

SUMMER FOUNDATION CURRENT RESEARCH PROJECTS

Health needs, costs and service utilisation of people with disability and complex needs

Research Partners: Living with Disability Research Centre, La Trobe University, Melbourne, Australia

What is the problem?

People with disability and complex needs typically experience a range of health issues that significantly impact on their need for medical and nursing support. Secondary conditions can make young people in residential aged care (RAC) critically ill or result in premature death. Common secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Most (88%) of young people in RAC have three or more health problems.

One of the key systemic reasons why younger people are admitted to RAC is that there are not enough community-based alternatives that combine residential support with complex clinical care (Department of Human Services, 2005). Younger people with very high care needs living in RAC have, potentially, many years of life ahead of them. However, some people in this population have been described as having a 'narrow margin of health'. This means that they are highly susceptible to secondary conditions that can make them critically ill or result in premature death.

What are the key research questions?

1. What are the specific health needs, costs and service utilisation of people with disability and complex needs?
2. What exemplars are there of proactive community and primary health services for people with disability and complex needs?

How are we going to answer these questions?

Systematic literature review and environmental scan.

How is this project going to assist us to resolve the issue of young people in aged care?

Many of the episodes of illness experienced by people with disability and the resultant hospital admissions appear to be predictable and preventable and further research is required to determine if health promotion and preventative measures can improve the health outcomes for this population. A coordinated approach to managing these conditions has the potential to decrease hospital admissions and improve the health and longevity of both younger people who move out of RAC and those who remain living in RAC.

Timeframe: July 2018 – December 2018

Further information: research@summerfoundation.org.au

Moving into new housing designed for people with disability: evaluation of tenant outcomes

Research Partners: Living with Disability Research Centre, La Trobe University, Melbourne, Australia

What is the problem?

The lack of timely access to the housing and support people need to live in the community is one of the key reasons young people live in aged care. Improving the range and scale of community based housing and support is needed to reduce the flow of young people into RAC.

The predominant model of housing for people with disability is a group home with 5-6 people with a disability living in a house. Group homes work for some people with disability but they are not suitable for everyone. Younger people in aged care often have a severe brain injury from an assault or an accident or they are diagnosed with a condition like MS. Over 50% have a partner. 27% of young people in aged care are parents of school-age children. They want to live in their own homes.

It is critical the National Disability Accommodation (NDIS) funding to increase housing options is well targeted to create the diversity of housing options that young people with disability require. This study builds on emerging evidence regarding the long-term outcomes and cost benefits of individualised models of housing and support.

What are the key research questions?

For people with disability moving into Summer Housing projects and other individualised models of housing and support:

1. What impact does the change in living environment have on the participant's health, physical and behavioural function, care needs, goals, autonomy and choice, emotional wellbeing, social connection, environmental influences, community participation and global subjective quality of life?
2. What impact does Specialist Disability Accommodation (SDA) have on the strain, wellbeing, social support and quality of life for the participant and those close to them?
3. What impact does SDA have on the financial input (housing and support costs) of the participant and those close to them?

How are we going to answer these questions?

This study will document the individual experiences and measure the outcomes of people with disability and complex needs who move into appropriately designed housing in the community. This mixed-methods study involves interviews with Summer Housing tenants and those close to them pre-move and at regular intervals up to three years post move.

How is this project going to assist us to resolve the issue of young people in aged care?

This framework aims to measure the impact of well-located, good quality, accessible and adaptable housing that incorporates technology on tenant outcomes. This framework will provide the empirical data needed to work with actuaries to project changes in lifetime care costs and quantify the cost-benefit of investing in quality housing for people with disability. The framework will also enable comparison between various sites with a similar model of housing and different types of housing designed for people with disability.

Timeframe: March 2017 – June 2020

Further information: research@summerfoundation.org.au

Younger people discharged from inpatient rehabilitation to aged care: comparison with patients discharged to the community and costs of delayed discharge

Research Partners

Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia

Living with Disability Research Centre, La Trobe University, Melbourne, Australia

Chris Latham, Actuary

What is the problem?

The issue is around young people with disability and complex needs who have extended stays in hospital. This group includes people with newly acquired disabilities (e.g. acquired brain injury and spinal cord injury) and patients with a pre-existing disability that have a significant change in their health, level of function or circumstances. Most (59%) of younger people are admitted to an acute or rehabilitation hospital before their first admission to RAC. Improving the pathway from hospital to the community is the key to reducing the number of younger Victorians in RAC. Understanding as much as we can about the people at risk of admission and the transition from hospital to aged care is key to developing interventions that prevent new admissions of young people to aged care.

What are the aims of the study?

The aims of this study are:

1. To explore the Australasian Rehabilitation Outcomes Centre (AROC) data in relation to the characteristics and rehabilitation outcomes of people under 65 years participating in rehabilitation in Australia.
2. To quantify to length of stay in inpatient rehabilitation of younger people subsequently discharged to aged care and estimate the cost of delayed discharge.
3. To compare younger patients who were discharged to RAC to a similar cohort who were discharged to the community.
4. To identify any clinical or social factors which might assist with early identification of younger patients who were more at risk of being discharged to aged care.

How are we going to answer these questions?

This project interrogated the AROC database to glean insights into the discharge of younger people from rehabilitation to RAC. The AROC collects standardised data against each inpatient rehabilitation episode of care. This study included 1,682 patients aged up to 65 years old who were discharged to RAC at the completion of their inpatient rehabilitation in the five financial years between July 2012 and June 2017.

How is this project going to assist us to resolve the issue of young people in aged care?

Analysis of national data regarding rehabilitation inpatients discharged to aged care may provide insights about interventions that could reduce the number of young people admitted to aged care from hospital e.g. key reasons for delays in discharge. Social and clinical factors that predict discharge to RAC could be used in the development of a screening tool to identify patients at risk of discharge delay and poor outcomes.

Timeframe: September 2017 – December 2018

Further information: research@summerfoundation.org.au

Younger people discharged from Victorian hospitals to aged care: characteristics, predictors, care pathways, discharge delays and costs

Research Partners: Department of Epidemiology and Preventive Medicine,
School of Public Health and Preventive Medicine, Monash University
Outcome Health
Chris Latham, Actuary

What is the problem?

The issue is around young people with disability and complex needs who have extended stays in hospital. This includes people with newly acquired disabilities (e.g. acquired brain injury and spinal cord injury) and patients with a pre-existing disability that have a significant change in their health, level of function or circumstances. Most (59%) of younger people are admitted to an acute or rehabilitation hospital before their first admission to RAC. Analysis of AROC data found that while 1,682 patients aged up to 65 years old were discharged to RAC at the completion of their inpatient rehabilitation between July 2012 and June 2017, 2,189 people per annum were discharged to another in-hospital unit.

What are the key research questions?

The aims of this study are:

1. To explore the VAED and VEMD data in relation to the characteristics and outcomes of patients under 65 years discharged to or admitted from aged care.
2. To document the care pathways of younger people discharged to or admitted from aged care.
3. To quantify the length of stay of younger people subsequently discharged to aged care and estimate the cost of delayed discharge.

How are we going to answer these questions?

Analysis of linked Victorian admitted patient and emergency datasets will help understand the pathways of younger people to RAC from all hospital units, discharge delays and the associated costs. We will describe the care pathway, identify predictors of younger people discharged to RAC and key points for intervention to reduce discharge delays and prevent new admissions. This research will estimate the total annual costs to the state of delayed discharges for this cohort.

How is this project going to assist us to resolve the issue of young people in aged care?

By 2020 all Australians with a severe disability will be eligible for the support they need to live in the community. This project uses administrative data to understand the characteristics, care pathways and discharge delays of younger people entering RAC. This evidence base will be used to reduce length of stay, improve discharge planning and streamline access to NDIS funded services. This will provide an evidence base for hospitals to fund more innovative, skilled and resource intensive discharge planning.

Timeframe: March 2018 – June 2019

Further information: research@summerfoundation.org.au

Evaluation of participant led videos

Research Partners: Living with Disability Research Centre, La Trobe University, Melbourne, Australia

What is the problem?

At least 5% of people in Australia have cognitive disability and require support to complete everyday tasks, activities at home and in the community. Typically, support is provided by disability support workers. In 2016-17, the NDIS spent \$3.2 billion on disability supports, which will grow to \$14.5 billion at full scheme. The NDIS workforce will see many new support workers enter the labour force with limited disability experience or education. This is especially problematic for people with high and complex care needs. It is essential that support workers understand how the person prefers to be supported and respects the person's choice. The best way to ensure this understanding occurs is for the person to direct their own support. Many NDIS participants do not have the cognitive or communication capacity "in the moment" to exercise choice and control and direct support services. One of the greatest weaknesses of the NDIS is the reliance on an unskilled workforce to support NDIS participants with cognitive and communication difficulties to obtain a good life, achieve their goals and increase their independence.

What are the key research questions?

This project will evaluate the impact of working with NDIS participants with cognitive and communication impairments to produce participant led training videos that inform support workers about how NDIS participants want to be supported.

The key research questions are:

1. Do participant led videos increase the capacity of NDIS participants to exercise choice and control and direct their lives and support services?
2. Do participant led videos provide a cost effective and scalable way to increase the quality and effectiveness of disability supports provided to NDIS participants?
3. Do participant led videos enable NDIS participants to make measurable progress towards their goals and reduce the long-term liability of the NDIS?

How are we going to answer these questions?

Six NDIS participants were supported to produce participant led training videos. An initial evaluation saw NDIS participants interviewed after they produced and viewed their video. We also obtained the perspective of support workers, families and support agencies working with the NDIS participants on the use of the video for training.

A follow-up study will interview the six NDIS participants, support workers and families on the use and impact of the participant led videos six months after the production of the videos. Future research will involve an observational study with a larger sample that observes NDIS participant and worker interaction and conducts interviews before and after the videos are used.

How is this project going to assist us to resolve the issue of young people in aged care?

Anecdotal evidence suggests that most of the disability support provided in Australia today is ineffective in fostering the independence and autonomy of people with disability. Supporting NDIS participants to produce and use participant led training videos has the potential to dramatically improve the quality of support provided to NDIS participants with communication and cognitive impairments. The resources produced through this project can be used to operationalise the core principles of the NDIS by empowering participants to set goals, direct their support workers and achieve their goals. Participant led videos could be catalytic in empowering people with disability and transforming the disability support workforce.

Timeframe: March 2018 – December 2019

Further information: research@summerfoundation.org.au