

**SUMMER FOUNDATION  
– LA TROBE UNIVERSITY  
RESEARCH PROGRAM**

**30 JUNE 2020**

# 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.



# METHODOLOGY

A range of methodologies 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 and environmental scans, analysis of administrative data or primary research.

|  |  |
|--|--|
| <b>Literature reviews</b>              | Understand the problem<br>What has been tried and what works?                |
| <b>Analysis of administrative data</b> | Glean what we can from data available<br>Understand the systems and pathways |
| <b>Primary research</b>                | Needs, preferences and outcomes<br>Impact of NDIS, pilots and prototypes     |

Figure 1. Summary of the methodologies used in the Summer Foundation - La Trobe University Research Program

## 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 and environmental scans 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 latest 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 the past to identify potential solutions and inform the design of pilots and prototypes. We seek to harness the best thinking from literature, incubators, other non-profits, universities and think tanks. These literature reviews and environmental scans will ensure that when we are designing potential solutions we are building on previous local and international work. The content of the literature reviews and environmental scans will be foundational for a range of publications, including journal articles, reports, policy papers, government submissions, opinion pieces and funding applications.

## Analysis of administrative data

Given that data collection in longitudinal studies is time consuming and expensive, our first priority is to utilise data science and more traditional 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, machine learning and data wrangling of large disability, health, housing or aged care data sets. We are also building our in-house capacity for analysing large datasets and now have a data science manager within the Research Unit.

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 of 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.**

| <b>Institute</b>     | <b>Researcher</b>       | <b>Project Title</b>  | <b>SF Project Code</b> | <b>Progress</b>                             |
|----------------------|-------------------------|---|------------------------|---|
| AIHW                 | Jenni Joenpera          | Pathways of younger people in aged care   | CRG AIHW               | Complete                                    |
| 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 | CRG Monash             | Journal manuscript submitted                |
| Outcome Health       | Assoc Prof Chris Pearce | Health needs and service utilisation of NDIS participants: Data linkage, visualisation and research   | CRG Outcome Health     | Ethics approved; NDIA data request underway |
| UNSW                 | Prof Julian Trollor     | Understanding the health needs of younger people with disabilities discharged from hospital to RAC  | CRG UNSW               | First manuscript drafted                    |
| Griffith             | Prof Michele Foster     | READY study: Readyng hospitalised patients with disability who need NDIS supports for discharge   | CRG Griffith           | Data analysis complete                      |
| Macquarie University | Simon Guthrie           | PhD Scholarship: Modelling the long-term care pathways for people with acquired neurological injury in NSW and Victoria                                 | CRG Macquarie          | Ethics submitted for first study            |

## Primary research

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 research projects are mixed methods, collecting both quantitative and qualitative data.

Primary research is resource intensive and often takes many 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.

# 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 National Disability Insurance Scheme (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 (see Figure 2), we can provide the evidence needed to create systems change that will solve this problem.

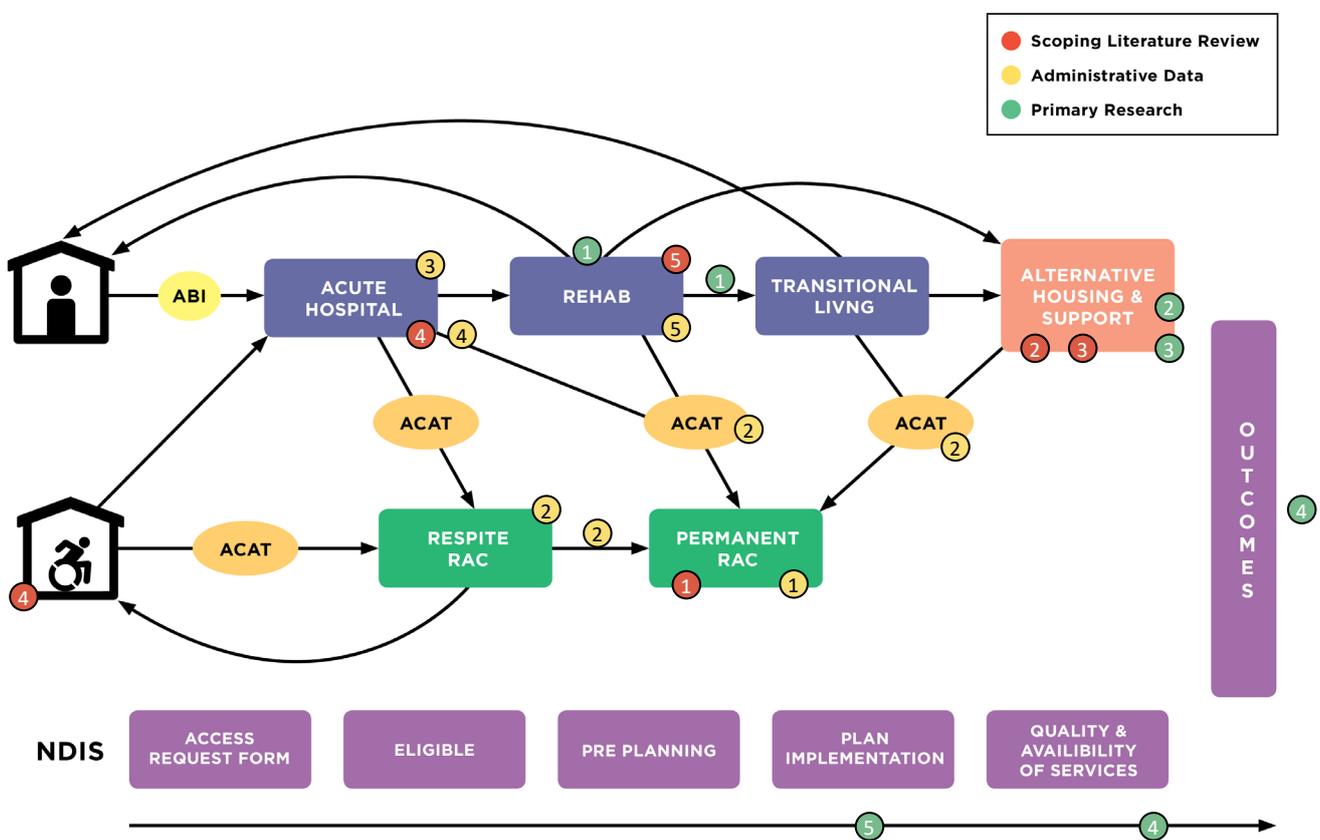


Figure 2. The Summer Foundation - La Trobe University Research Program includes scoping literature reviews, analysis of administrative data and primary research across multiple sectors. Each number in the figure represents a specific research project, described in Table 2.

Table 2. Projects within the Summer Foundation – La Trobe Research Program that will lead to systems change.

| No                                     | Project Title   | Project No  | Next Deliverable                     | Progress                                   |
|--|---|-------------|--------------------------------------|--|
| <b>Scoping literature reviews</b>      |   |             |                                      |  |
| 1                                      | Experiences and outcomes of younger people living in aged care  | YPIRAC001   | Journal manuscript                   | Manuscript submitted                       |
| 2                                      | Outcomes of individualised housing for people with disability and complex needs   | Housing001  | Journal manuscript                   | In press                                   |
| 3                                      | Smart home technology that can be used to support independent living for people with disability   | Housing002  | Journal manuscript                   | Manuscript submitted                       |
| 4                                      | Health, costs and service utilisation   | Health001   | Journal manuscript                   |  |
| 5                                      | Discharge planning from hospital for people with severe acquired disability and for people with complex support needs                                   | Hospital008 | Journal manuscript                   |  |
| <b>Analysis of administrative data</b> |   |             |                                      |  |
| 1                                      | Evaluation of population trends of young people in residential aged care, 2008-2018   | AgedCare002 | Journal manuscript                   | In press                                   |
| 2                                      | Pathways of younger people in aged care   | CRG AIHW    | <a href="#">Report</a>               | Completed                                  |
| 3                                      | Characteristics, service utilisation and pathways of young people in Victorian hospitals who are admitted from, or discharged to, residential aged care | CRG Monash  | Report                               | Manuscript submitted                       |
| 4                                      | Understanding the health needs of younger people with disabilities discharged from hospital to RAC  | CRG UNSW    | Interim report                       | Due for completion, June 2022              |
| 5                                      | Young people discharged to RAC from rehabilitation hospitals in Australia   | Hospital004 | Journal manuscript                   | Manuscript drafted; NDIA data request made |
| <b>Primary research</b>                |   |             |                                      |  |
| 1                                      | Evaluating the discharge planning process: barriers, challenges and facilitators of timely and effective discharge                                      | Hospital005 | Preliminary administrative data      | Data collected for 120 participants        |
| 2                                      | Moving into new housing designed for people with disability: Evaluation of tenant outcomes  | SDA001      | Preliminary data                     | Data collected for 32 participants         |
| 3                                      | Evaluating support, technology and built design in housing for people with disability and complex care needs  | SDA002      | Collect pilot data on 3 participants | Data collected for 1 participant           |
| 4                                      | Analysis of NDIS Plans, SDA eligibility and participant outcomes  | NDIS002     | Collect pilot data on 3 participants | Ethics obtained                            |
| 5                                      | Understanding the skills and characteristics of a good support coordinator who assists people with disability and complex needs                         | Support004  | Preliminary data                     | Ethics obtained                            |

Note: the numbers in this table correspond to those in Figure 2.

# RESEARCH PROGRAM PROGRESS

## SCOPING REVIEWS

### **Experiences and outcomes of younger people living in aged care**

**Aims:** To map the literature on the experiences and outcomes of young people with disability who are placed in aged care. To collate recommendations for policy, practice and research that address the issue of young people living in aged care.

**Progress:** The scoping review has been completed. Outputs include:

- Oliver S, Gosden-Kaye EZ, Jarman H, Winkler D, Douglas JM. A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities, submitted to Brain Injury.

**Potential Impact:** This review clearly demonstrates the negative outcomes young people experience while living in aged care and how their basic human needs often go unmet in this unsuitable environment. Systemic changes are required to meet the needs of young people with complex needs at risk of admission to aged care including timely rehabilitation, housing and support options.

### **Outcomes of individualised housing for people with disability and complex needs**

**Aim:** To determine what is currently known about outcomes associated with individualised housing for adults with disability and complex needs.

**Progress:** The scoping review has been completed. Outputs include:

- Oliver S, Gosden-Kaye EZ, Winkler D, Douglas JM. The outcomes of individualised housing for people with disability and complex needs: A scoping review, Disability and Rehabilitation, in press. (accepted 16/6/20)

**Potential Impact:** This review demonstrates that individualised housing options have the potential to offer improved self-determination, choice and autonomy for people with disability and complex needs. There is however still a considerable need to investigate individualised housing outcomes for people with an acquired disability.

### **Smart home and communication technology for people with disability**

**Aim:** To explore the impact of smart home and communication technology on the outcomes (e.g. independence, autonomy) of people with disability and complex needs.

**Progress:** The scoping review has been completed. Outputs include:

- Jamwal R, Jarman H, Roseingrave E, Douglas JM, Winkler D. Smart home and communication technology for people with disability: A scoping review, submitted to Disability and Rehabilitation: Assistive Technology.

**Potential Impact:** Identifying gaps in the evidence base will help to direct future research into examining how smart home technology can be used to help improve outcomes of people with disability.

## **Discharge planning from hospital for people with severe acquired disability and for people with complex support needs**

**Aims:** To understand how discharge planning is an effective part of the care continuum for people with disability. To understand the barriers and facilitators to discharge planning in the hospital.

**Progress:** Data has been extracted from studies that met the scoping review criteria and analysis is currently underway.

**Potential Impact:** Identifying gaps in the evidence base will help to direct future research into examining how discharge planning can be facilitated to improve the outcomes of people with disability and complex support needs.

## **Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs**

**Aim:** This scoping review aims to further understand the factors that influence the quality of paid disability support for adults with acquired disability and complex needs.

**Progress:** The review has been completed. Outputs include:

- Topping M, Douglas J, Winkler D. (2019) Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: A scoping review protocol, *BMJ Open*, 9:e034654.
- Topping M, Douglas J, Winkler D. Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: A scoping review and thematic analysis, submitted to *Disability and Rehabilitation*.

**Potential Impact:** This review has the potential to impact practice and policy and provide a better understanding of what factors facilitate effective support from disability support workers, and what the barriers to receiving quality support are. Review findings will be made available to relevant stakeholders through a peer-reviewed publication, conference presentations and workshops.

## **The primary health needs and service utilisation of people with disability and complex needs: A scoping review**

**Aims:** To determine what is known about the primary health needs and service utilisation of people with disability and complex needs. To summarise and disseminate research findings to inform policy makers, practitioners and consumers.

**Progress:** The searches have been completed and screening is currently being undertaken.

**Potential Impact:** This review has the potential to impact practice and policy by providing a better understanding of how health promotion and preventative measures can improve the health outcomes for this population. Review findings will be made available to relevant stakeholders through a peer-reviewed publication, conference presentations and workshops.

## ENVIRONMENTAL SCAN

### **Transitional housing and support in Australia for people with disability**

**Aim:** To provide an evidence base about transitional housing and support options suitable for people with disability and complex needs, identify gaps in the system and determine potential solutions.

**Progress:** The study has been completed. The following output was generated:

- Winkler D, Moore S, Hilton G, Bucolo C, Mitsch V, Bishop GM. (2020) [Transitional Housing and Support in Australia for People with Disability: Environmental Scan](#). Melbourne, Australia: Summer Foundation.

**Potential Impact:** Provides details of transitional housing and support options that fit the criteria of being 'home like' and are currently available across Australia, which could be used by people with disability who are in the process of returning to community living after being discharged from hospital.

## ANALYSIS OF ADMINISTRATIVE DATA

### Evaluation of population trends of young people in residential aged care, 2008-2018

**Aim:** To evaluate trends in rates of young people entering and leaving permanent residential aged care from 2008 to 2018.

**Progress:** This study has been completed. Outputs include:

- Brown MG, Bishop GM, Winkler D, Douglas JM. Young people in Australian residential aged care: Evaluating trends 2008 to 2018, *Australian Health Review*, in press. (accepted 15/10/19)

**Potential Impact:** The results from this study will provide a benchmark against which to judge the future impact of the NDIS.

### Characteristics of younger people in residential aged care in 2017-2018

**Aim:** To utilise the available administrative data to describe the characteristics, support needs and geographical distribution of young people in permanent residential aged care in Australia 2017-2018.

**Progress:** This study has been completed. The following output was generated:

- Bishop GM, Zail J, Bo'sher L, Winkler D. (2019) [Young People in Residential Aged Care \(2017-2018\): A Snapshot](#), Melbourne, Australia: Summer Foundation.

**Potential Impact:** Knowledge about the current population of younger people in aged care is critical and can be used to inform organisations and government bodies that are working to create the systems change needed to resolve the issue of young people in aged care in Australia.

### Pathways of younger people in aged care

*Project led by Jenni Joenpera, Australian Institute of Health and Welfare; funded by the Summer Foundation.*

**Aim:** To investigate the characteristics, patterns and pathways of people who first entered permanent residential aged care at a younger age.

**Progress:** This study has been completed. The following output was generated:

- Australian Institute of Health and Welfare 2019. [Pathways of younger people entering permanent residential aged care](#). Cat. no. AGE 89. Canberra: AIHW.

**Potential Impact:** Understanding the pathways by which younger people enter aged care highlights potential places for interventions that can prevent younger people from entering aged care.

## **Characteristics, service utilisation and pathways of young people in Victorian hospitals who are admitted from, or discharged to, residential aged care**

*Project led by Dr Renata Morello, Monash University; funded by the Summer Foundation.*

**Aim:** To use secondary hospital utilisation data to explore the characteristics and hospital utilisation of young people transferred from residential aged care to hospital, or to residential aged care from hospital.

**Progress:** This study has been completed and a manuscript has been submitted to a peer-reviewed journal.

**Potential Impact:** The data is critical to informing interventions to support young people to return to their communities and improve the lives of these individuals.

## **Health needs and service utilisation of NDIS participants: Data linkage, visualisation and research**

*Project led by Associate Professor Chris Pearce, Outcome Health; funded by the Summer Foundation.*

**Aim:** To link primary health data and hospital data to explore the health needs and service utilisation (e.g. GP and hospital) of NDIS participants, including young people in aged care facilities.

**Progress:** Stakeholder engagement has been conducted. Ethics approval has been received and negotiations are currently underway with the National Disability Insurance Agency (NDIA) to link a de-identified geographic group of NDIS participants to the GP and hospital data for analysis.

**Potential Impact:** Understanding the health needs and experiences of people with a disability across multiple health sectors will allow the development of service solutions across the health system that will improve the health outcomes of people with disability.

## **Understanding the health needs of younger people with disabilities discharged from hospital to RAC**

*Project led by Professor Julian Trollor, University of New South Wales; funded by the Summer Foundation.*

**Aim:** To evaluate hospital admissions data to understand the health needs and outcomes of younger people with disabilities who are discharged from hospital to residential aged care.

**Progress:** The first manuscript is being prepared for publication.

**Potential Impact:** We will have capacity to investigate real world issues for younger people with disabilities including: identification of the complex health and support needs of those discharged to RAC; the broad predictors of RAC placement; rates and predictors of preventable emergency department visits and hospitalisations; mortality rates and causes of death.

## **READY study: Readying hospitalised patients with disability who need NDIS supports for discharge**

*Project led by Professor Michele Foster, Griffith University; funded by the Summer Foundation.*

**Aim:** To examine how hospital discharge planning processes interface with NDIS processes and timelines to better understand the complications, risks and outcomes for patients who require NDIS funded supports on discharge.

**Progress:** Administrative data has been collected for 224 patients and data analysis has begun.

**Potential Impact:** By describing what is happening at the hospital discharge-NDIS interface, we can inform on improvements required and what these might look like.

## **Modelling the long-term care pathways for people with acquired neurological injury in NSW and Victoria**

*PhD scholarship awarded by the Summer Foundation to Simon Guthrie, Macquarie University.*

**Aim:** To predict the long-term care needs and pathways through the health sector for people with acquired brain injury and spinal cord injury, who live in NSW and Victoria.

**Progress:** Ethics approval has been received and NDIA data request has been made.

**Potential Impact:** If we understand the long-term health care needs and outcomes of people with acquired neurological disability, the health sector can better direct their care to increase beneficial outcomes for people with disability.

## PRIMARY RESEARCH

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

**Aim:** To evaluate the discharge process of people with acquired disability to identify facilitators, challenges and barriers of effective discharge.

**Progress:** 5 hospital sites are open for data collection; 4 more hospital sites are approved by ethics and are awaiting individual hospital site ethical approval. Administrative hospital data has been collected from 120 patients in 5 hospital sites. 6 primary participants have been recruited for follow-up interviews. The onset of COVID-19 resulted in most hospital sites suspending data collection and participant recruitment; however, administrative data collection has now resumed in all open sites and participant recruitment has resumed at 1 site.

**Potential Impact:** The outcome data from this study will contribute to building a much-needed evidence base on the experience of people with complex needs and/or acquired disability during their transition from hospital to the community. The data will also be used to inform individual health services about the timeframes involved in their discharge processes so that they can develop more efficient systems to improve discharge planning and patient outcomes.

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

**Aim:** To better understand the individual experiences and outcomes of people with disability and complex needs who move into appropriately designed housing in the community.

**Progress:** We have recruited 33 participants, spanning 4 states (VIC, NSW, SA, QLD) and 4 housing providers (Summer Housing, Guardian Living, Access2Place, Ability SDA). 32 participants have completed the first time point and 13 have completed the second time point, with an additional 26 interviews being completed with close others. The onset of COVID-19 required a change in interview procedures to ensure participant safety, however the project is continuing using online technologies. Outputs include:

- Winkler D, Douglas J, Jamwal R. (March 2019) Outcomes & impact of new SDA. Get Building SDA National Conference, Melbourne, Australia.
- Winkler D, Douglas J. (May 2019) Integrated apartments for people with disability: Individual experience and outcomes. ASSBI NZRA Inaugural Trans-Tasman Conference, Wellington, New Zealand.

**Potential Impact:** This project will enable us to evaluate at the level of the individual the impact of living in appropriately designed housing. We will obtain perspectives about how Specialist Disability Accommodation (SDA) affects strain, wellbeing, social support and quality of life for people with disability and those close to them. It will also consider financial input, including housing and support costs under SDA.

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

**Aim:** To evaluate the built design, technology and support environments within housing that was designed for people with disability and complex care needs.

**Progress:** We have developed, trialled and refined a data collection tool for use in the observation component of the study. We have completed 2 interviews and 3 observation trials with our first participant. However, since the observation trials require researchers to be in close proximity with participants, recruitment has been put on hold due to COVID-19 and will not resume until we can be certain of participant safety.

**Potential Impact:** An increased understanding of how people with disability interact with their home environment will provide an evidence base to iteratively improve the design of cost-effective housing and support that enables people with disability to live an ordinary life.

## **Training sector professionals to support people with disability to develop participant led videos: An independent evaluation**

**Aim:** To independently evaluate a workshop designed to train sector professionals to support people with disability to develop participant led videos (PLVs). PLVs are an innovative tool that enables people with cognitive and communication impairments to direct the training of their support workers.

**Progress:** This project has been completed. Outputs include:

- Topping M, Douglas J, Winkler D. (June 2020) Training sector professionals to support people with disability to develop participant led videos: An independent evaluation, oral presentation at ASSBI 2020 Conference Bite Size!, Australia.

**Potential Impact:** This evaluation demonstrates that production of PLVs is not dependent on the innovative expertise at the Summer Foundation and that sector professionals can be trained to support people with disability to develop PLVs. PLVs have the potential to improve delivery of support and maximise outcomes by enabling people to have choice and control, set their own goals and direct their supports.

## **Maximising community connection for people with acquired brain injury (M-ComConnect)**

*ISCRR funded research project awarded to La Trobe University, Living with Disability Research Centre, led by Professor Jacinta Douglas and collaborating with researchers at the Summer Foundation.*

**Aim:** To implement and evaluate the efficacy of a multi-component community connection program (M-ComConnect) to maximise social connections and community inclusion for people with severe brain injury living in the community.

**Progress:** The project began in 2016, data collection is about to conclude and the project is on track for completion by December 2020.

**Potential Impact:** This project demonstrates that an individualised multi-component community connection program has enormous potential to assist people with brain injury to maximise their social connections and community inclusion, which has significant implications for their quality of life and wellbeing.

## Understanding the experience and impact of narrative storytelling following acquired brain injury

Summer Foundation PhD Scholarship awarded to Kate D'Cruz, La Trobe Living with Disability Research Centre

**Aim:** To explore the subjective experience of narrative storytelling following brain injury.

**Progress:** PhD thesis was submitted in December 2019. Research included 28 interviews that were analysed using constructivist grounded theory methods. The outputs generated include 3 published journal articles and 1 under review.

**Potential Impact:** This is the first study to investigate the use of narrative storytelling for adults with brain injury in an advocacy context, and from the perspective of both storytellers and facilitators. Narrative storytelling was found to be a humanising experience. Central to this finding was the advocacy context of the storytelling, in which sharing personal stories held meaningful occupational purpose, valuing lived experience of disability. The findings of this research contribute new insights, with practice recommendations considered in the context of holistic ABI rehabilitation.

## Personal protective equipment needs of NDIS participants during COVID-19

**Aim:** To understand the personal protective equipment (PPE) needs of NDIS participants and support workers during the COVID-19 pandemic.

**Progress:** We administered an online survey in April 2020 to NDIS participants and received over 350 responses. The initial analysis and report has been completed:

- Winkler D, Douglas JM, Rinehart N, Jamwal R, Bishop GM & Jarman H. (2020) [Personal Protective Equipment Needs of NDIS Participants during COVID-19: Preliminary Results](#). Melbourne, Australia: Summer Foundation.

**Potential Impact:** People with disability, especially those with underlying medical conditions, are disproportionately vulnerable during COVID-19. Understanding the needs of NDIS participants for PPE to keep them and their support workers safe during the COVID-19 pandemic can be used to help improve the supply of PPE, along with an understanding of how to use it, and reduce the impact of COVID-19 on a highly vulnerable population.

## ACTION RESEARCH

### Housing Brokerage Service

**Aim:** To use an action research framework to evaluate the Housing Brokerage Service intervention, a service implemented by the Summer Foundation in response to COVID-19. The purpose of the Housing Brokerage Service is to develop and pilot a service to improve timely discharge of long-stay hospital patients to appropriate interim and sustainable long-term housing options.

**Progress:** The Housing Brokerage Service has received 24 referrals of people in need of a suitable housing destination. Staff of the service are being interviewed regarding their experiences to identify common challenges, facilitators and gaps of the service. Using the action research framework, the results are fed back into the service on a fortnightly basis to resolve identified gaps and challenges.

**Potential Impact:** The action research method contributes to the natural reflection and refinement process of the Housing Brokerage Service, facilitating the capture of important moments in project development, as well as contributing to a shared sense of team decision-making. This process will assist in the refinement of a much-needed service, along with the development of resources, which together have the potential to impact on strategies used during the hospital discharge process.

### Discharge Follow-Up Service

**Aim:** To use an action research framework to evaluate the Discharge Follow-Up Service intervention, a service implemented by the Summer Foundation in response to COVID-19. The purpose of the Discharge Follow-up Service is to provide information to people with disability and complex support needs, and their support networks, who have been discharged early from hospital as a result of COVID-19.

**Progress:** The Discharge Follow-Up Service has received 7 referrals of people in need of discharge follow-up. A weekly report is generated based on data gathered from team member interviews, participant referral and exit forms, and email and phone inquiries. Using the action research framework, the results are used in weekly meetings to discuss and agree on changes to the service.

**Potential Impact:** The action research framework has facilitated a platform for reflection, open discussions, team learning and shared decision-making, leading to refinement of the Discharge Follow-Up Service so that it better meets the needs of people with disability, while also supporting staff delivering the service. This will assist in the continued evolution of this service, along with key resources, that will support people with disability who have been discharged from hospital early as a result of COVID-19.

## Phone Outreach and Peer Support Service

**Aim:** To use an action research framework to evaluate the Phone Outreach and Peer Support Service, a service implemented by the Summer Foundation in response to COVID-19. The purpose of the Phone Outreach and Peer Support Service is to connect with people with disabilities and their close others to check on their health and wellbeing, provide a point of social contact, and provide practical information and support with problem solving challenges.

**Progress:** Over 150 potential participants were identified from the Summer Foundation cohort, so far resulting in 144 initial contact calls, 68 second contact calls, 23 third contact calls and 5 fourth contact calls. Descriptive data has been obtained from the phone outreach calls and from qualitative interviews with phone outreach staff. The results are discussed at weekly team meetings, providing a forum for continuous learning and reflection, while facilitating accountability and service growth.

**Potential Impact:** The action research framework has assisted in the development of the Phone Outreach and Peer Support Service as it evolves in response to the needs of people with disability and their close others. In particular, this reflective process is creating an understanding of what peer support means, which will be used to evolve the service into a peer-led service. In this way, peer support workers will be trained so they can provide support to people with disability and close others.

# APPENDIX: DISSEMINATION OF RESEARCH FINDINGS

## RESEARCH OUTPUTS IN 2019 AND 2020

### Reports

- Oliver SB, Gosden-Kaye EZ, Jarman HK, Winkler D, Douglas JM. (2019) A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities: Interim Report. Melbourne, Australia: Summer Foundation.
- Bishop GM, Zail J, Bo'sher L, Winkler D. (2019) Young People in Residential Aged Care (2017–2018): A Snapshot, Melbourne, Australia: Summer Foundation. [www.summerfoundation.org.au/wp-content/uploads/YoungPeopleinRAC17-18-final-web.pdf](http://www.summerfoundation.org.au/wp-content/uploads/YoungPeopleinRAC17-18-final-web.pdf)
- Winkler D, Moore S, Hilton G, Bucolo C, Mitsch V, Bishop, GM. (2020) Transitional Housing and Support in Australia for People with Disability: Environmental Scan. Melbourne, Australia: Summer Foundation. [www.summerfoundation.org.au/wp-content/uploads/2020/05/Transitional\\_Housing\\_and\\_Support-web.pdf](http://www.summerfoundation.org.au/wp-content/uploads/2020/05/Transitional_Housing_and_Support-web.pdf)
- Winkler D, Douglas JM, Rinehart N, Jamwal R, Bishop GM & Jarman H. (2020) [Personal Protective Equipment Needs of NDIS Participants during COVID-19: Preliminary Results](#). Melbourne, Australia: Summer Foundation.
- Douglas J, Bigby C, Smith E. (2020). Building Capability to Support Client Decision Making, TAC Project T-005. Melbourne: Living with Disability Research Centre, LaTrobe University.

### Journal Articles

- D'Cruz K, Douglas J, Serry T. Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. *Neuropsychological Rehabilitation*, in press. (accepted 22/2/19). <https://doi.org/10.1080/09602011.2019.1586733>
- Douglas J. (2019). Loss of friendship following traumatic brain injury: A model grounded in the experience of adults with severe injury. *Neuropsychological Rehabilitation*. <https://doi.org/10.1080/09602011.2019.1574589>
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## Conferences and Presentations

- Winkler D, Douglas J, Jamwal R. (March 2019) Outcomes & impact of new SDA. Get Building SDA National Conference, Melbourne, Australia.
- D'Cruz K, Douglas J, Serry T. (May 2019) Humanising healthcare: Understanding the potential of narrative storytelling. Oral presentation. ASSBI NZRA Inaugural Trans-Tasman conference, Wellington, New Zealand.
- Winkler D, Douglas J. (May 2019) Integrated apartments for people with disability: Individual experience and outcomes. ASSBI NZRA Inaugural Trans-Tasman Conference, Wellington, New Zealand.
- Winkler D, Douglas J, D'Cruz K, Bucolo C, Finis C. (May 2019) Co-design, pilot and evaluation of participant led videos to train support workers, ASSBI NZRA Inaugural Trans-Tasman Conference, Wellington, New Zealand.
- Douglas J, Winkler D, D'Cruz K, Bucolo C, Finis C. (June 2019) Development and evaluation of participant led videos to train support workers of people with severe acquired brain injury. WFNR Neuropsychological Rehabilitation Symposium, Granada, Spain.
- Winkler D, Bucolo C, Douglas J, Finis C, D'Cruz K. (July 2019) Outcomes of participant led videos: Supporting people with severe brain injury to have choice and control, set goals and direct their supports. OTAUS ePoster, Sydney, Australia.
- Winkler D. (November 2019) Summer Foundation Hunter: A real-life case study. CSIA: NDIS Six Years On, Insights from the Hunter, Brisbane, Australia.
- Topping M, Douglas J, Winkler D. (June 2020) Training sector professionals to support people with disability to develop participant led videos: an independent evaluation, oral presentation at ASSBI 2020 Conference Bite Size!, Australia.

## Other

- Summer Foundation Research Unit. (April 2020) How to use the Community Integration Questionnaire (Revised), Online video training, Summer Foundation, Melbourne, Australia:  
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## UPCOMING RESEARCH DISSEMINATION IN 2020

### Journal Articles

- Oliver S, Gosden-Kaye EZ, Jarman H, Winkler D, Douglas JM. A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities, submitted to *Brain Injury*.
- Topping M, Douglas J, Winkler D. Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: A scoping review and thematic analysis, submitted to *Disability and Rehabilitation*.
- Jamwal R, Jarman H, Roseingrave E, Douglas JM, Winkler D. Smart home and communication technology for people with disability: A scoping review, submitted to *Disability and Rehabilitation: Assistive Technology*.

### Conferences and Presentations

- Jamwal R, Naismith J, Tran Q, Winkler D, Douglas J. (October 2020) Evaluating support, technology and built design in housing for people with disability and complex care needs, Flash Talk presentation at Universal Design 2020 conference, Melbourne, Australia.

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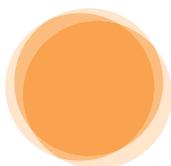
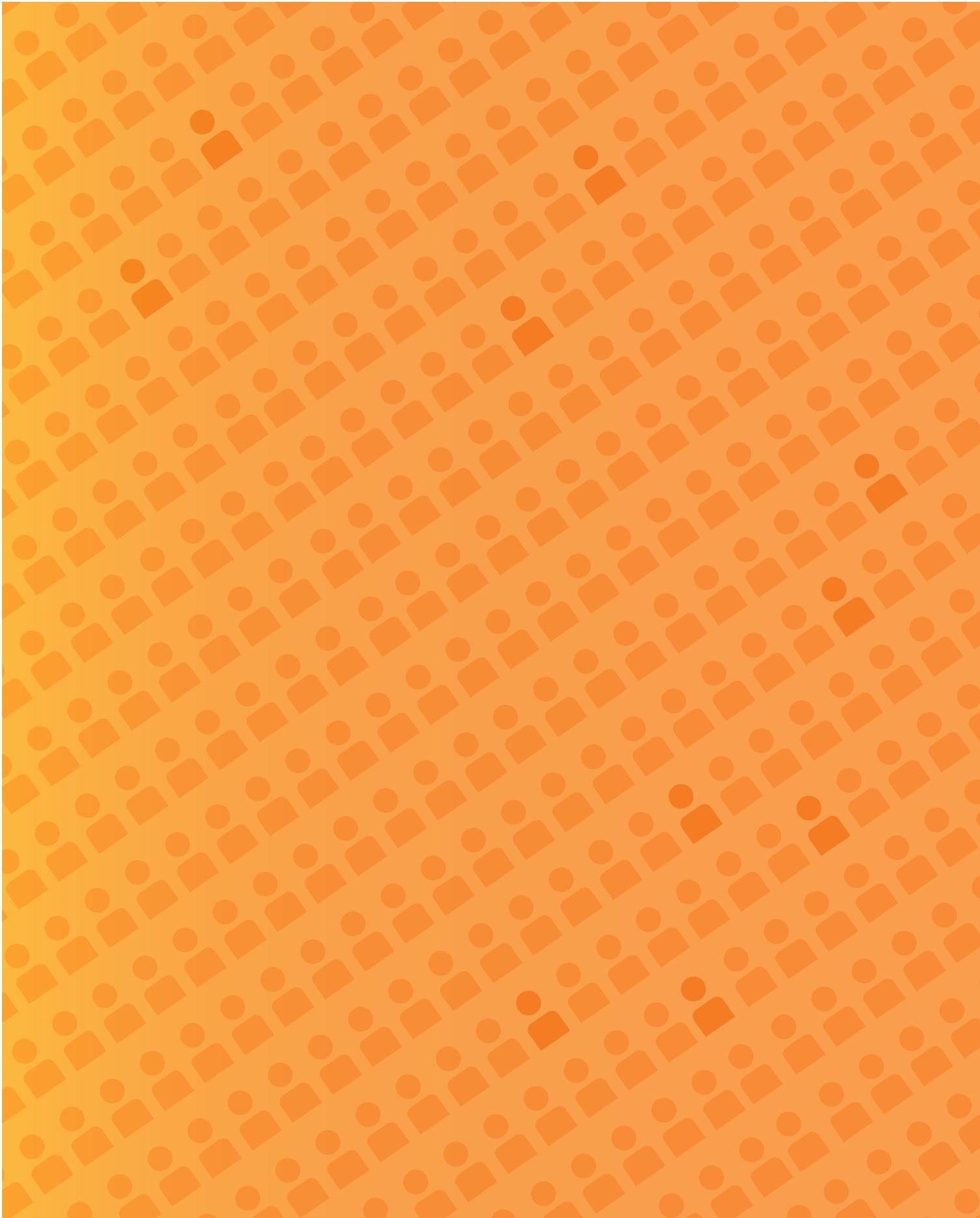
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