



Summer Foundation – La Trobe University Research Program 2021/2022

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Foreword

The enduring research partnership between the Summer Foundation and La Trobe University's Living with Disability Research Centre is testament to what is possible when rigorous academic methods are applied to real-world problems. The research program at the Summer Foundation is unashamedly ambitious. It needs to be in order to address the manifold challenges experienced by people with disability in Australia today.

Our Research Team consists of more than 20 researchers, including seasoned academics, clinical experts, research assistants, and doctoral candidates. They come from diverse backgrounds, including psychology, speech pathology, occupational therapy, and architecture. Together, the team work on more than 15 active projects covering topics as broad as younger people in residential aged care, hospital discharge, the disability housing market, and factors contributing to quality disability support.

The lockdowns of late 2021 due to COVID-19, and lingering effects into 2022 presented both new and familiar challenges as we continued to work in hybrid mode, attended academic conferences by distance, and interviewed participants over video conference. More broadly, the policy context also affected and shaped our work, as issues with funding for Specialist Disability Accommodation (SDA), and progress towards the Federal Government's Younger People in Residential Aged Care (YPIRAC) targets needed to be addressed.

Despite these challenges, our team went from strength to strength, as we welcomed new faces and farewelled old friends. While our achievements cannot only be measured by our scholarly outputs, we are proud of them nonetheless. Together, our team produced:

- 9 peer-reviewed journal articles or book chapters
- 14 industry reports
- 16 academic conference papers

Furthermore, there are 6 manuscripts currently under peer-review, and more than 10 being drafted. In the next few months we will be presenting at conferences including the World Federation of Occupational Therapists.

Of particular note are the findings that are emerging from our longitudinal study of outcomes for people with disability living in SDA. Early results reinforce what makes sense intuitively: disability housing built with tenant outcomes in mind improves independence, health, wellbeing and community integration.

None of this work is possible without our dedicated staff, and the support of La Trobe University, for which we are very grateful. As our team expanded over the last 12 months, we took the important decision of appointing two co-managers of the research team: Dr Kate D'Cruz, and Dr Lee Cubis. Both Kate and Lee bring with them the crucial and rare mix of clinical and academic expertise which is foundational to the issues we are addressing. Kate is an occupational therapist by training, holds a PhD from La Trobe University, and is an expert qualitative researcher which allows her to oversee many of our qualitative projects. Lee is a clinical psychologist, holds a PhD from Griffith University, and uses his expertise to oversee many of our administrative data and quantitative projects.

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Purpose

The Summer Foundation–La Trobe University Research Program makes a difference to the lives of people with disability and complex needs by using research to:

1. Understand

- The preferences and needs of people with disability
- What has been tried and what works in Australia and globally
- Systems, drivers and barriers that limit the capacity of people with disability to live like everyone else

2. Design

- Frameworks to guide the rigorous evaluation of usual practice and interventions
- Potential solutions, new services and systems change by using rigorous evidence and co-design with people with disability and other agencies

3. Evaluate

- Effectiveness and impact of pilots, prototypes and changes in policy and practice

Principles

Three key principles underpin the Summer Foundation’s approach to research:

1. Engagement of research end users where possible, particularly young people with disability or with complex support needs in aged care or at risk of entering aged care, as well as community organisations, mainstream services and policy makers.
2. Impact on policy, practice and systems change is central to the purpose and design of research.
3. That all research upholds knowledge exchange to ensure research efforts are most likely to result in making a difference. Collaboration and opportunities for engagement of stakeholders will be maximised throughout the research process.



Research methods

A range of research methods is required to develop the breadth of evidence we need to inform policy and practice related to the issue of young people in residential aged care (RAC). Most of the current projects fall into 3 categories: Scoping literature reviews, administrative data projects and primary data projects.

Scoping literature reviews

- What is the problem?
- What solutions have been found?
- What gaps are there and what opportunities for future research?

Administrative data projects

- What data exists on the problem?
- Does the data point to solutions?

Primary data projects

- What evidence is missing to help solve the problem?
- What evidence is needed to change systems and practice?
- What do people with disability want and need?

Scoping literature reviews

We systematically search, review and summarise the academic and grey literature to develop a deep understanding of the systems that admit young people to aged care and leave them there. The Research Unit completes scoping reviews to provide an evidence base to underpin our 4 organisational objectives. The method for each of these reviews will be carefully documented so that we can update the reviews and scans efficiently. Every 2 years, we will update the reviews by using the same search method and incorporating literature that has been published since the last review. These reviews will also be rigorous enough to publish in peer reviewed journals.

We don't want to reinvent the wheel. We research and analyse the strategies that others have tried in order to identify potential solutions and inform the design of pilots and prototypes. We seek to harness the best thinking from literature, other non-profits, universities and think tanks. These scoping reviews will ensure that when we are designing potential solutions we are building on previous local and international work. The content of these reviews will be foundational for a range of publications, including journal articles, reports, policy papers, government submissions, opinion pieces and funding applications.

Administrative data projects

Given that data collection in longitudinal studies is time consuming and expensive, our first priority is to utilise statistical analysis to unlock the full potential of existing administrative and population data. We partner with data custodians and data scientists to clean and manipulate large datasets, combine data from different systems, make deeper insights and reach data informed conclusions. Projects may involve predictive analytics, data visualisation, and data wrangling of large disability, health, housing or aged care data sets.

The Summer Foundation–La Trobe University Research Program has an ambitious research agenda. While the Summer Foundation has a strong research record, the organisation does not have ready access to all the data needed to analyse administrative data across aged care, disability, hospitals and primary health in a timely way. Our \$1 million Competitive Research Grant implemented in 2018 established partnerships with a range of universities and other institutions with data science expertise and access to relevant data assets. See Table 1 for a list of the funded projects.

Table 1. Projects funded through the Competitive Research Grant

Institute	Researcher	Project	Progress
Monash University	Dr Renata Morello	Characteristics, service utilisation and pathways of young people in Victorian hospitals who are admitted from, or discharged to, residential aged care	Manuscript under review
Outcome Health	A Prof Chris Pearce	Health needs and service utilisation of NDIS participants: Data linkage, visualisation and research	Data analysis and manuscript drafting
UNSW	Prof Julian Trollor	Understanding the health needs of younger people with disability discharged from hospital to RAC	Manuscript drafted
Griffith University	Prof Michele Foster	READY study: Readyng hospitalised patients with disability who need NDIS supports for discharge	Completed and results are being disseminated
Macquarie University	Simon Guthrie	Modelling the long-term care pathways for people with acquired neurological injury in NSW and Victoria	Data analysis underway
Australian Institute of Health and Welfare	Jenni Joenpera	Pathways of younger people entering permanent residential aged care	Report

Primary data projects

Literature reviews and the analysis of administrative and population data alone will not provide a sufficient evidence base. The perspectives of people with disability are key to developing potential solutions and solving the issue of young people in RAC. Most of our primary data research projects are mixed methods, collecting both quantitative and qualitative data.

Primary data research is resource intensive and often takes several years to design, obtain and analyse data and summarise findings. The second priority of the Research Unit is to make better use of data available within the Summer Foundation. This includes the information provided by people with disability, family members and workers that contact us, provide information through the Housing Hub or Tenancy Matching Service, or via the storytelling team.



A research program designed to create systems change

Young people living in aged care is a wicked problem involving multiple sectors including hospitals, housing, disability, aged care and primary and community health. The most common pathway into aged care is via hospital. Nearly all young people in aged care are eligible for the NDIS. In addition to navigating the other complex systems and pathways, young people at risk of entering aged care also need to navigate NDIS systems and processes.

The Summer Foundation–La Trobe University Research Program is designed to understand the issue of young people in aged care and the associated systems and pathways. By researching the issues at each stage of the critical pathways that lead young people to aged care, we can provide the evidence needed to create systems change that will solve this problem.



Current scoping literature reviews

Health001: Health needs, costs and service utilisation of people with disability and complex needs

Aims: People with disability and complex needs typically experience a range of health issues that significantly impact their need for medical and nursing support. This reviews existing literature to understand the specific health needs, costs and service utilisation of people with disability who have complex needs.

Progress: Manuscript under peer-review.

Hospital008: Discharge planning from hospital for people with severe acquired disability and for people with complex support needs

Aims: Discharge planning is often appropriate in cases when injury or illness causes permanent and often new and complex significant disability. Discharge planning is appropriate for these people because the significant change in their circumstances often means that they cannot live as they did prior to entering hospital. Discharge planning will ensure that their new needs will be supported when they leave hospital. This study explores the barriers to effective discharge planning, facilitators for planning and the broader outcomes from planning.

Progress: Drafting manuscript.

Huntington's001: Effective housing and support models for people with Huntington's Disease

Aims: It is important to understand the most effective housing and support models for people with Huntington's Disease and understand how NDIS funding can support people for the duration of their lives and avoid admission to residential aged care. This study aims to identify the most effective housing and support models for people with Huntington's Disease. It conducts a scoping review and environmental scan of existing academic and grey literature on housing and support models for people with Huntington's.

Progress: Drafting manuscript.

Co-design 002: Utilisation of co-design with adults with acquired neurological disability in the community

The use of co-design in healthcare is becoming increasingly prominent; however, well-defined guidelines on best practice implementation are yet to be developed. This review aims to synthesise available peer-reviewed literature which investigates the use of co-design in research and/or service development with adults who have an acquired neurological disability and live within the community. The findings will help to guide future co-design practice, ensuring people with acquired neurological disability are best supported and engaged in the process.

Progress: Protocol manuscript under review and literature search underway

Current administrative data projects

CRG Outcome Health: Primary health needs and service utilisation of people with disability

Aims: People with a disability under 65 years tend to experience substantially more health problems than the general population. General practitioners (GPs) play an important role in health management of people with disability and early intervention for the prevention of comorbidities and health complications. The project is a collaboration between Outcome Health and the Summer Foundation to analyse linked data from the NDIS and Eastern Melbourne Primary Health Network for people with disability in order to contribute to the knowledge base of primary health needs of people with disability.

Progress: Analysis underway and manuscripts being drafted.

Current primary data projects

Co-design002: Co-design engagement of adults with lived experience of disability

Aims: Co-design approaches to research present an opportunity to enable the voice of people with disability to be heard, while increasing the impact of research outcomes. However, there is limited evidence guiding the use of co-design approaches with people with complex disability. This study aims to develop an in-depth understanding of the experience of co-design engagement, exploring enablers and barriers to engaging people with complex acquired disabilities. We also seek to identify potential benefits of co-design engagement including peer connection and capacity building.

Progress: Manuscript in progress.

Hospital005: Evaluating the discharge planning process: Barriers, challenges and facilitators of timely and effective discharge

Aims: Improving the pathway from hospital to the community is the key to reducing the number of younger Australians in RAC. However, leaving hospital and returning to the community after a traumatic accident or injury is a complex transition that requires effective coordination between the health system and the NDIS. This study involves retrospective and prospective data collection over 3 years at up to 10 hospital sites across Australia. Data is being collected on the discharge planning process of young people who have been identified as likely to be eligible for the NDIS while in hospital.

Progress: Manuscript with preliminary results being drafted.

NCC004: Supporting the design and construction sector to transition to minimum accessible standards in new homes: A qualitative study

By 2060, it is estimated that over 5 million Australians will have a mobility impairment. However, Australia has an insufficient supply of accessible housing. In response, in early 2021 Australia's building ministers agreed to amend the National Construction Code (NCC) to include mandatory minimum accessibility standards, which would apply to most new houses and apartments. However, not all states and territories have agreed to these standards. Rigorous evidence is needed to support the implementation and transition and national adoption of accessible design standards.

Progress: Manuscript with preliminary results being drafted.

NDIS002: NDIS plans, SDA eligibility and participant outcomes

Aims: The aim of this study is to understand the experience of the NDIS for people with disability living in residential aged care, and the impact of the NDIS on progress towards their goals, participation and quality of life. This study will provide important information to develop resources to support people with disability navigate the NDIS and understand the types of supports they are entitled to.

Progress: Participant recruitment.

NDIS004: What does an improved NDIS look like? Learning from the NDIS participant experience

Aims: The aim of this study is to understand the experience of the NDIS for participants. It seeks to understand their insights and potential recommendations for policy and practice about the elements of quality and cost-effective support.

Progress: Data collection and analysis continuing; preliminary findings shared in podcast interview and article for The Conversation.

SDA001: Moving into new housing designed for people with disability: Evaluation of tenant outcomes

Aims: 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 aged care. This study builds on emerging evidence regarding the long-term outcomes and cost benefits of individualised models of housing and support. It documents the individual experiences and measures the outcomes of people with disability and complex needs who move into appropriately designed housing in the community.

Progress: Quantitative results published, qualitative manuscript under review.

SDA002: Evaluating support, technology and built design in housing for people with disability and complex care needs

Aims: A number of housing demonstration projects have been developed in Australia to integrate housing for people with complex care needs into mainstream housing. These projects are based on the premise that well located and appropriately designed housing, combined with quality support can increase independence, wellbeing and community integration, while reducing reliance on paid support and lifetime care and associated costs. This study investigates the ways people with disability use and interact with the built design, technology features and support systems involved in their homes. Research findings will inform the development of a framework that will be used to guide future housing design.

Progress: Participant recruitment to recommence after delays due to COVID-19 restrictions.

Support003: Evaluation of participant-led videos

Aims: This project evaluated the experience of and satisfaction with working with NDIS participants with cognitive and communication impairments to produce participant-led training videos (PLV) that inform support workers about how NDIS participants want to be supported. Additionally, this project will evaluate the effectiveness of a PLV training workshop for sector professionals.

Progress: One manuscript accepted and another manuscript in draft.

Support004: Understanding the skills and characteristics of a good support coordinator who assists people with disability and complex needs

Aims: In order for people with disability and complex needs to have choice and control and achieve positive outcomes under the NDIS they need to be empowered to navigate the scheme. A high-quality workforce of support coordinators is critical to enable this. This study investigates the skills and characteristics that make a good support coordinator, as well as the barriers they face.

Progress: Participant recruitment.

Support005: A grounded theory study of the quality of paid disability support for adults with acquired neurological disability

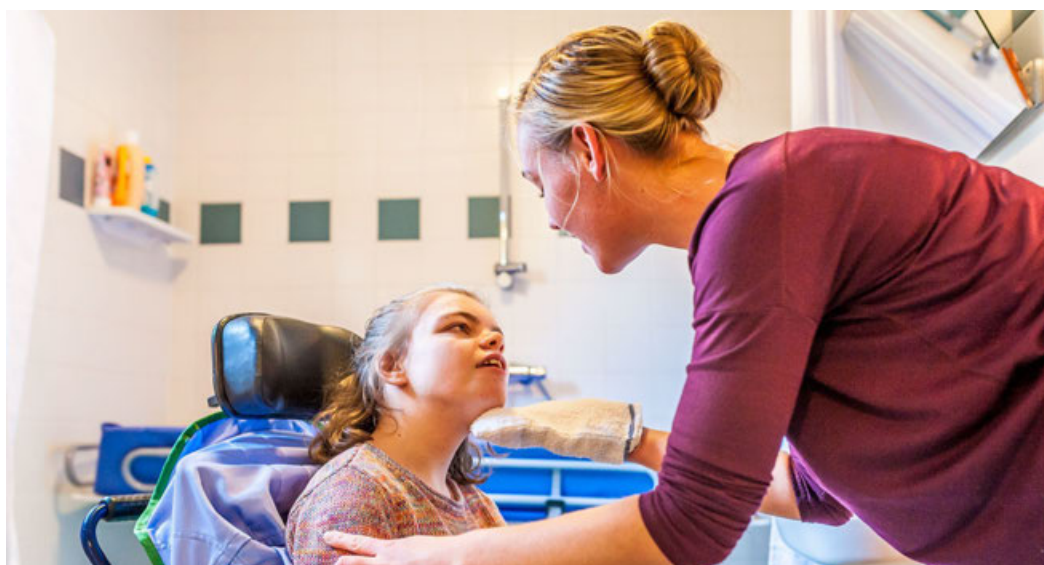
Aims: Paid disability support is often key to living an ordinary life and exercising fundamental human rights for many adults with an acquired neurological disability. This study will develop a comprehensive understanding of the factors that influence the quality of paid disability support grounded in the lived experience of people with acquired neurological disability, close others and disability support workers.

Progress: Scoping review published. Manuscript reporting perspective of people with disability published. Support worker perspective manuscript submitted. Analysing close other data.

Support009: Evaluating participant led videos from the perspective of disability support workers and service providers

Aims: Many NDIS participants living with chronic disability do not have the cognitive or communication capacity “in the moment” to direct support services. For people with cognitive and communication impairments, training and leading their support workers is likely to be considerably more difficult than for people with other types of disability. In response to this issue, we developed a mechanism by which people with cognitive and communication impairments can direct support workers and lead their supports – Participant Led Videos (PLVs). The pilot and subsequent evaluation were endorsed by the people with disability who made the videos, and their close others. This study builds upon the pilot study by seeking the perspective of support workers and disability support service providers.

Progress: Participant recruitment.



Research outputs

Journal articles

July 2021–June 2022

1. Topping, M., Douglas, J., & Winkler, D. (2022). "They treat you like a person, they ask you what you want": A grounded theory study of quality paid disability support for adults with acquired neurological disability. *Disability and Rehabilitation*.
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<https://onlinelibrary.wiley.com/doi/full/10.1002/ajs4.214>
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<https://methods.sagepub.com/case/adapting-remote-interviewing-factors-quality-paid-disability-support>
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9. Topping, M., Douglas, J., & Winkler, D. (2021). General considerations for conducting online qualitative research and practice implications for interviewing people with acquired brain injury. *International Journal of Qualitative Methods*.
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<https://doi.org/10.1177/0308022619898085>
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Reports

July 2021–June 2022

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Conferences and presentations

July 2021–June 2022

1. D’Cruz, K., Douglas, J., Winkler, D. (2022). "This is better but not fully there": Experiences of participating in a co-design project from the perspective of adults with neurological disability and facilitators. 45th ASSBI Brain Impairment Conference. Perth, Australia.
2. Topping, M., Douglas, J., Winkler, D. (2022). "They treat you like a person, they ask you what you want": Exploring Factors that Influence the Quality of Paid Disability Support for Adults with Acquired Neurological Disability. 45th ASSBI Brain Impairment Conference. Perth, Australia.
3. Roseingrave, E., Cubis, L. Minter, E., Winkler, D., Douglas, J. (2022). Living in Limbo: Navigating the Hospital and Discharge Process for People with Disability and Complex Needs. 45th ASSBI Brain Impairment Conference. Perth, Australia.
4. Cubis, L., Roseingrave, E., Winkler, D., Gosdenkaye, E., & Douglas, J. (2021). Components of effective hospital discharge for people with acquired disability and complex needs: A Scoping Review. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
5. Cubis, L., Roseingrave, E., Winkler, D., Topping, M., Minter, E-R., & Douglas, J. (2021). Hospital to home: Evaluating the discharge planning process for people with acquired disability and complex support needs. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
6. D’Cruz, K., Douglas, J., & Winkler, D. (2021). "I have always wanted to do work like this but felt it was out of reach": Hopes and expectations of participating in a co-design storytelling project. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
7. Douglas, J., Leeson, R., & Collins, M. (2021). Evaluation of a Multi-component Community Connection program (M-ComConnect) for people with severe traumatic brain injury: Preliminary results. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
8. Leeson, R., Douglas, J., & Collins, M. (2021). Finding focus: The process of deriving person-centred goals in a multi-component community connection program (M-ComConnect) for people with severe traumatic brain injury. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
9. Oliver, S., D’Cruz, K., Minter, E-R., Naismith, J., Douglas, J., & Winkler, D. (2021). Being a pioneer: A qualitative study of the experience of moving into SDA accommodation from the perspective of adults with neurological disability. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
10. Shorland, J., Douglas, J., & O’Halloran, R. (2021). Older adult admissions to subacute rehabilitation following traumatic brain injury: A comparison of characteristics, speech pathology input and outcome indices across the adult age-span. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.

11. Topping, M., Douglas, J., & Winkler, D. (2021). Factors that Influence the Quality of Paid Support for Adults with Acquired Neurological Disability: Scoping Review and In-Depth Interviews. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
12. Winkler, D., & Douglas, J. (2021). No choices and nothing to do: Changing policy, practice and systems through programmatic research to prevent young people with acquired brain injury from being forced to live in aged care. Paper accepted for presentation at the 6th Pacific Rim Conference. Hybrid conference, Australia.
13. Douglas, J., & Bigby, C. (2021). Building capability of health professionals to support the participation of adults with acquired brain injury (ABI). Paper accepted for presentation at the 18th Neuropsychological Special Interest Group of the World Federation of Neurorehabilitation hybrid conference, Australia.
14. Topping, M., Douglas, J., & Winkler, D. (2021). Considerations for Conducting Online Qualitative Research and Practice Implications for Interviewing People with Acquired Brain Injury. Paper accepted for presentation at the 18th Neuropsychological Special Interest Group of the World Federation of Neurorehabilitation hybrid conference, Australia.
15. D'Cruz, K., Winkler, D., Douglas, J., Goodwin, I., Wellecke, C., Mulherin, P., Davis, E (2022). Making housing more accessible: Perspectives of people with physical impairment, occupational therapists and architects. Paper accepted for presentation at the IBIA Virtual World Congress on Brain Injury.
16. D'Cruz, K., Douglas, J & Serry, T. (2021). Sharing stories of lived experience of acquired brain injury: A model of narrative storytelling to guide the use of storytelling in rehabilitation [Conference presentation] 29th National Occupational Therapy Conference, Melbourne, Australia.

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17. D'Cruz, K., Douglas, J & Serry, T. (2021). Sharing stories of lived experience of acquired brain injury: A model of narrative storytelling to guide the use of storytelling in rehabilitation [Conference presentation] 29th National Occupational Therapy Conference, Melbourne, Australia.
18. Roseingrave, E., Cubis, L., Winkler, D., Douglas, J., Topping, M., Jamwal, B., Harradine, K., and Feltham, J. (2020). Hospital to home: Evaluating the discharge planning process and lived experience of people with acquired disability and complex support needs [Conference presentation]. Austin Health Researchfest 2020, Australia.
19. Topping, M., Douglas, J., Winkler, D. (2020). Training sector professionals to support people with disability to develop participant led videos: An independent evaluation [Conference presentation]. ASSBI 2020 Conference Bite Size!, Australia.

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