



Summer Foundation – La Trobe University Research Program 2022/23

November 2023



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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 experienced academics, clinical experts, research assistants, and doctoral candidates. They come from diverse backgrounds, including psychology, speech pathology, occupational therapy, physiotherapy and architecture. Together, the team work on more than 20 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.

This year has been an eventful year at the Summer Foundation, both professionally and personally for the team. In recognition of our growing track record for research and our excellence, we were awarded a Linkage Grant by the Australian Research Council, as well as an incubator grant from MS Australia. These grants are a substantial investment in the Summer Foundation's research, and will position us to pursue further research and funding opportunities in the future.

Researchers at the Summer Foundation have also received individual recognition this year. Most notably, one of our PhD students, Megan Topping, received the Nancy Millis Award at La Trobe University, which is awarded for outstanding theses. Also, Ella-Rose Minter received the Mindlink Brightwater Award for best Interdisciplinary Research at the 46th annual conference of the Australasian Society for the Study of Brain Impairment. We congratulate and celebrate our successful researchers!

Together, our team produced:

- 13 peer-reviewed journal articles or book chapters
- 7 industry reports
- 19 academic conference presentations and posters

Furthermore, there are 16 manuscripts currently being prepared for submission.

As our team and research program grows, we look forward to the challenges of strengthening and elevating our research. We look to increase the impact our research has as we work towards our goals.

None of this work is possible without our dedicated staff, and the support of La Trobe University, for which we are very grateful.

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Adjunct Associate Professor,
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Jacinta Douglas PhD

Summer Foundation Research Chair (Living Well with Brain Injury)
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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 aged 18 - 65 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. Where possible, we aim to partner with people with lived experience and others with subject matter expertise at the outset of, and throughout the course of each study.

Scoping literature reviews

- What is the problem?
- What solutions have been found?
- What gaps are there and what are the 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 keep them there. The Research team completes scoping reviews to provide an evidence base to underpin our 4 organisational priorities (i.e., Stopping the flow into RAC; Leaving RAC; Access to Quality Housing; and an effective NDIS for younger people with disability and complex needs). The rigorous method for each of these reviews is carefully documented to ensure systematic and timely review, publication in peer reviewed journals and ability to be updated every few years.

We don't believe in reinventing the wheel. These scoping reviews ensure that when we are designing potential research studies and solutions, we are building on previous local and international work. The content of these reviews is 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, the Research team utilises statistical analysis to unlock the full potential of existing administrative and population data. We partner with data custodians and data scientists to extract, clean and manipulate large data sets, combine data from different systems, develop 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 is currently partnering with Outcome Health to examine health needs, costs and service utilisation of people with disability and complex needs. We are also continuing to collect administrative data from hospitals across the country to explore the hospital and NDIS timeframes associated with safe and effective hospital discharge. A priority of the Research team 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 via the Co-design team.

Primary data projects

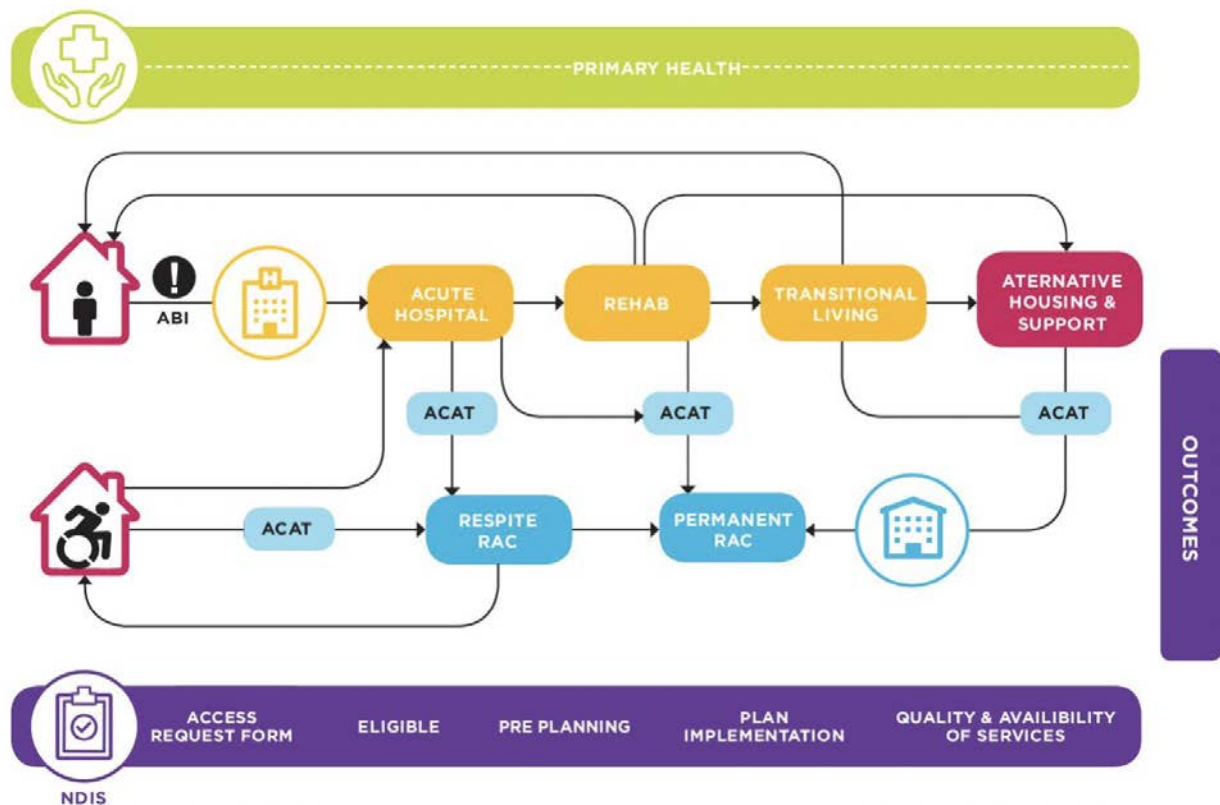
Literature reviews and the analysis of administrative and population data alone will not provide a sufficient evidence base. The perspectives of people with disability are key to developing potential solutions and solving the issue of young people in RAC. Most of our primary data research projects are mixed methods, collecting both quantitative and qualitative data. Primary data projects allow us to develop specific research questions and gain rich insights from those most impacted by the issues at hand (i.e., people with disability) as well as those working within the systems involved (e.g., health professionals). Current primary data projects focus on hospitals and hospital discharge, outcomes for people moving into SDA, including use of a Home and Living Outcome Framework, development of a measure of quality disability support and an evaluation of the NDIS. We also have three PhD students, supervised by Professor Jacinta Douglas, conducting studies that are aimed at better supporting the community participation and social integration of people with disability living in SDA housing.



A research program designed to create systems change

Young people living in aged care is a complex 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 typically 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

Hosp008: Discharge planning from hospital for people with severe acquired disability and for people with complex support needs

Aims: Young adults with acquired disability and complex support needs often experience significant delays to hospital discharge, resulting in high costs for hospital systems and poor outcomes for people with acquired disability. A scoping review was completed to explore the components of successful hospital discharge for people with acquired disability and complex support needs aged 18-65 years.

Progress: Accepted for publication.

HD001: 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. A scoping review was undertaken to identify and integrate the peer-reviewed publications that provide data on the housing and support models for people with HD.

Progress: Results were presented at the Australasian Society for the Study of Brain Impairment conference. The manuscript is being drafted.

Co-des003: Utilisation of co-design with adults with acquired neurological disability in the community.

The aim of the scoping review is to synthesise available peer-reviewed literature which examines the use of co-design in service development and/or research with adults with acquired neurological disability and who live within the community.

Progress: Protocol manuscript has been published, and the scoping review manuscript draft is being prepared.

MS001: Housing and support needs and preferences of people with multiple sclerosis

Aims: People with multiple sclerosis (MS) aged 18-65 are at risk of long hospitalisations and admission to RAC. Due to the progressive and often unpredictable nature of MS, housing and support needs and preferences for this population differ from those with non-progressive disability. The overarching aims of this study are to evaluate the ways that hospitals and the NDIS support people with MS to live a life that aligns with their needs and preferences, and to identify barriers, facilitators and opportunities for people with MS to receive optimal support to live independently in the community and avoid admission to RAC.

Progress: The initial search revealed many studies that met criteria. This project will be split into 2 scoping reviews: Housing, and Support.

Support004: Support coordination: Scoping review and qualitative study

Aims: The NDIS is a massive and complex reform that aims to provide individualised, person-centred processes. However, in order for people with disability and complex needs to have choice and control and achieve positive outcomes under the NDIS, they often require support to navigate the scheme. A high quality workforce of support coordinators is critical to enable this. To help build the capacity of the workforce of support coordinators, we need to first understand:

1. What makes a good support coordinator?
2. What are the key challenges and barriers faced by support coordinators?
3. What resources would assist support coordinators to be more effective in their role?

Progress: Data for this scoping review has been extracted, and an initial presentation made at the Australasian Society for the Study of Brain Impairment conference. The manuscript is being drafted.

G06050: Desktop research report for NDIS Quality and Safeguards Commission project. “Resources to assist NDIS participants to understand their rights, make complaints and raise issues with a supported accommodation provider”

Aims: This project is the first component of a larger project called *Co-designed resources to drive continuous improvement in Supported Accommodation* that is funded through a grant from the NDIS Commission and conducted in partnership with the Co-design team. The desktop scan will identify and review existing resources and data so that the co-designed resources developed build on what is currently available and avoid duplication.

Progress: Desktop scan complete.

Current administrative data projects

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: Research protocol published. Data analysis underway and manuscripts being drafted.

Hosp005: 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 5 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: New data is being acquired, and a manuscript is being drafted.

MS002: Housing and support needs and preferences of people with MS

Aims: People with MS have unique housing and support needs that are essential to maintain independence at home; however, there is limited research to guide housing and supports for this population. This study aims to synthesise existing data from participants with MS from larger projects exploring the needs and preferences of people with disability in the domains of housing, hospital discharge outcomes, and paid support. A further aim of this study is to inform the planning of a co-designed intervention based on this study's findings.

Progress: Manuscript drafted and submitted for publication.

Current primary data projects

Co-des002: 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: Project completed, manuscript in progress.

NDIS005: Redesigning the NDIS: An international perspective on an Australian disability support system.

Aims: Commissioned by Disability Advocacy Network Australia, the report was a collaboration between international expert Simon Duffy and the Summer Foundation's Mark Brown. The report praises the National Disability Insurance Scheme (NDIS) as a significant initiative in the global disability rights movement, but highlights critical flaws in the system's design, pointing out its unsustainability and excessive reliance on bureaucratic processes. This has resulted in rising costs, inadequate cost-control mechanisms, and a negative user experience, potentially jeopardising Australia's commitment to disability rights. The report advocates for a radical redesign of the NDIS, emphasising the need for a regenerative vision of inclusion and citizenship. It argues for a shift in focus from funding services to investing in people, communities, and innovation, and calls for giving more power and responsibility to individuals with disabilities and their communities. The report outlines 4 urgent changes: creating meaningful entitlements, embracing peer support, rooting support in community, and renewing governance. These proposals aim to ensure the NDIS operates in a more human and effective way, adhering to its original principles and vision.

Progress: Project completed, report published.

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, transition, and national adoption of accessible design standards. This study explored the perspectives of practising design and construction professionals engaged in designing and delivering housing in Australia.

Progress: Project completed, report is being finalised for submission.

YPIRAC002 (formerly NDIS002): Evidence base on barriers and enablers to leaving RAC

Aims: This study seeks to understand the NDIS from the perspective of young people living in residential aged care (YPIRAC). The goal of the study is to understand what is contributing to the slow rate of transition out of aged care. It explores the housing needs and preferences of YPIRAC and the barriers experienced in achieving housing choice and control in the NDIS context.

Progress: Participant recruitment, data collection and analysis is in progress.

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: Manuscript has been submitted

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: Two pilot studies published; 4 separate manuscripts are in preparation; data collection ongoing.

PLV001: Evaluation of participant-led videos

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 of PLVs were endorsed by the people with disability who made the videos, and their close others.

Progress: First manuscript published and second manuscript is being drafted.

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. In addition to the abovementioned scoping review, this qualitative study investigates the skills and characteristics that make a good support coordinator, as well as the barriers they face by interviewing people with disability, family members and support coordinators

Progress: Data collection has been completed, and the manuscript is being drafted.

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: Two final manuscripts are being drafted.

Enliv001: Evaluation of the Enliven community initiative

Aims: Traditional models of shared support arrangements (e.g. specialist disability accommodation (SDA), group homes), once in place and fully funded, leave little ability for residents to choose and influence how supports are delivered. Within these models we rarely see the separation of tenancy and support services, and this conflict of interest disempowers residents. Enliven Housing is a for-profit SDA provider that designed Enliven Community, a shared support facilitation model, to operate alongside the apartments they build and lease. Key to the Enliven Community model is an independent facilitator that coordinates and communicates residents' directions to the housing and support providers they have engaged. This research project will evaluate the effectiveness of the Enliven Community facilitation model in achieving good outcomes for residents.

Progress: Participant recruitment and data collection and analysis.

Research outputs

Journal articles

July 2022–June 2023

1. Douglas, J., Winkler, D., McLeod, A., Oliver, S., Gardner, K., Supple, J., & Pearce, C. (2023). Primary healthcare needs and service utilisation of people with disability: A data linkage protocol. <https://bmjopen.bmj.com/content/13/4/e068059>
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3. Topping, M., Douglas, J., & Winkler, D. (2022). “You’re supporting the whole person”: A grounded theory study of quality support according to close others of people with neurological disability, *Neuropsychological Rehabilitation* <https://doi.org/10.1080/09602011.2022.2153149>
4. D’Cruz, K., Antonopoulos, S., Rothman, R., Douglas, J., Winkler, D., & Oliver, S. (2022). Co-designing with adults with acquired neurological disability in the community: A scoping review protocol. *BMJ Open*. <https://bmjopen.bmj.com/content/bmjopen/12/12/e064921.full.pdf>
5. Topping, M., Douglas, J., Winkler, D. (2022). “Let the people you’re supporting be how you learn”: A grounded theory study on quality support from the perspective of disability support workers. *Disability and Rehabilitation*. <https://www.tandfonline.com/doi/full/10.1080/09638288.2022.2148300>
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8. Douglas, J., D’Cruz, K., Winkler, D., Topping, M., Bucolo, C., and Finis, C. (2022). Development and preliminary evaluation of a novel participant-led video intervention to train disability support workers. *Health and Social Care in the Community*. <https://onlinelibrary.wiley.com/doi/10.1111/hsc.13961>
9. Currie, S., Douglas, J., and Winkler, D. (2022). ‘What’s next?’ The journey from hospital to community engagement from the perspectives of adults following severe acquired brain injury: A scoping review protocol. *BMJ Open*. <https://bmjopen.bmj.com/content/12/9/e064226.full>

Pre-July 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*.
<https://www.tandfonline.com/doi/pdf/10.1080/09638288.2022.2086636>
2. Goodwin, I., Davis, E., Winkler, D., Douglas, J., Wellecke, C., D'Cruz, K., Mulherin, P., & Liddicoat, S. (2022). Making homes more accessible for people with mobility impairment: A lived experience perspective. *Australian Journal of Social Issues*.
<https://onlinelibrary.wiley.com/doi/full/10.1002/ajs4.214>
3. Douglas, J., Winkler, D., Oliver, S., Liddicoat, S., & D'Cruz, K. (2022). Moving into new housing designed for people with disability: Preliminary evaluation of outcomes. *Disability and Rehabilitation*.
<https://www.tandfonline.com/doi/full/10.1080/09638288.2022.2060343>
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<https://methods.sagepub.com/case/adapting-remote-interviewing-factors-quality-paid-disability-support>
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7. D'Cruz, K., Douglas, J., & Serry, T. (2021). Humanising brain injury rehabilitation: A qualitative study examining humanising approaches to engagement in the context of a storytelling advocacy programme. *Brain Impairment*.
<https://doi.org/10.1017/BrImp.2021.16>
8. D'Cruz K., Douglas J., & Serry T. (2021). Researching narrative storytelling with adults with acquired brain injury. In: Liamputtong P. (eds) *Handbook of Social Inclusion*. Springer, Cham.
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<https://doi.org/10.1177/16094069211019615>
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<https://doi.org/10.1071/AH19172>
11. D'Cruz, K., Douglas, K., & Serry, T. (2020). Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. *Neuropsychological Rehabilitation*.
<https://doi.org/10.1080/09602011.2019.1586733>
12. D'Cruz, K., Douglas, J., & Serry, T. (2020). Sharing stories of lived experience: A qualitative analysis of the intersection of experiences between storytellers with acquired brain injury and storytelling facilitators. *British Journal of Occupational Therapy*.
<https://doi.org/10.1177/0308022619898085>

13. Jamwal, R., Jarman, H., Roseingrave, E., Douglas, J., & Winkler, D. (2020). Smart home and communication technology for people with disability: A scoping review. *Disability and Rehabilitation: Assistive Technology*.
<https://doi.org/10.1080/17483107.2020.1818138>
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<https://doi.org/10.1080/02699052.2020.1805124>
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Reports

July 2022–June 2023

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Opinion Pieces

July 2022–June 2023

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3. Topping, M., Douglas, J., “‘They treat you like a person, they ask you what you want’: what NDIS participants value in support workers”, published online on The Conversation, September 2022.
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Conferences and presentations

July 2022–June 2023

1. Winkler, D., Douglas, J. (2023). Achieving the Younger People in Residential Aged Care Targets. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
2. Dearn, E., Brown, M., D'Cruz, K., Winkler, D.(2023). "Hurry up and get me out of here": Why are young people (still) stuck in aged care? 46th ASSBI Brain Impairment Conference. Darwin, Australia.
3. Douglas, J., Winkler, D. (2023). "Having moved and being able to be quite independent." Outcomes over two years for people with neurological disability and complex needs after moving into new individualised apartments. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
4. D'Cruz, K., Rothman, R., Antonopoulos, S., Douglas, J., Winkler, D., Oliver, S. (2023). Co-designing with Adults with Acquired Neurological Disability in the Community: A Scoping Literature Review. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
5. Minter, E-R. Cubis, L., Roseingrave, E., Winkler, D., Douglas, J. (2023). Barriers to Hospital Discharge for People With Disability and Complex Needs: A Survey of Health Professionals. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
6. Cubis, L., McDonald, S., Dearn, E., Winkler, D., Douglas, J. (2023). Factors That influence the Quality of Support Coordination for People with Neurological Disability and Complex Needs: A Scoping Review. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
7. D'Cruz, K., Brown, M., Oliver, S., Winkler, D., Douglas, J. (2023). A national survey of NDIS participants: Rebuilding trust based on solutions grounded in the experiences and perspectives of NDIS participants with neurological disability. 46th ASSBI Brain Impairment Conference. Darwin, Australia.
8. Topping, M., Douglas, J., Winkler, D. "You're Supporting the Whole Person": Model of Quality Support Grounded in the Experience of Adults with Acquired Neurological Disability, Disability Support Workers and Close Others. (2023). 46th ASSBI Brain Impairment Conference. Darwin, Australia.
9. Oliver, S., Winkler, D., Douglas, J., McLeod, A., Rothman, R. (2023): Primary health care needs and service utilisation of NDIS participants with stroke and acquired brain injury (2023). 46th ASSBI Brain Impairment Conference. Darwin, Australia.
10. Ramme, R., Cubis, L., Winkler, D., Douglas, J. Using an Action Research Methodology to Develop a Rapid Response Service Supporting People with Neurological Disability to Discharge Home From Hospital. (2023). 46th ASSBI Brain Impairment Conference. Darwin, Australia.
11. McDonald, S., Cubis, L., Winkler, D., Douglas, J. "Know Everything, Be Everything": Skills, Attributes and Challenges for Effective Support Coordination in the National Disability Insurance Scheme. (2023). 46th ASSBI Brain Impairment Conference. Darwin, Australia.
12. Topping, M., Douglas, J., Winkler, D. "They treat you like a person, they ask you what you want" - Quality support grounded in the lived experience of people with neurological disability, close others and disability support workers. (2023). 14th World Congress on Brain Injury. Dublin, Ireland
13. D'Cruz, K., & Nielson, S. Enabling people with disability to live in their own home. (2023). Occupational Therapy Australia webinar, Melbourne, Australia.

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