

CONSUMER & FAMILY CARER NETWORK



In August I attended the launch of Brain Injury Awareness Week, where the theme was "Talking young stroke". Stroke is one cause of Acquired Brain Injury (ABI), the most prevalent disability for young people in nursing homes. Many of the young people who spoke at the event explained how help came in a rush immediately after their stroke and then faded away. There is little recognition within existing stroke services that young people have the rest of their lives to live. Young people need access to age appropriate rehabilitation to support them to set and achieve relevant goals. They need assistance to come to terms with their changed circumstances and rebuild meaningful lives. The call to action is for the establishment of age appropriate services including slow stream rehabilitation, support and accessible housing. These reforms would help to resolve the issue of young people living in nursing homes.

The national rollout of the NDIS is underway and you will be aware there are significant teething issues. There is however a reservoir of goodwill for this important reform, and everyone is working hard to build a national scheme that works for people with disabilities and their families. If you are struggling to navigate the NDIS, please contact me on 1300 626 560.

In July we launched the Summer Foundation's Hunter Housing Demonstration Project in New South Wales. The ten apartments demonstrate an alternative to residential aged care for people with disability. Find out more on page 3.

In conjunction with our Annual Public Forum, the Summer Foundation will run specific sessions for Ambassadors, consumers and family carers to share our findings on the past two years of work connecting young people in nursing homes with the NDIS. Our learnings can assist all young people with disability to get the best from this important reform. Don't forget to bring your questions.

Warm regards,

Penny Paul
Information and Connections Coordinator

IN THIS ISSUE	
NDIS CONNECTIONS UPDATE	2
LAUNCH OF HOUSING DEMONSTRATION PROJECT	3
NDIS PORTAL: MYPLACE	4

NDIS CONNECTIONS UPDATE

On 1 July the NDIS rolled out to new regions across Australia, with North Eastern Melbourne (NEMA) as the first new region added in Victoria. The national NDIS rollout has seen some changes to the connection process. Contracted local area coordinators (LACs) will now provide first point of contact, some planning and follow up for Scheme participants in Victoria. For those with more complex support needs, planning will continue to be done internally by the NDIA – a process we know will need additional support for most young people in nursing homes.

The Summer Foundation has been providing additional support in connecting young people to the NDIS in the Barwon and Hunter trial sites through the NDIS Connections Project. Over two and a half years, the Summer Foundation helped connect 108 people to the NDIS who otherwise would not have connected to the Scheme. This project has demonstrated that people with complex support needs often require intensive assistance to engage with the NDIS.

Initial findings from the NDIS Connections Project demonstrate that there are significant gaps in the service system for young people in nursing homes. The streamlined approach embodied in the "My First Plan" concept assumes an existing relationship to the disability system. However only 25% of young people in residential aged care were found to have had any relationship to the disability system in trial sites. The NDIS needs to provide additional support to assist people with complex needs to register, prepare and implement their plan.

Drawing on findings from our project work, the Summer Foundation has created a Practice Guide for connecting young people in nursing homes to the NDIS. The guide is a tool to help support the capacity of the sector to connect with young people in nursing homes. Download it at: summerfoundation.org.au/practice-guide

The Summer Foundation will continue to work in NDIS rollout areas for as long as necessary to assist young people in nursing homes to connect and engage with the NDIS. We recently welcomed Melody Carbarns to the NDIS Connections Team to assist with this work in the NEMA region and we look forward to reporting on our findings as the rollout continues.



CASE STUDY: SIMON PLINT

Simon Plint led a very active and social life before acquiring a brain injury two years ago.

A hang-gliding accident left Simon with a severe brain injury that impaired both his memory and cognitive function.

Simon spent the next two years living in hospital, while his wife and daughters rented a house nearby.

Simon's wife Tanya was a strong advocate for Simon. A healthcare professional, Tanya had the knowledge required to navigate the NDIS. She helped Simon to identify goals for his NDIS plan and made sure he had the resources he required. Simon also had a proactive NDIS planner who communicated openly and effectively with Simon and Tanya.

An opening in the Summer Foundation's new housing project was crucial to Simon returning home. Had this place not been available, Simon would have been discharged to a nursing home. Support from the NDIS allowed Simon to transition smoothly from hospital to his new home.

With support, Simon is now starting to explore shops and cafes around his home. His family live in the vicinity of the apartment, and Simon looks forward to their regular visits.

An accessible new home has allowed Simon to exercise some independence, while still having access to support at all times.

We are working to replicate this model of housing and support, so that more people with disability in Australia have the opportunity to live as independently as possible.



LAUNCH OF HOUSING DEMONSTRATION PROJECT

The Hunter Housing Demonstration Project was officially launched on 28 July. The demonstration project consists of ten apartments for people with disability peppered throughout a 110-unit private development. The apartments incorporate clever design features and smart-home technology to allow tenants to enjoy their independence while still having access to 24-hour on call support.

Our goal is to see this model of housing replicated in all medium and high density housing developments in Australia to create the range and scale of housing needed for people with disability who wish to live more independently. To find out more, read Simon Plint's story on the preceding page.

Some people may be eligible to receive funding for specialist disability accommodation. Find out more with the specialist disability accommodation fact sheet:

myplace.ndis.gov.au/ndisstorefront/document/specialist-disability-accommodation-fact.html

DISCHARGE PLANNER'S FORUMS

The Summer Foundation continues to examine ways of preventing new admissions of young people to nursing homes through targeted forums that bring together representatives from health, disability, aged care and the NDIS. We have gathered information about current practices, barriers and potential ways forward, examining any impact that the NDIS has made.

Initial forums held in the Barwon, ACT, Hunter and Perth Hills trial sites have demonstrated that many people working in discharge roles in the health system are struggling to understand some aspects of the NDIS. While there have been some great examples of individuals

championing alternatives to nursing homes, this outcome largely depends on having access to an advocate.

A commitment to working collaboratively across systems is the main way good outcomes are being achieved for people with complex brain injury, neurological disease and other high support needs. We also found that in almost all circumstances there is a need for a specialised liaison position in acute and rehabilitation wards to negotiate between the health and NDIS systems to ensure that people don't get caught between the two systems.

We are currently planning more of these forums in NDIS rollout areas and will continue to share our findings.

JOIN THE UPSTREAM CHALLENGE

5 NOVEMBER 2016, 50KM OR 20KM RUN/WALK
Register at: www.upstreamfoundation.org

NDIS PORTAL: MYPLACE

You may be aware that there have been significant issues with the NDIS portal myPlace. This is the website used by the NDIS, providers and participants to communicate. The myPlace participant portal allows NDIS participants or their nominees to view their NDIS plans, request payments and manage services with providers.

The current glitches with myPlace are diverting attention from the more fundamental problem that participants are required to communicate with the NDIA and service providers via the internet. Approximately one third of NDIS participants have cognitive issues and may not be able to exercise choice and control online. In addition, most young people in nursing homes that we work with don't have access to a reliable computer or the internet. We will continue to raise this as an issue and recommend that you have plenty of hours of support coordination funded in your NDIS plan to ensure that you can access the portal and engage with the services you need to reach your goals.

See more: myplace.ndis.gov.au/ndisstorefront/news/NDIS-Provider-Portal-Update-11Aug.html



**THE 2016 ALLEN MARTIN
RESEARCH SCHOLARSHIP
APPLICATIONS NOW OPEN**

Find out more at: summerfoundation.org.au/scholarship



Enable Me is an online community and information source developed with stroke survivors.

If you or someone you know has suffered a stroke, the website may provide useful information in the form of fact sheets, videos and resources.

Go to www.enableme.org.au or call Penny for more details on 1300 626 560.



YOUNG PEOPLE LIVING IN NURSING HOMES AND THE NEW NDIS WORLD

A DISCUSSION ABOUT REALITY, EXPECTATIONS, AND THE UNKNOWN

The NDIS is a long awaited reform that has enormous potential to improve the lives of people with disability, especially those living in, or at risk of entering a nursing home. But what impact has it had and what are the implications of a system rolling out while still finding its feet?

Join us for this year's annual public forum where we will discuss some of the issues and opportunities surrounding the NDIS. This is a free event, but bookings are required.

Book now at: www.trybooking.com/MTID

DATE: THURSDAY 20 OCTOBER 2016, 12.30 - 2.00PM

VENUE: NAB, DOCKLANDS (LIVE STREAMED VIA WEB)

Breakfast Club Lectures 2016

The development of a gold-standard clinical assessment for associated reactions of the arm following brain injury with Michelle Kahn

LECTURE 4
21 SEP
BOOK
NOW

- VENUE:** Royal Talbot Rehabilitation Centre,
1 Yarra Boulevard, Kew, 3121
- DATE:** Wednesday 21 September 2016
- TIME:** 8.00am. Breakfast from 7.30am
- PRESENTER:** Michelle Kahn, Senior Physiotherapist,
Epworth Rehabilitation and PhD Candidate

Consumers and family carers welcome.

www.trybooking.com/KGIV

Podcasts at: summerfoundation.org.au/lectures-2016