity reduces the long term costs of the NDIS.*

Well planned, episodic and long term rehabilitation in a person's home and community is now recognised as best practice and the appropriate model for this is delivered through a combined health and disability framework. We also have evidence that extended rehabilitation is associated with measurable functional gains and a decrease in support costs.

Neither Health nor the NDIS are providing this service, particularly now with the progressive withdrawal of the *ABI: Slow to Recover* program in Victoria. Under the NDIS, we are seeing that the 'acute' phase of someone's rehabilitation, which is provided by Health, is completed, the provision of essential rehabilitative supports is not being provided in the community.

In June 2015, the *Senate Inquiry Into The Adequacy Of Existing Residential Care Arrangements Available For Young People With Severe Physical, Mental Or Intellectual Disabilities In Australia* recommended that the Council of Australian Governments (COAG) develop and implement a national rehabilitation strategy including a framework for the delivery of slow stream rehabilitation in all jurisdictions. In November 2016, the Australian government response to that recommendation was that it was "Not supported".



## Housing

People with complex and high-level physical disabilities are forced to live in aged care because they have limited access to necessary support and limited suitable housing options. The introduction of the NDIS will provide the support needed to live independently and for some it will also provide funding through Specialist Disability Accommodation (SDA) payments, to meet the cost of accessible housing. However, Australia's current housing market will not come close to meeting the demand for such housing unless Governments take action to stimulate supply. At recent Senate Estimates hearings in March 2017 it was reported that hardly any SDA payments have been made and this reflects the lack of SDA housing options in the community (Parliament of Australia, Senate Community Affairs Committee, March 2, 2017).

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

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

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

*We need a range of options to fill the gap in accessible and affordable housing for people with disabilities including models that enable people to live with their partner and/or children. Many (46%) young people in RAC are in partner relationships and 27% are parents of school aged children 2. Australia desperately needs a to create more housing that is both accessible and affordable. Rather than continuing to build segregated specialist housing, the housing needs of people with disability need to be incorporated into mainstream housing strategy.*

The Summer Foundation is taking action by developing new innovative housing and support models to demonstrate new living options for people with high-level physical disabilities. Our aim is to begin addressing the unmet need for accessible housing and to demonstrate design features for people with complex needs that can be replicated and improved upon. These projects bring together the latest in technology and adaptable design in conjunction with innovative approaches to support, and the use of assistive technology support people with significant disabilities to live with greater independence.

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

In November 2015, David acquired a brain injury that would dramatically and permanently change the direction of his life and that of his family. Devoted and persistent advocacy from his wife, combined with fortunate timing has prevented this man from falling through the cracks and ending up in a nursing home. He lived in an NDIS site at the time of his accident and while he was receiving inpatient rehabilitation, a rare supported housing opportunity emerged. The team supporting his rehabilitation worked with the housing provider, support service provider and the NDIS to implement a transition plan. The advocacy required to co-ordinate his move to a new supported home was extensive, and largely driven by his wife. Such a great outcome is rare, and aside from the heavy-duty advocacy required to achieve this, a pathway to a new permanent home from hospital is exactly how it should be in an ideal system. His wife reflects, "It's such a relief, its such a lovely lovely outcome for all of us...I know it would have been hard for our children to come and visit David in a nursing home, that was never going to be OK."

## **Transport**

Access to affordable transport is another significant gap, particularly for people living in regional and remote areas. People in metropolitan areas also face difficulties accessing transport that meets their needs and that they can afford. Our connections workers have observed that if a person is funded to undertake new activities in their NDIS plan, there is usually no provision for transport and no allocated funding. The result is that people are not able to undertake the activities that are necessary to improve their quality of life and they continue to be isolated. For young people in aged care, this means that they continue to be stuck in the nursing home and unable to achieve the goals identified in their plan.

## **Information Linkages and Capacity (ILC) and Local Area Coordination (LAC)**

The ILC funding was not used as it was intended by the Productivity Commission. Currently we are seeing ILC funding being used to fund planning for people in the roll-out zones of the scheme. The key role of capacity building for people with disability and mainstream services (so that they can be responsive to the needs of people with a disability), as well as responding to the needs of Tier 2 has mostly remained undelivered. In those instances where someone has not been found eligible we have not seen evidence of any attempts to refer that person into Tier 2 mainstream services. According to a member of our connections team, a rejection letter was sent to a gentleman we are currently supporting with no mention of any ILC support that he might be eligible for or how he might contact them, only how he might appeal the process

*There remains an urgent need to provide outreach that can identify young people in aged care, and engage each of them in the opportunity to become an NDIS participant. Coordinated services are needed to help them to understand and prepare for a planning meeting, as most cannot do this independently. For those who are currently in RAC, timeliness is important, as the longer they remain in RAC, without any additional supports, the more resources and effort are going to be required to enable them to return to active community participation.*

## **National Injury Insurance Scheme (NIIS)**

A no-fault insurance scheme for accident and injury should mean that a number of young people who have ended up in aged care (mostly those with traumatic brain and spinal injuries from home, farm and outdoor incident, but not car or workplaces accidents) should swap over from the NDIS to the NIIS. The NIIS will not take over responsibility for those with non-traumatic brain injuries (e.g. stroke, aneurisms, hypoxia and substance induced impairments). The service types required across traumatic and non-traumatic ABI may differ in detail but are common across funding streams, so jointly the NIIS and NDIS should create some scalable efficiencies.

Current injury related schemes do take on the liability for both Health and Disability related supports and service, which is not the case in the NDIS. There will be a demand for service that bridge the two sectors, but the NDIS will need to ensure this is possible or it risks poorer outcomes that will be possible under the NIIS.

The full establishment of the NIIS should result in a reduction in the overall liability of the NDIS as people with injury related disability switch to the NIIS. Those with complex support needs are generally high cost participants, so the number of those individual packages should reduce.

## PLANNING PROCESSES

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

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

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

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

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

Once in the planning process, wide variation in the skills and experience levels of planners has meant some plans have been woefully inadequate. However, with good support, and advocacy, and a planner who understands the person and their condition, people have been able to achieve excellent plans. We have found that the best outcomes occur when the planner is prepared to take the necessary time needed to understand person, as well as seeking out information from family members and practitioners who know the person well.

*For plans to be effective and well-informed, we recommend that greater effort is placed on engaging YPIRAC's 'communities of support' in the planning process as currently many families and friends feel peripheral to the process. Finding an effective way of including them would in the longer term save the NDIA money.*

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

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

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

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

Once the NDIS trial period had finished, the daughter's plan became due for review. The mother and daughter were confronted by the reality that the new planner was hopelessly inexperienced, *"This planner did not have a disability experience background and had no idea of the philosophy behind the NDIS and how it was meant to work out for the most important person – the client. I had to tell her how this was meant to work and what my daughter's requirements were and how to actually bring that to being!"*

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

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

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

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

*Additional consideration also needs to be given to exploring more meaningful social and economic integration for people with disabilities. Sadly much of the one to one support provision we see being*

*provided results in increased community presence and not true participation for its recipients. Employment opportunities are also not being explored at present for this cohort. Given the opportunity that employment would bring to improve quality of life and deliver socio-economic outcomes, this is disappointing and requires further effort and attention.*

Planners will always be focused on achieving outcomes for participants. For people with complex needs, particularly those who have had a history of institutionalisation, outcomes are likely to be slow, and unlikely to be smooth, so evaluating the planning process needs to account for those factors.

## **The first plan approach**

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

The first NDIS plan for many young people currently in aged care needs to include a Housing Options Package. This will give the participant 12 months to work out their housing goals and identify appropriate community options. This Housing Options Package funds a skilled practitioner to work through the questions listed above, as well as purchasing of specialist assessments from professionals such as an Occupational Therapist

With the first year of the NDIS plan taken up with these questions, it is not until the second year plan when the participant has the funding to approach the market and find their option. It can then take up to 24 months for a housing provider to build the required housing. This journey is three years from getting into the NDIS to leaving aged care for some young people. Three years is far too long for many young people with disabilities in aged care, particularly for those who have to wait until 2019 for the NDIS to reach their local area. Bringing forward the housing options package to all young people currently in aged care is one way to address the long wait.

We understand that there is some merit in a "first plan" approach for people with acquired disability, especially as they initially transfer from the sub-acute system in health to the community. This approach has been adopted in Victoria in the ABI-STR program, and recognises that functional capacity does not easily transfer between locations, and that goals can change rapidly according to the environment.

However, those first plans need to recognise that plan reviews will often need to be done after three or six months, and that consequent plans may be quite different in their make up and the resource required to achieve new goals.

We are also concerned that the 'First Plan' approach goes against the principle of 'person centeredness and choice and control'. We understand this is a pragmatic solution by the NDIA to getting as many people signed up to the NDIS in the shortest time possible but we don't support the process that compromises the underpinning principles of the scheme.

A member of our Connections Team observed that:

Part of developing people with disabilities' skills and independence is familiarising them with the market economy and their active role in it. They need to experience being consumers of services and not passive recipient of them. This is about setting expectations. Sadly if people's initial experience of the NDIS is receiving an 'off the shelf' – reference plans – then the promise of the NDIS for an individualised response is severely compromised. The NDIS is a once in a lifetime opportunity to reform the way in which disability services are provided and we have a role in ensuring that the NDIA do not renege on this. The NDIS must invest more time and resources into assisting people to develop their plans from when they enter the scheme so we can deliver something better than the broken system that we want to leave behind.

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

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

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

We recommend creating team structures that support planners working with those with complex needs, that can be robust over time, and maintain collective knowledge about assessment processes as team membership changes, is an avenue to retain and refine 'active' assessment processes and tools.



A member of the Summer Foundation connections team observed:

The NDIS relies heavily on Allied Health Professionals to Assess NDIS participants' needs. In general the assessment tools used by these professionals are valid and reliable. However, they tend to be only partial as it is the NDIS who dictates what needs to be assessed. OT's for example, are frequently asked to assess a person's equipment or technology needs but no time or resources are channelled into evaluating people's existing or potential skills levels. Opportunities to do what the NDIS originally set out to do, namely build individuals capacity and increase independence are therefore frequently missed.

### **NDIA's budget-based approach to planning**

*There are emerging problems in the interpretation of the price guide, as the language used starts to influence the way that services are requested. When the only way to get funding for goals is to ensure they are matched with the price guide, we see missed opportunities to provide valuable support that will reduce long term costs.*

Our connections workers have observed that budget-based approaches to planning have reduced planning to discussions about 'fundable' items rather than goals and desired outcomes. This is changing the framework from a person-driven, whole of life approach to a much more pragmatic discussion about quickly getting a plan completed. It has meant that many plans no longer are provided in draft form prior to being locked in, and when they are not adequate, require formal appeals or plan review requests.

### **Avenues for resolving disagreements about participant supports**

*It is important that there are cost-effective and easily accessible processes in place for resolving disputes and complaints as well as appealing decisions made by the NDIA. For people with communication difficulties and intellectual impairments, access to advocacy will be critically important for there to be a level playing field. In fact, timely and free access to advocacy is required by all participants of the scheme.*

Legal advocacy will be critically important in circumstances when complaints escalate to the Administrative Appeals Tribunal and all efforts should be made to resolve complaints without the need for legal representation.

When commenting on the NDIA's approach to resolving disagreements, a member of our Connections Team reported that:

The process for appealing a rejection of NDIS eligibility has many holes in it. For example, the rejection letter that a gentleman we supported to apply for the NDIS recently received had no date on it, rather important given that people are given a set amount of time to appeal the process. It also instructed him to phone or email the NDIA to start the appeals process – neither of which he had the skills or resources (access to mobile phone or computer) to do, effectively excluding him from the appeals process.



## MARKET READINESS

### Will Participants Be Ready

Engagement with the NDIS process relies upon an individual having a particular level of knowledge, experience and agency. Indeed the success of the NDIS is based upon ‘assumed capacity’ or the implicit belief that all prospective NDIS participants either possess these attributes or will be assisted to possess them (although by whom is still not clear). Sadly this is not the case for many young people in aged care whose knowledge, experience and agency are frequently compromised by their significant impairments, social isolation, lack of skills and knowledge, low expectations or loss of hope. Tackling these ‘disadvantages’ takes time and often skilled, assistance is needed if people with complex needs are to engage with the NDIS process in anything other than a tokenistic way.

*The current administration of the NDIS creates a high barrier for participation by individuals with complex needs. Young people in RAC typically have few informal supports and many have cognitive impairment. Most don't have ready access to a computer and/or are not able to navigate the Internet, both of which are required to activate plans and to find and negotiate supports with providers.*

Martin is a man in his early 50s with a lifelong disability who was permanently admitted to residential aged care (RAC) in 2012. Martin attended a special school where expectations were low and, despite a formidable mind, has poor literacy skills.

Martin lives on Disability Support Pension. His basic daily fee in RAC is 85% of his basic Pension. With the money left over each fortnight he struggles to cover his personal expenses. Martin can't afford a mobile phone contract that would provide him with with a smartphone and Internet access.

When Martin got his NDIS plan he had no idea how to activate it. He was frustrated to learn from his Support Coordinator that he needed to set up a myGov account to access the NDIS Portal. Martin has never used the Internet or email, and his RAC provider has refused to allow him to access their WiFi to build his capacity in this area. Martin feels disempowered by his total reliance on his Support Coordinator to manage all aspects his NDIS plan. A situation that he feels echo's his lack of control over any aspect of his life in RAC.

Various organisations are running information sessions for potential NDIS participants and their families ahead of rollout, providing an overview of the Scheme eligibility requirements and jurisdiction in an attempt to build their capacity to interact with the scheme. However, young people in residential aged care and their families, most of whom are unaware of the Scheme and their eligibility, often find it difficult to attend face-to-face sessions. More accessible and flexible approaches to delivering information and building the capacity of people with disabilities and their families are desperately needed.

## Will Providers Be Ready

*Provider readiness is essential to enable young people with severe and complex disabilities to live a good life in the community. This includes a workforce with the experience, skills and attitudes as well as community health services that are responsive and accessible to people with high support needs. Health outreach services that combine direct care with a 24-hour on-call service are needed for people in the target group who require intermittent nursing care.*

A pilot program jointly supported by Health and NDIA based on the [Alfred Mobile Assessment and Treatment Service](#) (MATS) program provides an evidence base for a model of community based health support for people with disability with high and complex needs to be rolled out across Australia. This pilot is likely to demonstrate cost efficiencies for both Health and the NDIA.

A major area of concern for Summer Foundation is the lack of SDA readiness, which is reflected in the lack of appropriate housing for people with complex needs.

*Organisations and investors wanting to provide housing in the NDIS are currently facing serious issues, particularly with respect to quality and safeguarding, that are holding them back from building housing for younger people in aged care.*

Firstly, NDIS is a national initiative, however disability housing requirements vary by state. Designing specialist housing is a small scale and intensive activity – navigating a maze of different regulations and redesigning housing models to meet each state’s requirements drives up the cost of housing. National variation also leads to inequality of housing options for people with disability across the country. The NDIS was intended to overcome these inter-state inequalities where some people with disability have access to housing options by virtue of their state of residency that are not available for people with disability in other states.

Secondly, State Government housing policies are overly restrictive and undermine choice and control; and community integration. Many State Government regulations for disability housing were designed decades prior to the NDIS. They focus on protecting people with disability against all risks at the expense of the core values of the NDIS, including restricting choice and control, autonomy and community participation. Requirements in some states could prevent people with disability from living in two-storey buildings, and require fire sprinklers to be installed throughout a home. This makes a person’s house feel like an hospital, rather than a home and doesn’t take into account the many other strategies that mitigate fire risk in apartment buildings.

Thirdly, specialist housing requirements remain unclear, and risk of misinterpretation to providers, including people with disability trying to enter home ownership. NDIS housing needs to comply not only with general state building requirements but also with special disability safeguards that are additional to normal buildings and therefore rarely known to builders. These requirements are poorly communicated to the market. As a result community housing providers and people with disability are currently building housing that could be non-compliant with the State’s requirements and therefore illegal to use for disability housing.

We are also concerned that the National Disability Insurance Agency is withholding SDA payments until each state makes its decisions around quality and safeguards. Current SDA providers housing people with disability are not being paid by the NDIS for this service. This is due to the NDIA's decision to prevent these providers from claiming any payments until each State establishes their quality and safeguards requirements. This uncertainty is having a serious impact on the sustainability of current SDA housing and is holding up future projects.

Finally, SDA readiness and choice and control within the SDA market is also being jeopardised by the SDA rules that require planners to allocate an in-kind SDA option, that is, government run housing in favour of other options that may be available in the market. This will limit market development and discourage investment in new and innovative housing options. It also reduces choice for NDIS participants. The SDA rules that providers must bear the full cost of vacancies, while appropriate in larger markets, will be problematic in the market such as those in regional/remote locations. In these locations the likely to see severe capital and borrowing restrictions because the risks will be seen as too high. Finally, the requirement in New South Wales that an SDA provider must be a Community Housing Provider places further restrictions on the SDA market.

## RECOMMENDATIONS

### Remove the bureaucratic hurdles people preventing young from accessing the NDIS

The Commonwealth should designate being in residential aged care a program that makes these young people automatically meet the NDIS requirements. The Commonwealth should write to the NDIA and direct them to add aged care to the list of 75 programs across Australia that are listed as giving automatic entry to the NDIS. Should any young people not meet the access requirements, the NDIS retains the power to revoke access to the NDIS.

*Removing bureaucratic hurdles for entry into the NDIS will result in cost savings by reducing the need for detailed access assessments.*

The Commonwealth and NDIA should commit to a one-off initiative to get all young people in aged care fully connected to the NDIS. The NDIA should set a target of Local Area Coordinators to work with every young person in aged care; or should fund a specialist LAC service for young people in aged care. Alternatively, the Commonwealth could fund a dedicated outreach initiative to make sure all 6,000 young people get an NDIS funded plan.

The NDIA should update its training to NDIS planners to ensure that all young people in aged care coming into the NDIS have the opportunity to leave aged care. The NDIA's policy is that all young people should be asked whether they wish to consider leaving aged care and the NDIA should automatically include a 'Housing Options Package' in their plan. This is not happening on the ground and requires more training and quality assurance reviews by NDIA to ensure it is being operationalised.

### Bring young people in aged care into the NDIS faster and with a higher priority

*Bringing young people in aged care into the NDIS faster will have long-term economic benefits because leaving aged care or being diverted away from aged care is associated with positive health outcomes, facilitate rehabilitation and reduces the likelihood of institutionalisation.*

The State and Commonwealth Governments should amend the 'phasing schedule' for the NDIS so that young people in aged care be eligible for the NDIS within the first three months of the NDIS becoming available.

The NDIS should report publicly on the number of young people in aged care who have become eligible participants, and the number of young people who have not yet been registered with the Scheme. This should be compared against the 'phasing schedule' set down by governments, reported quarterly and broken down by NDIS site

## Bring forward support for young people in aged care who live in the last rollout sites

The Commonwealth should bring forward the NDIS 'Housing Options Package' funding for all young people in aged care who live in locations where the NDIS is only available after November 2017. This would fund young people in aged care to undertake all the preparations to leave aged care so their first NDIA plan is the funding to leave aged care, not just to develop a plan to leave. These young people can work through their complex housing and support needs before they get into the NDIS. At their first NDIS planning meeting they will know exactly what support they need to leave their aged care facility straight away. The Summer Foundation estimates it would cost around \$8.5m (plus program management costs) to deliver.

*This effectively brings forward the investment in participants to develop their housing options, which the NDIA would have paid for once the participant is in the NDIS. This would transform the lives of hundreds of young people in aged care across Australia, allowing them to most back to the community much faster.*

The Commonwealth and States could also consider amending the 'Facilitating Participants Plans' Rule to allow a young person at serious risk of aged care entry to become an NDIS Participant immediately, allowing people who do not live in a location where the NDIS has Officially begun to submit an out of area request.

## Build the capacity of aged care providers to be ready for the NDIS

Aged care providers have very little knowledge of the NDIS and this is stopping them from getting their residents ready for the NDIS. The Commonwealth Department of Health should run an information campaign for aged care providers to get their residents ready for the NDIS. Running a targeted campaign with hands on workshops to educate aged care providers will make sure that every nursing home with a young person knows how to get their young person ready for the NDIS.

## Stop the pipeline of entry into aged care from the health system

The NDIS and health systems need to work more closely together to ensure that when a young person is ready to leave hospital they can return to the community as quickly as possible, rather than being discharged into aged care.

*Diverting young people away from aged care and back into the community faster will result in positive health outcomes and long-term savings to the NDIS as the physical and mental deterioration associated with aged care admission will be prevented.*

The State and Commonwealth should declare fixing the hospital discharge pathway with the NDIS a strategic priority for 2017. This would involve the following actions:

- The Disability Reform Council to establish a group of experts that reports back with a strategic plan to addressing this the health-disability interface, including discharge planning, access to slow stream rehabilitation and clinical services in the community.

- Develop working arrangements between the NDIA and each hospital and Aged Care Assessment Team to ensure that young people in hospital are ready for discharge are immediately provided with an NDIS plan to return to the community, and not discharged into aged care. This must include consideration of whether an additional discharge planning role is needed to make sure young people in hospital do not fall through the cracks or suffer from blame and cost shifting between NDIA and hospitals. This role would facilitate discharge planning by exploring discharge options and coordinating supports, home modifications and equipment as early as possible in the hospital stay.
- The NDIA must review its internal access request and planning processes to ensure that these requests are processed quickly, particularly when individuals are stuck in hospital or at risk of entering aged care.
- The State and Commonwealth Governments must ensure that young people in hospital at risk of aged care become participants immediately by amending the 'Facilitating Participants Plans' Rule and associated 'phasing schedule' for the NDIS to allow immediate access.
- ☐ The NDIA and the Department of Health should report publicly on the number of young people who have entered aged care in sites where the NDIS is operating and this should be regularly considered by the Disability Reform Council as part of the NDIS performance framework.

## Build the capacity of people with disabilities in aged care to effectively participate in the NDIS

*Building the capacity of participants to actively and confidently engage with the NDIS will result in better planning, higher levels of self-management and reduce the long-term reliance on professional support, thereby reducing NDIS costs.*

Resources are needed to build the capacity of young people in RAC and their families to register for the NDIS, preplan, meaningfully participate in the planning process, as well as understand and (where appropriate) challenge administrative decisions. Therefore, we recommend investment in:

- Short videos that document the experience and outcomes of a range of young people in RAC in the NDIS trial sites and their families.
- Multi-media online resources to capture the actual pre-planning and planning process by 2-3 people that provide examples of how to prepare for and actively participate in the planning process.
- A nationwide advocacy and outreach program that will be responsible for connecting all young people in aged care to the NDIS. In addition to NDIS connections, these workers will have the skills and training to Inform, build capacity and support this group through the planning process.

## Build the capacity of people with disabilities to use technology

*The NDIA should support people with flexible funding to allow them to access technology that can help them to achieve their NDIS goals, increase their independence, improve their quality of life, and reduce long-term costs to the NDIS.*

In order for this investment in technology to be maximised, a greater understanding of the potential of the latest technology is required. This can be achieved through increasing applied research into effective technology and the translation of this research into practical applications for people with disabilities to increase the independence.

## Take action to address the broken interface between health and disability

*Investment is needed in a range of initiatives and programs that address the broken interface between health and disability and reduce costs to the NDIS and the health system.*

Example of worthwhile initiatives include:

- Nationwide outcomes focused workshops involving health (acute and rehabilitation), Aged Care Assessment Teams, NDIA and disability service providers to understand and address challenges and barriers to returning people with high and complex support needs to community living, and to clarify and identify common goals, and develop outcome measures and potential solutions.
- Slow stream rehabilitation and transitional health services across Australia including outreach to regional and rural areas. This will support people with severe brain injuries to improve their functional abilities and an increase their socio-economic participation thereby decreasing costs to the NDIS.
- Health outreach services that combine direct care with a 24-hour on-call service are required for people in the target group who require intermittent nursing care. These services work with the individual, their support network and doctors to develop action plans to monitor and address predictable medical conditions (e.g. recurrent urinary tract or chest infections, epilepsy and pressure areas). These plans would enable support staff to proactively identify early warning signs and initiate appropriate intervention. Proactive health planning will reduce the incidence of secondary complications and acute hospital admissions.
- Proactive, effective and ongoing support coordination should be provided when required to respond to complex and changing needs. For people with degenerative disorders (e.g. multiple sclerosis, Huntington's disease and motor neuron disease) living in the community ongoing support coordination needs to be available to facilitate a rapid response.



## Develop an effective national approach to quality and safeguarding for SDA

*An effective national approach to quality and safeguarding requires a national framework that is coherent and outcomes focused. An inconsistent and disjointed approach to quality and safeguarding will hamper the market and reduce client choice and control.*

An effective quality and safeguarding framework:

- Builds on mainstream regulation and safeguards – People with disability should be adequately protected like all Australians through the Building Code of Australia and state tenancy laws.
- Enables independent community living - Quality and safeguards should outline the minimum design requirements for accessibility based on the goal of maximising independence and enabling social inclusion.
- Maximises the role of technology - The latest technological advances should be maximised to safeguard participants and maximise the independence.
- Fosters innovation and investment - Regulation should be reasonable and necessary for safety while maximising investment in new innovative housing in the community.
- Meets diverse functional and cognitive abilities - quality and safeguards should recognise the diversity of the cohort that will be accessing SDA payments so that housing solutions can be individualised and fit for purpose.
- Clearly defines roles and responsibilities – there will be a range of players responsible for the implementation of SDA including housing providers, support providers, tenancy managers, support coordinators and investors. The obligations and responsibilities with respect to compliance with rules and regulations need to be clearly and appropriately defined and assigned.

## Support SDA market readiness

In order to encourage the development of the SDA market we recommend that:

- The SDA rules are modified to remove the preference of in-kind SDA over other forms of SDA
- The NDIA should prioritise including the Specialist Disability Accommodation payment in the packages of young people in aged care in existing NDIS sites.
- The NDIA, housing providers and financiers should work closely to examine the level of confidence that investors have in developing housing through the NDIS payments framework. Where there is high investment risk (especially in regional and remote areas) governments should develop alternative strategies to reduce risk and encourage investment.



- Governments should fund the market-enabling infrastructure needed to support an NDIS housing market. A priority for this work should be to overcome information barriers through a platform to identify housing needs and connect participants with housing providers.
- Governments should make system-level investments in housing by creating a hub to share knowledge on disability housing design and lead innovation.

### **Invest in building the capacity of people with disabilities to self manage their supports**

Participants need to be supported to build their capacity to self direct their supports. The NDIA should increase investment in training staff, outsourced planners and LACs to provide information and support around self-direction. Information and support with respect to self-direction should also be available on the NDIA website in arranging formats including easy to follow video instructions. Digital stories around self-direction would also assist people to understand what is possible.

The NDIA should also make self-direction more accessible by reinstating the float which provided upfront funding from where self managers could draw on to pay for their supports.

*Increasing flexibility around what can be purchased and being able to carry forward savings to spend on achieving NDIS goals is also needed so that participants so that participants are incentivised to seek out value for money.*

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