# Building better lives for young people in nursing homes

## Summer Foundation Annual Report 2017/18

# Thousands of young Australians with disability live in aged care because there is nowhere else for them.

## The Issue: Young People in Nursing Homes

Many of these people are aged in their 30s and 40s, living with people in their 80s. These are people who could live in the community if they had the right housing and support.

These young people often feel lonely and bored. More than half of them are visited by a friend less than once a year. And almost none of them get to visit their family and friends outside the aged care facility (Winkler et al, 2006).

The National Disability Insurance Scheme (NDIS) is a big opportunity to stop young people going into aged care. It is also a big opportunity to give those young people already living in aged care a better life, and get them into more suitable housing. If the NDIS, health and aged care systems work well together, young people with disability will be able to choose where they live and who they live with.

#### “I was grateful when I left the nursing home but feel guilty for those I left behind.”

Kate Skene,
Who spent two years in a
nursing home in her 30s

# About The Summer Foundation

The Summer Foundation began in 2006. We are working to solve the issue of young people having to live in aged care. Like everyone else, young people with disability should have the right to choose where they live and who they live with. They deserve to be properly supported to make these choices.

We think that the issue of younger people having to live in aged care can be solved within the next 10 years – if everyone works together. To solve the problem, the Summer Foundation is focusing on four areas:

**HOUSING** – Australia needs a lot more housing that is suitable for people with complex support needs

**NDIS** – young people living in aged care (or at risk of moving into aged care) need to have NDIS plans that reflect and support their goals

**PATHWAYS HOME** – hospitals and health services need to work closely with the NDIS and other services to make sure that young people can return to living in the community when they leave hospital

**COMMUNITY & PRIMARY HEALTH** – people’s health needs must be properly supported in the community. As people’s health goes down, their support needs go up, which is the reason In this report, you can read about the work we have been doing in these areas.

Luke Bo’sher Paul Conroy
Chief Executive Officer Chairman

#### Approximately 6,245 young people (under 65) with disability live in aged care acrossAustralia

#### More than 50 young people (under 65) with disability enter aged care every week

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Annual report for year ending 30 June 2018
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# The way we work

We are working to change the way health, housing and disability services think and act. We do this in five ways:

## Research

You can’t fix a problem unless you understand it. Research helps us to understand why young people end up in aged care, and what parts of the health, housing and disability systems must be changed to stop it happening.

## Storytelling

We support young people in aged care and their families to share their stories. These stories help the general public, decision makers and politicians to understand how important it is to stop young people from having to live in nursing homes, which we refer to as aged care.

## Policy influence

Changing the rules that apply to health, housing, aged care and disability services can improve people’s access to the support they need. We work with local, state and Commonwealth governments to modify the way services are funded and operate. We use evidence and data to show governments how they can make changes to stop young people being forced to live in aged care.

## Capacity building

Stories, research and prototypes are most useful if we share them with everyone who can help stop young people with disability from having to live in aged care. So we share everything we learn – with people with disability and their families, with support workers, health professionals, aged care professionals, the housing sector, the NDIS and the government.

## Prototypes

Based on what we find out through research, we design and try things to see how well they work. When these prototypes work well – like our housing prototypes for people with complex support needs or our Connections project linking people to the NDIS – we show other people how to do it too.

# Kirsty’s story

Kirsty is an artist. She got a scholarship to study in New York
and was living the dream when she was diagnosed with MS.

She moved back to South Australia and had three hours of support a week. Kirsty was working as an artist and living in a flat with housemates when she got a bladder infection and went
to hospital.

Kirsty was in hospital for 9 days then went to rehab. She got worse and couldn’t walk, but after a week she was told she was ready to go home. A walking frame was organised and a ramp for the front step.

Kirsty spent a weekend at home but she couldn’t get into her bathroom because she couldn’t walk, so she had to go back to rehab while other options were considered. She was in hospital for 3 months and had to give up her job.

The health services were paying for her rehab hours, so the disability service wouldn’t pay for more support hours to allow her to move back to the community. Kirsty was still paying rent and was fed up - she contacted the media and suddenly the additional hours were approved.

Kirsty then moved to a more accessible flat – it was a big change to be living on her own. She remembers feeling abandoned and frightened, thinking “how am I going to live like this?”

Kirsty believes people should have thought about this more in her discharge planning - even just for a few days or weeks to organise someone to check in to see how she was going, and
to support her with using public transport, maintaining friendships and getting back to work in a wheelchair.

Recently, Kirsty’s catheter was blocked, so she called the Extended Care Paramedic and was told there was no service between midnight and 7am. Kirsty wrote to every person she could think of to highlight the need for this service. It’s available 24 hours a day now.

Kirsty’s artistic journey is on the right road too – she recently won an award in New York for a short film and with hours in her NDIS package for a studio assistant, she can’t wait to get back to her art.

#### “You might feel like your life is over, but life still goes on whether you’re in a wheelchair or not.”

# Our people

## We have a new CEO

In April 2018, Luke Bo’sher became the Summer Foundation’s new CEO.

Luke joined the Summer Foundation in 2016. Di Winkler – who started the Summer Foundation in 2006 and has been the foundation’s CEO since – remains a key part of the organisation, in both her role as the foundation’s Chief of Research and Innovation and
as a member of the Summer Foundation board.

The Summer Foundation has grown as our workload has increased.
Here is a list of the people who have worked with us this year to resolve
 the issue of young people in nursing homes.

Andrea Lockwood –
Practice Coordinator

Antony Brown –
Graphic Designer

Brynn Lewin –
Hospital Discharge –
National Lead

Carolyn Finis –
Chief of Staff

Cathy Bucolo –
Clinical Practice Leader

Damian Grant –
Web Designer and Administrator

Dayanna Torres –
Strategic Projects Officer

Dianne Trevisan –
Receptionist

Di Winkler –
Chief of Research and Innovation

Liz McFarlin –
Curriculum Development &
Training Officer

George Taleporos –
Policy Manager

Gillean Hilton –
NDIS and Health Interface Specialist

Gina Fall –
Storytelling Project Officer

Helen Jeisman –
Event Coordinator

Jessica Simms –
Executive Assistant

Joanna Middleton –
Practice Coordinator

Joanna Stewart –
Practice Coordinator

Jodie Gallacher –
Digital Editor

Joy Campbell –
Executive Assistant

Julie Gibson –
Operations Coordinator

Julie Robertson –
Strategic Projects Manager

Karina Grift –
Content Editor

Kirsten Larwill –
Project Officer

Louise Dixon –
Senior Administration Officer – Research

Luke Bo-sher –
Chief Executive Officer

Megan Topping –
Research Centre Administrator

Melody Carbarns –
Housing Matching Coordinator

Monique De Costa –
Storytelling Program Manager

Natalie Butler – Project Coordinator (Housing & Support)

Natasha Hendricks –
Executive Assistant

Olga Elia –
Project Relations Officer

Penny Paul –
Information and Connections Coordinator

Robin Zakharov –
Senior Policy Advisor

Rosalyn Roberts –
Policy Research Officer

Sally Green –
Participant Program Officer

Sharon Jenkins –
Executive Assistant

Sophie Moore –
Practice Coordinator

Stephanie Press –
Finance and HR Coordinator

Susi Hammond –
Chief Finance and Operations Officer

Tim Salter –
Project Accountant

Tom Worsnop –
Executive Manager – Practice

Tricia Quirk –
Content Editor

Vanessa Robinson –
NDIS & Health Interface Specialist

Vince Patton – Communications Manager

Zoe Shearer –
Practice Team Leader

#### “I hadn’t had any involvement with disability before I started this job… I hadn’t really ever thought about where young people with disability lived. Now it’s all I think about. It’s a bit of a mission for me.”

Stephen Vick,
Manager. Guardian Living

# Michele’s story

After Michele’s dad passed away in 2000, close family friends, Vanessa and Henry,
took over a lot of Michele’s support, including Power of Attorney and organising support workers.

Up until 2014, Michele was living in her own home with support, but when her MS progressed and her care needs increased, Michele had to move into aged care.

Robyn from the nursing home went with Michele to her first NDIS planning meeting. Michele and Robyn weren’t sure what to expect or what the NDIS would fund. It was up to Robyn to find out exactly what the NDIS was and how it could help Michele.

Michele was feeling good after that first NDIS meeting. She was given funding for a new wheelchair, transport and 9 support hours a week so she could go out. Michele loved being able to go out again to concerts and the library.

They didn’t get a lot of information about the right way to buy equipment with NDIS funding. A new wheelchair was bought for Michele, but the NDIS rules weren’t followed, so Vanessa and Michele’s support coordinator had to help her work out the problem.

Nobody talked about housing at Michele’s first NDIS planning meeting. But Michele couldn’t afford to keep paying the nursing home fees without selling her family’s house, so they asked for an NDIS plan review.

In December 2017, the NDIS said it would fund Michele’s aged care means-tested fees.

This has been a huge relief for Michele. She would have been heartbroken to lose the home she grew up in. It also means Michele does not have to pay more than other young people with NDIS funding who don’t live in aged care.

She is still waiting for her new wheelchair and hopefully, a communication device. These will enable Michele to live a better life.

#### ”She would have been heartbroken to lose the home she grew up in.”

# Our supporters

The Summer Foundation recognises and warmly thanks the organisations
and individuals that have supported our work through grants, fundraising, in-kind support and collaboration.

## Corporate support

Hometrack Australia Sigma Healthcare
National Australia Bank Workplace giving donors through
Responsible Investment Association Good2Give
Rotary Club of Kew Wyndham City Council
Rotary Club of Mont Albert & Surrey Hills

## Trusts and Foundations

The Cranwell Family Trust No.2 National Disability Services
Dorman Family Foundation – Innovative Workforce Fund
Equity Trustees Rees Family Foundation
McLeod Family Foundation William Buckland Foundation
Michaela Arnott Foundation

## Donors and Bequests

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Darren Wilcox Jonathon Caelli
David Lipshut Mark Hooper
Diane & Graham Cowley Michael Dalton
Fotini & Gareth Canterford Patricia Hurley
Graham Middleton

## Government support

National Disability Insurance Agency
Department of Social Services (Cwth)
Department of Health and Human Services (VIC)
Department of Human Services (SA)
Department of Industry (NSW)
Department of Communities, Disability Services and Seniors (QLD)
Department of Communities Tasmania
Queensland Health
Transport Accident Commission (VIC)

# Housing

What if you had no choice about where you lived, who you lived with or you couldn’t move out if you wanted to?

## Why is housing so important?

It is important for people’s independence and wellbeing to have choice and control over where they live, and who they live with.

At the moment, many younger people with high support needs don’t have much choice about where they live. Too many end up in aged care because there is nowhere else for them to live.

We also know, from our own housing work, that there is a better way. Quality, accessible housing, with a built-in support model is possible. This is what people with disability want. The benefits go far beyond the bricks and mortar.

## The challenge we face

One of the main reasons younger people live in aged care is because there is nowhere else for them to go.

When people have lived in aged care for a while, this can make the problem worse. People lose skills and this means they can end up ‘stuck’ living in aged care after
many years.

For the issue of young people in aged care to be resolved, people must have more housing options – more choice about where and how they want to live.

The NDIS pays for people with very high support needs to live in specially-designed housing that the NDIS calls specialist disability accommodation (SDA).

Our study into the need for SDA showed that around 33,200 people coming into the NDIS either live in aged care or elsewhere and have very high support needs. They do not live in supported accommodation at the moment. SDA payments from the NDIS are designed to encourage providers to build a lot more SDA. It is estimated that the SDA market needs an extra $5 billion in capital investment. Governments will also need to design additional initiatives to meet the housing needs of young people at risk of aged care who aren’t eligible for SDA.

#### 10,680 new specialist disability accommodation places are needed across Australia\*

\*Source: SDA Market Insights, March 2018

## Understanding SDA in the NDIS

The NDIS decides whether a person is eligible for SDA, based on having very high support needs or extreme functional impairment. The number of NDIS participants likely to be
eligible for SDA is very small – around 6% – so most people with disability will live in mainstream housing.

There are multiple steps to work out if you are eligible for SDA – first you have to show that you can’t live in mainstream housing. And then you need to show that you meet all the other SDA eligibility criteria. If the NDIS decides you are eligible for SDA payments, they will also decide what category of SDA is best for your needs. This gives you the amount of SDA payment included in your plan. SDA payments can range from $4,503 to $107,236 a year.
You can see the actual amount of SDA payment in your plan but the funding goes to the SDA housing provider.

The SDA eligibility and process for the NDIA making decisions is still in its infancy. This means the process has been time consuming and ambiguous for people applying for SDA. We are hopeful these hurdles will be overcome in the coming year.

#### 33**,**200 – The number of Australians with very high support needs who are likely to need specialist housing in the future\*

1**,**000 – By 2021 we want to see
1,000 more SDA properties built, for people
to live either alone or to share\*

#### 17,510 – The number of people living in existing specialist disability accommodation (most people living in group homes)\*

\*Source: SDA Market Insights, March 2018

####

## What we are doing

To solve the issue of housing for people with very high support needs, it is important to understand the need for SDA across Australia, as well as where and how people want to live.

The Summer Foundation did a study of SDA need across Australia. In conjunction with the Australian Housing and Urban Research Institute and SGS Economics and Planning.

The findings of this study were presented to investors, developers, builders, government officials, financial institutions, people with disability and their families at public forums around the country. We wanted to get people interested in the housing market to understand the opportunities and risks in building SDA.

The Summer Foundation and many disability groups have asked the government to be clearer about SDA eligibility and its commitment to choice and control for people with disability.

From our experience working with both housing providers and people who are trying to get SDA funded in their NDIS plans, we have submitted our views to a government review about the SDA funding framework.

## What’s next?

Our goal for the next three years is for a big increase in the amount of accessible and affordable housing for people with disability.

By 2021 we want to see 1000 more SDA properties built, for people to live either alone or to share with 1 or 2 other people.

We are also working on a rapid housing prototype that could be temporary housing for people while they are waiting for modifications to their home to be finished, or waiting for SDA to be ready. This would stop many people going into aged care during this time.

And we want to match 500 people with disability to suitable housing by 2021; to look at housing solutions for people not eligible for SDA; and to evaluate support models for 10 more housing projects.

#### “We know that most people who are living in SDA at the moment are in group homes, but many have told us they want more privacy, space and independence.”

Luke Bo’sher, CEO Summer Foundation

# Chris’ story

Chris is 43, the youngest of 5, and has lived most of his life
in Launceston, Tasmania.

Two and half years ago he became unwell and was taken to hospital. After this he needed extra support and could not return to his home, where he had been living by himself with 36 hours of support a week.

His parents were over an hour away in the north west township of Ulverstone and he wanted to live closer to them. With no housing available there he had no choice but to move into aged care. He lived there for two years, while on a waiting list for alternative housing.

“This sounds bad, but the people around me are elderly and they die. I’ve really had enough of that in my life. It’s distressing,” Chris said.

His advocates worked hard for him and eventually a unit came up. It took 6 weeks to get Chris’ support package in place. After an accessibility check on the unit, modifications were made to the bathroom and the front door to make it remote controlled.

Chris moved into the unit in January 2018.

He gets 40 hours of support a week and he sees his mum and dad daily as they are just around the corner.

This is a good interim solution. Longer term, Chris is hoping the NDIS will help him move somewhere with a bit more space and continue support hours that will help him become more and more independent.

Chris’ social life has really got better. He’s also on the board of Citizens Advocacy and on the Tasmanian Government’s Minister’s Disability Advisory Committee (a sub-committee of the Premier’s Disability Advisory Council).

#### “This sounds bad, but the people around me are elderly and they die. I’ve really had enough of that in my life. It’s distressing.”

# NDIS

The NDIS is the biggest opportunity in Australia’s history to stop young people being admitted to aged care.

## Why the NDIS is so important

The National Disability Insurance Scheme (NDIS) can give people with very high support needs the choice of where they live, who they live with and who provides their support.

This means new options for young people living in aged care, as well as people who may be at risk of ending up in aged care. People with complex support needs who are living with ageing parents, living in a hospital or rehabilitation centre, or a group home or supported accommodation where they are not happy, will have new choices too.

The right level of individual support promised under the NDIS can finally give people more choice about how they want to live their life.

## How is the NDIS going?

It has been five years since the NDIS rolled out in the first trial sites in the ACT, Hunter (NSW) and Barwon (Victoria). Those trial sites give us an idea of how well the NDIS is working to reduce the number of younger people going to live in aged care.

Since 2013, the number of younger people admitted into nursing homes has dropped by 5% overall. This is a small step in the right direction.

The NDIS began a focussed effort in September 2017 to link younger people in aged care to the NDIS, and by 31 March 2018, 2,082 of the approximately 6,200 younger people in aged care had joined the scheme.

#### We want to ensure that 80% of young people living in aged care are NDIS participants

#### More than 1 in 20young people living in aged care were told they were ineligible to join the NDIS\*.

\*Source: NDIS Report Card, June 2018

## The challenges we face

While more young people living in nursing homes are joining the NDIS, the data doesn’t yet show if it is improving their lives or helping them to get out of aged care if that’s what they want.

What we do know is that more than 1 in 20 young people living in aged care were told they were ineligible to join the NDIS. What we don’t know are the reasons
for this. We are asking the NDIS to explain why so many young people in aged
care are ineligible.

While there has been a quick increase in the number of young people with NDIS plans, the average amount for young people in aged care was $104,563. By the time aged care costs are deducted from this amount, a person is left with $31,990 for disability-related supports. We do not think this is enough to prepare a young person to leave aged care and start living independently in the community.

## What we are doing

Part of our work in the past year has been supporting management and workers in aged care, to show them what the NDIS can offer young people living in their facilities – for example, a new, specially fitted wheelchair or doing things in the community every week, or how to look for more suitable housing if they want to.

We have also been working with professionals in the health and disability sectors to show them that, with support from the NDIS, there are better options than aged care for many young people with complex support needs.

With funding from the NDIA, we have developed resources for aged care workers, aged care assessment teams, health professionals, plan managers and support coordinators. We have also held workshops, forums and training sessions, attended by more than 2,800 people across Australia, to inform, collaborate and build relationships between the NDIS and other services.

In June we produced our second NDIS Report Card, which reports on the outcomes the NDIS is having for younger people living in aged care.

#### The average NDIS plan for a young person in residential aged care$72,573$31,990

####  cost of bed in budget for NDIS aged care supports

# Deborah’s story

It started on Christmas Eve 2015. Deborah went from thinking about what she was cooking for Christmas Day for her family to being in ICU in an induced coma with all her organs shutting down.

A few days earlier a kitten had scratched her leg. It turned into necrotising fasciitis.

Deborah spent the next 12 months in hospital and rehab. It was a far cry from her life as a secondary school English teacher.

Three months into her rehab, progress was slow, but Deborah had always assumed that she would be going home. Then one day a nurse marched into her room and said: “You know you’re going to have to go into a nursing home?” It was a shock for Deborah – no one had discussed this idea with her.

She was discharged to the nursing home with a rented wheelchair and commode. The hospital paid for this equipment for one month, then Deborah had to pay $320 a month just for the wheelchair on top of aged care fees.

“One thing everybody takes for granted is that you get to choose where you live and who you live with. I didn’t get to make that choice,” she said.

Once in the nursing home Deborah received a call from DHHS to say it was likely she would be eligible for early access to the NDIS. They told her she’d hear back in a few weeks.

Four months later Deborah received a letter advising that she had been accepted into the NDIS. It was another two months before her first planning meeting. The plan was approved, but then held up while waiting on a doctor’s letter to prove the permanency of her condition.

Deborah’s NDIS plan helped her move out of aged care. She is now living with her family and doing some part-time tutoring work.

Deborah says she was really lucky, she had a fantastic planner. She felt totally supported by him and he followed through on everything he said he would do. She was able to contact him directly and she appreciated that he spoke to her like an intelligent human because she finds many don’t when people are in a wheelchair. She says the questions from him were genuinely client-focused.

#### “Being funded by the NDIS has meant I can stop worrying. I know it will allow me to go home.”

#### “Thank you all for doing this for me. This is the greatest gift anyone has ever given me.”

Richard, after he saw his support worker training video for the first time.

19 76
individual film shoots hours of filming

## Training videos

The Summer Foundation is also supporting people with disability to make their own training videos for their support workers. This will create a big positive change in people’s lives and mean they can keep living in their communities safely, happily and in good health.

We developed a range of resources so that people with disability can make short, personalised training videos for their support workers – with the help of support coordinators, allied health professionals, informal supports and service provider organisations.

The resources include how-to videos, a step-by-step workbook for people with disability and a guide for their own videos as part of the project, that was paid for by the Department of Social Services – Innovative Workforce Fund.

## What’s next?

By 2021, we want 80% of young people living in aged care to be NDIS participants.

While our mission is for no new admissions into aged care of people aged under 65, we understand that the changes that will allow this to happen take time.

By 2021, we want 90% of all people aged under 65 who do enter aged care to have high-quality NDIS plans in place before they are admitted.

When the NDIS is working as it should, people’s experience of entering the NDIS will be streamlined, their right to choice and control will be upheld, a good life in the community will be seen as reasonable and necessary, and support providers will be able to appropriately support people with high or complex needs.

#### “But when we saw James’ amazing reaction while he watched his video... we knew it was spot on.”

See James’ story on the next page >

# James’ story

James was assaulted in 2006, on his 20th birthday. James has an acquired brain injury and very high support needs.

James was asked to be involved in a Summer Foundation project where he could make a training video for his support workers. He agreed, and so did his Mum. James can’t talk after his assault, but he communicates in other ways. His Mum and key support worker always make sure James is given the chance to tell people what he wants, in his own way.

James and his key support worker talked with a therapist and they worked out what was important to James in his life. James decided he wanted his training video to give his
support workers confidence to be able to help him, talk to him and to show them how he communicates too.

James asked Andrew, his key support worker for over 6 years, to be his “voice” in the video. Andrew always double-checks with James what he thinks he’s understood, to know if he is
right or wrong.

James’ video is definitely ‘all James’ but it has Andrew speaking. Andrew tells the support workers that James has a thirst for knowledge.

He says James usually understands everything that’s happening around him and is an incredibly intelligent man. He has a love of art in all its forms, along with history and sport. Andrew says James is a gentle soul, with a cheeky sense of humour.

Andrew explains throughout the video the best ways of interacting with James, with practical advice like “ask if it’s ok to touch him, no one likes to be touched without expecting it or giving permission”. James relies on someone asking him the right questions to share his thoughts and opinions. Andrew says:

“I wouldn’t ask James how his morning’s been, but I would ask if he’s had a good morning.”

On the video Andrew says he feels that people sometimes might be nervous working with James, or worry about upsetting him. Andrew tells support workers James’ thoughts about this problem and says it helps to understand James is a person who understands his situation. “If there’s trust and James knows you’re trying that’s ok.…Don’t stop trying… It takes a huge amount of effort for James to engage in the conversation. It’s helpful to remember and value the effort he’s making.”

James wanted his video to say that his wants, needs and hopes are the same as everyone else. And that genuine, respectful, meaningful relationships are as important to him as they are to all of us.

Andrew was in the video a lot and we wondered if it was ok. But when we saw James’ amazing happy reaction while he watched his final video that he had made, we knew it was spot on – it was ‘all James.’

# Pathways home

Too often, young people with disability have to stay in hospital or rehabilitation longer than they need to because there is no clear pathway home.

## Understanding the journey

For many young people with disability, there is no clear pathway back to living in the community from hospital or rehabilitation. Often they can be stuck in hospital for too long
or they can be discharged to aged care - no one wants either of these things to happen.
With the right support, at the right happen, the NDIS and health system must get better at working together.

## What we are doing

We are working with hospitals, governments, the NDIS and the aged care sector to improve the pathway from hospital back into the community.

Our focus is on hospital discharge planning, understanding NDIS processes, and supporting clinicians, family members and support coordinators to identify housing options for people when they leave hospital.

We have created guides for health, disability and aged care staff to use, presented forums
and training sessions for staff across Australia and assisted people with disability to share
their experiences.

Our hospital discharge project, funded by the William Buckland Foundation, has been designing an improved hospital discharge process that is now being trialled in Ballarat and Barwon hospitals in Victoria. Once we have tested it and can show that it works, we want to make this discharge process available to hospitals across Australia.

#### We aim to reduce hospital stays for young people with complex needs by 50% nationally

#### 1,400 Health, disability services and aged care staff attended training

88% of participants said the training
increased their knowledge

#### 66 Sessions including workshops, conferences, forums, seminars & networking events

18 written resources & 10 videos developed
for health, disability services and aged care staff

##

#### Approximately 111,221Kms travelled by staff for state & national seminars, training & events

## What’s next?

Over the next three years, a new Flagship Project (Hospital Discharge) aims for a 20% reduction in the number of discharges into aged care across Australia and a 60% reduction of aged care admissions in 2 large hospital network locations. We also aim to reduce hospital stays for young people with complex needs by 50% nationally, and ensure that 80% of young people discharged into aged care have NDIS supports funded in their plans.

# Kim’s story

Kim often got phone calls to tell her information about her son Bevan, who has Asperger’s syndrome. She was at work in Toowoomba one day when she received a call to say Bevan had been in an accident.

Arriving at the hospital Kim was told Bevan had been in a dirt bike accident and was hanging on to his life. They were stabilising him to fly to Brisbane. Kim’s daughter drove her there – a trip she describes as the longest of her life.

Bevan survived surgery but his injuries were extensive.

Kim had just completed modifications at home ready for her sister, who has a disability, to move in. These were now needed for Bevan.

Kim’s hope for Bevan was for him to be able to do a standing transfer so she could manage him at home.

She got the government approval needed for rehab, but the rehab facilities were saying ‘no’. Kim was determined to work out why and to change their minds.

“I had to put myself in their shoes when I was flat out walking in my own,” she said.

Kim sold the idea of herself and Bevan as a team. She agreed to be there every day, freeing up staff. Kim knew how to work within regulations and they decided to take him. Bevan remained in rehab for 7 months, improving out of sight.

The social worker and allied health team worked tirelessly to get Bevan and Kim back home and he was discharged 15 months after his accident. They were home for the first day of spring.

Bevan went home with a package from Disability Services Queensland, then Kim set about finding professionals to work with him.

Kim remembers one night sitting with Bevan, telling him how distraught she felt. Bevan replied simply, “It’s ok, we’ve got this.”

#### “For me, Bevan dying would have been hard, but a nursing home would have been worse.”

# Community & Primary Health

With the right support to live well in their communities, more people will avoid the health problems that lead to time spent in hospital and a reduced ability to live independently.

## Importance of connection

People with complex support needs rely on good health services in the community to make sure they stay well.

These health services are vital for people with complex support needs to avoid hospital stays and be able to go back to living in their homes when they leave hospital. With the right support from health services in the community, fewer people would be forced to move into aged care.

## What we are doing

We want to develop a model for health care in the community. This will ensure health services provide the right things for people with complex support needs. It will aim to help people stay healthy and out of hospital, and help them access rehab when needed.

We are doing research to find out what parts of the community health system need to change and how they need to change for the model to work.

This includes a project with La Trobe University’s Living with Disability Research Centre to look at the specific health needs, costs and services used by people with disability and complex needs. It will also look at how health promotion and services working together may be able to help people stay well and out of hospital or aged care.

#### “If these health conditions are better managed in the community, it means fewer trips to hospital and less chance of getting really sick and not being able to return home.”

Dr Di Winkler,
Chief of Research & Innovation,
Summer Foundation

# Directors’ report

The directors are pleased to present their report on Summer Foundation limited
for the year ending 30 June 2018.

## Directors

The names of directors in office at any time during or since the end of the year are:

* Dr Di Winkler
* Professor Malcolm Hopwood
* Paul Conroy
* Benjamin Marks
* Jason Chequer
* Professor Jacinta Douglas
* Graeme Innes AM

## Principal activities

Summer Foundation Limited is a not-for-profit organisation that aims to resolve
the issue of young people in nursing homes. The Summer Foundation Limited focuses on conducting practical research, informing and empowering people with disability and their support networks, and developing pragmatic solutions for systemic change.

## Review of operations

Revenue from continuing activities for the year was $5,636,271 (2017: $4,437,189) resulting in surplus funds of $490,020 (2017: $923,816). Due to the nature of the not-for-profit sector, funding is received for a particular project prior to commencement. This surplus for the period is as a direct result of grants and donations received for projects yet to be completed and excludes the $7,179,290 loss on transfer of the Abbotsford & Belmont Apartments to Summer Housing Limited.

Summer Housing Limited was established in January 2017 to replicate and scale the initial housing demonstration projects developed by Summer Foundation Ltd, building on the proven success of the Abbotsford and Hunter Housing Projects.

The entities exist independently, but up until the Abbotsford and Hunter properties were gifted to Summer Housing Limited in December 2017, Summer Foundation Limited provided financial support to Summer Housing Limited by way of payment of operating costs and overheads. Recovery of these expenses is included in Accounts Receivable, in addition, a $200,000 cash loan was provided to Summer Housing Limited which also remains outstanding at 30 June 2018.

Summer Foundation Limited has not yet called on the receivable or loan debt as Summer Housing Limited is still in its establishment phase. Summer Housing

Limited’s revenue in the financial year was lower than expected due to payments from the NDIS not being received as originally estimated. Summer Foundation

Limited will not call on the receivable or loan debt until Summer Housing Limited’s cash position changes.

Summer Housing Limited’s cash position is expected to allow a repayment of this receivable and loan debt in the coming months once tenants for their properties have their eligibility confirmed by the NDIA.

## After balance date events

No matters or circumstances have arisen since the end of the financial period which significantly affected or may significantly affect the operations of Summer Foundation Limited, the results of those operations, or the state of affairs of Summer Foundation Limited in future financial years.

# Information on Directors

## Dr Di Winkler

### Executive Director

**HonLLD Monash, PhD, GAICD, BAppSc (Occ Ther), Grad Dip Neuroscience,
Grad Dip AppSc (Comp Sci), MAppSc**

Di Winkler is an occupational therapist who has worked with people with severe brain injury for more than twenty years. Di was the Chief Occupational Therapist at Ivanhoe Manor Private Rehabilitation Hospital prior to developing a private practice working with people with brain injury in the community.

Di completed a Masters by Research at La Trobe University entitled “Factors that lead to successful community integration following severe traumatic brain injury”. Di established the Summer Foundation in January 2006 and in 2012 completed a PhD at Monash University, which involved a series of studies that focused on young people in nursing homes.

Di also sits on the Board of the newly created entity, Summer Housing Ltd and Livable
Housing Australia.

In November 2013 Di was awarded the 2014 Stanford Australia Foundation Dyson Bequest Scholarship. This scholarship enabled Di to complete the six week Stanford Executive Program in 2014. Di was conferred with a Doctor of Laws honoris causa from Monash University in May 2018 for her distinguished service to the community through her leadership as a practising Occupational Therapist and researcher with a particular focus on dealing with young people affected by acquired brain injury.

## Paul Conroy

### Independent Non-Executive Chairman

**LLB (Hons) Bcom**

Paul is an experienced corporate lawyer who was most recently the General Counsel and Company Secretary of Treasury Wine Estates Limited and, prior to that, the Chief Legal
Officer and Company Secretary of Fosters Group Limited. Paul is currently the Group CEO
of the TIC Group.

Prior to joining Foster’s Group in 2005, Paul held a number of senior management roles with Southcorp Limited in Australia and the United States.

Previously, Paul was the Corporate Development Executive of MYOB Limited, was a corporate lawyer with Herbert Smith Freehills in Melbourne and Hanoi, and also worked in the London office of the international law firm, Mayer Brown, for three years.

Paul is a director of Summer Housing Ltd and FareShare Inc, and a graduate of Leadership Victoria’s Williamson Community Leadership Program.

## Professor Malcolm Hopwood

### Independent Non-Executive Director

**MBBS (1986 Melb), MD, MPM, FRANZCP**

Professor Mal Hopwood has taken up the position of Interim Head of Department of Psychiatry at The University of Melbourne in August 2017. He completed a Doctor of Medicine (MD) at the University of Melbourne in 1997. After working in the public health-care system for many years, he has held the position of Professor of Psychiatry with Ramsay Health Care at The University of Melbourne and Clinical Director, Professorial Psychiatry Unit at the Albert Road Clinic since 2013. His research interests include basic neurobiology and clinical aspects of mood and anxiety disorders, psychopharmacology, mental health care systems and psychiatric aspects of acquired brain injury. As Chief Investigator, he has been awarded current grant funding from the NHMRC, US Department of Defence and ISSCR totalling $4.8M.

Professor Hopwood has held a number of roles with the Royal Australian and New Zealand College of Psychiatry (RANZCP). These include a two-year term as College President (2015-2017) and Victorian Branch Chair (2009-2013). He was a member of General Council (2007-2009) and a member of the Board of Research for 10 years. He is a member of the Faculty of Psychiatry of Old Age and the Section of Neuropsychiatry. From 2009 to 2016 he was Chair of the Board of the Summer Foundation. In 2017, he was nominated as President Elect of the Asian Federation of Psychiatric Associations.

## Benjamin Marks

### Independent Non-Executive Director

**BCom, Dip. FP, CFP, MBA**

Benjamin Marks is a Partner and Founding Shareholder of Crestone Wealth Management. His primary responsibility is to provide wealth management and investment advice to individuals, families as well as to charitable foundations and not for profit organisations. Benjamin has been a Financial Adviser since 1998 and is a Certified Financial Planner. He also completed his Masters of Business Administration (Melbourne Business School) in March 2015.

During 2011 Benjamin worked on a project for the Summer Foundation and the Housing Demonstration Projects campaign through the Melbourne Business School. The aim of the project was to build a sustainable housing model, whereby new accommodation would be funded by the private sector for individuals living with disability. Benjamin continued to work on this model following the completion of the MBA subject in 2011.

In February 2012, Benjamin joined the Board of the Summer Foundation. He is also on the Board of the Crestone Foundation.

## Jason Chequer

### Independent Non-Executive Director, Risk & Audit Committee Chairman

**BCom, Dip. FP, ICAA, FPA**

Jason is an Executive Director of JBWere. Jason’s focus over a 26 year career in financial services has been advising some of Australia’s most successful families/ groups on their wealth, investment, philanthropy and succession strategies. Jason has worked with JBWere for the last 20 years and during this time has held various senior positions, including Victorian Manager
of Private Wealth Management for four years and National Head of Strategic Wealth Advice
for 7 years.

Jason takes a keen interest in the philanthropic services that JBWere offers to its clients, providing strategic advice to private philanthropists, boards and committees on donor strategies and structuring; investment charters and strategy and the running of private ancillary funds.

Through his leadership roles at JBWere, Jason has gained extensive experience in both business strategy development and execution across a range of areas, including product and service development and people management.

Prior to JBWere, Jason worked as a Chartered Accountant for over six years with PwC and Arthur Andersen.

Jason is currently a committee member of the Victorian Adviser Committee of the Family Business Association and a member of the Taxation Institute of Australia. Jason has had previous experience with the health sector, working on the Investment Sub Committee of the Public Health Association.

## Professor Jacinta Douglas

### Independent Non-Executive Director

**B App Sc (Sp Path), M Sc (Psych), PhD (Psych)**

Professor Douglas is the Summer Foundation Chair of Living Well with Brain Injury at La Trobe University in the Living with Disability Research Centre.

Jacinta’s qualifications span the disciplines of speech pathology, clinical psychology and neuropsychology. She has extensive research and clinical experience in the rehabilitation of adults with acquired brain injury (ABI).

Her research contribution is internationally recognised and has advanced knowledge in the domains of interpersonal communication and psychosocial functioning following brain injury. Her work in these areas focuses on maximising the ability of people with brain injury to participate fully in society across all levels of functioning. Jacinta has published more than 100 peer reviewed papers in international journals and authored 10 book chapters.

Since 2014 Jacinta has led the research partnership between La Trobe University and the Summer Foundation. This research program focuses on measurement of the outcomes of interventions related to the lifetime support of people with ABI across the domains of housing, health, and social inclusion.

Jacinta is the current president of the Australasian Society for the Study of Brain Impairment (ASSBI). She is a Fellow of ASSBI and the Speech Pathology Association of Australia and is founding co-editor of the multidisciplinary journal Brain Impairment.

## Graeme Innes AM

### Independent Non-Executive Director

**LLB**

Graeme Innes was Australia's Disability Discrimination Commissioner from December 2005 to July 2014. During that time he has also served as Australia's Human Rights Commissioner for three and a half years and as Race Discrimination Commissioner for two years.

Graeme is a Lawyer, Mediator and Company Director. He has been a Human Rights Practitioner for 30 years in NSW, WA and nationally.

As Commissioner, Graeme has led or contributed to the success of a number of initiatives. These have included the Same Sex: Same Entitlements inquiry, which resulted in removal of discrimination across federal law; the drafting of the United Nations Convention on the Rights of Persons with Disabilities, and its ratification by Australia.

Graeme was also crucial to the development of the National Disability Strategy and the Disability (Access to Premises – buildings) Standards 2010; as well as the establishment of Livable Housing Australia.

Graeme has also been an active high profile advocate for the implementation of cinema captioning and audio descriptions and, as Human Rights Commissioner, undertook three annual inspections of Australia’s Immigration Detention facilities.

Graeme has been a Member of the NSW Administrative Decisions Tribunal; the NSW Consumer, Trader and Tenancy Tribunal; and the Social Security Appeals Tribunal. He has also been a Hearing Commissioner with the Human Rights and Equal Opportunity Commission.

Graeme was Chair of the Disability Advisory Council of Australia, and the first Chair of Australia's national blindness agency, Vision Australia.

In 1995 Graeme was made a Member of the Order of Australia (AM). In 2003, he was a finalist for Australian of the Year.

## Meetings of Directors

The number of meetings of the Company’s Board of Directors held during the period ended
30 June 2018 and the numbers of meetings attended by each director were:

|  |  |  |
| --- | --- | --- |
| Director | A | B |
| Dr. Di Winkler | 4 | 4 |
| Prof. Malcolm Hopwood | 4 | 3 |
| Paul Conroy | 4 | 4 |
| Benjamin Marks | 4 | 3 |
| Jason Chequer | 4 | 4 |
| Prof. Jacinta Douglas | 4 | 3 |
| Graeme Innes | 4 | 4 |

A = Number of meetings eligible to attend
B = Number of meetings attended

## Committees to the Board

### Risk and Audit Committee

The Risk and Audit Committee commenced during September 2009. The main functions of the Committee are to develop and implement a risk management strategy, oversee the organisation’s finances, examine proposed budgets, review monthly or quarterly management accounts and consider the expenditure authorities delegated to staff. The Committee also works with external auditors to finalise the annual report and conducts periodic reviews of the organisation’s financial procedures and legal compliance to ensure proper controls exist to minimise risk exposure.

The following people form this Committee:

* Luke Bosher
* Jason Chequer (Chair)
* Benjamin Marks
* Susane Hammond (Chief Finance & Operations Officer/Company Secretary)

## Insurance of Officers

During or since the end of the financial period, Summer Foundation Limited has paid
a premium of $2,920 to cover Professional Indemnity for the Directors and Officers of
the Company.

The Company has CGU Insurance which covers the following:

* Professional Indemnity
* Directors’ and Officers’ Liability
* Employment Practices
* Fidelity Insurance
* Taxation Investigation
* WorkSafe Insurance

The Company has QBE Insurance which covers:

* Contents Insurance
* Public Liability Insurance

The Company has AIG Australia Limited – Chartis Insurance which covers:

* Voluntary Workers Insurance

## Auditors’ Independence Declaration

A copy of the auditors’ independence declaration as required under s.60-40 of the Australian Charities and Not-for-profits Commission Act of 2012 is set out onpage 9.

Signed in accordance with a resolution of the Board of Directors.

Jason Chequer Melbourne,
Director 25 September 2018