



LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



2019 2020

ANNUAL REPORT

LIVING WITH DISABILITY
RESEARCH CENTRE



Contents

Message from the Dean.....	4
Message from the Director.....	6
About the Living with Disability Research Centre.....	8
Personnel.....	10
Research themes.....	12
Effectiveness of disability services.....	13
Building the evidence base for participation.....	17
Enabling mainstream services to be more inclusive....	21
Research translation & resources for practice:	
Training resources.....	24
Notable achievements	26
Courses.....	27
Seminar series.....	29
Events.....	32
Research outputs & impacts:	
HDR graduations.....	34
Funded projects.....	36
Publications.....	38
Presentations.....	42
Partners.....	45

Message from the Dean



The work of the Living with Disability Research Centre is increasingly important in the context of the systemic change being driven by the roll out of the National Disability Insurance Scheme (NDIS). The Research Centre facilitates unique exchanges between industry partners and academic researchers, and is an exemplar for how to translate research into practice that can improve the lives of individuals and their communities.

The Research Centre's focus on research designed to improve the effectiveness of disability services, to improve access by people with disability to decision making support about service provision, and to assist services to be more accessible and responsive demonstrates La Trobe University's commitment to research excellence and community impact.

The research of the Centre is consciously multi-disciplinary in nature in order to tackle the complexity of disability service provision; involving health policy, a myriad of funding agencies, community groups, commercial service providers, expertise across specific disabilities and clients that receive services. The research therefore draws on expertise across La Trobe's many campuses including the La Trobe Rural Health School, and the School of Allied Health, Human Services and Sport and brings together a range of expertise and diverse disciplines to its research projects.

The Living with Disability Research Centre continues to secure significant research funding to support its many research projects and publishes in some of the world's best research journals. It also supports aspiring researchers by providing higher degree research students with access to world class supervisors, a regular seminar series to support collaboration and sharing of new ideas, and opportunities to work with a range of industry and community partners.

Everyone involved in the work of the Research Centre should be congratulated for its continued excellent work. I look forward to continuing to support the Centre and witnessing the contribution of the Living with Disability Research Centre in producing research with real impact and meaning for individuals and communities.

Professor Russell Hoyer
Dean, School of Allied Health, Human Services and Sport, La Trobe University



Message from the Director



This report covers the years 2019 and 2020. Over the past two years, most of us have experienced major disruptions to our everyday lives due to the global COVID-19 pandemic. But as a digitally connected academic living alone with lots of space, I can only begin to imagine what 2020 was like for people with intellectual disabilities, particularly those living in shared supported accommodation, as day programs closed, employment was suspended, and months passed without visits from friends or family.

For families, usual support or respite services were suspended and service providers scrambled to secure access to protective equipment, reorganise rosters, interpret ever changing operational directives and find strategies to enable the people they support to be socially connected and engaged digitally. Despite the exigencies of 2020, anecdotal stories suggest that some relationships were strengthened, new digital literacy skills were acquired and that the disability sector met these new challenges creatively.

At the Living with Disability Research, the year 2020 was like no other. The pandemic brought a halt to all our research fieldwork, and in doing so freed up time for writing and the refinement of research tools. In the week before lockdown in March 2020 we finished filming at Unisson Services and spent much of the year developing the recently launched training resources for Frontline Practice Leaders. COVID 19 also provided us with the opportunity to move our monthly Living with Disability Research Centre Research Seminar Series online and in doing so quadruple our audience, which now includes service providers and academics from across Australia and the world. On a personal note, I also had the opportunity to finish the *Routledge Handbook on Aging and Disability*, which I co-edited with Professor Michelle Putnam, from Simmons University, Boston, and which was published in early 2021.

During this time too, we made oral and written submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Joint Standing Committee on The National Disability Insurance Scheme, which were cited in subsequent reports of these bodies. We have continued to our longstanding partnerships with disability service providers

and advocacy groups and built new connections with organisations such as HELP Enterprises in Qld, Rocky Bay in WA, Dundaloo in NSW and Focus in Victoria.

Universities continue to be deeply affected by COVID-19, and in July 2020, Professor Jacinta Douglas took the opportunity to become an Emerita Professor. This esteemed position is awarded only to scholars who have made significant contributions to the University as a whole, and who have made internationally recognised contributions to knowledge in their field of research. When post COVID-19 normal returns, we will invite you to a seminar that will highlight the difference that Jacinta's research has made to the field of living well with acquired brain injury and celebrate her many contributions during 31 years as an academic at La Trobe University. Nevertheless, Jacinta has not gone far. She continues to supervise PhD students and to work closely with researchers at the Living with Disability Research Centre. An added bonus of her shift to Emeritus status has been a deepening of our partnership with the Summer Foundation, where she has taken the opportunity to consult with the Foundation on their research program.

I would like to thank every member of the Research Centre for their dedication to the work we do here at the Living with Disability Research Centre and for their collegiality during the past two years. Thank you also to Professor Russell Hoyer, who as Head of School of Allied Health, Human Services and Sport has been an unflagging ally. Finally, thanks to our partners in the disability sector for your continuing support for our research and your commitment to using research to improve the lives of people with cognitive disabilities.

Professor Chris Bigby, Director
Living with Disability Research Centre



The Honourable John Brumby AO, Chancellor, presenting the citation in recognition and celebration of Jacinta Douglas' position as Emerita Professor at La Trobe University.



About the Living with Disability Research Centre

Mission

The Living with Disability Research Centre is a leading Research Centre for social research into the lives and experiences of people living with cognitive disability in Australia. It has a national and international reputation for delivering high quality research outcomes.

Unique among Research Centres in Australia is our focus on the social inclusion and participation of people with cognitive disabilities, in particular those with intellectual disability or acquired brain injury. Our Research Centre has an outstanding track record of delivering rigorous, high quality research and for translating research findings into formats and resources that are accessible to mainstream service providers and other stakeholders across the disability sector.

Aims and Objectives

The aim of the Living with Disability Research Centre is to improve the social inclusion and participation of people with cognitive disability through research, education, and knowledge transfer and to strengthen the evidence base that informs practice and policy throughout the disability sector. To achieve this aim, our Research Centre conducts research across three broad and interconnected themes:

- Effectiveness of disability services
- Building the evidence base for community participation and inclusion
- Enabling mainstream services to be more inclusive

How We Work

To ensure our research is grounded in the real-world challenges of turning policy visions into changed life experiences for people with cognitive disabilities, we work in collaboration with disability service and advocacy organisations across the sector. In

total, the Research Centre partners in different ways with more than 40 organisations to design, conduct and disseminate research.

Our research is funded by competitive grants from the Australian Research Council, the National Health and Medical Research Council, and other industry and government funding bodies. The Summer Foundation co-funds the Summer Foundation Chair, Living Well with Brain Injury, held by Em. Professor Jacinta Douglas and the research program associated with this chair. As well as having dedicated research staff, the Research Centre works with staff from across La Trobe University, giving our Research Centre a strong multi-disciplinary perspective.

Governance

The activities of the Research Centre are overseen by an Executive Committee comprising the Director, Professor Christine Bigby, Em. Professor Jacinta Douglas, and Professor Teresa Iacono.

The Director of the Living with Disability Research Centre and the Executive Committee are supported by an Advisory Committee.

The role of the Advisory Committee is to:

- Advise on policy and strategy to meet the aims of the Centre
- Advise on the administration of the Centre
- Advise and assist in reporting on the management of Centre resources
- Identify potential new sources of funding for the Centre
- Receive and endorse the Annual Report of the Centre, and submit it to the Academic Board through the Provost (College of SHE) and the Deputy Vice-Chancellor (Research and Industry Engagement)

During 2019 and 2020, members of

the Advisory Committee comprised four internal members from La Trobe University and four external members from organisations in the disability sector.

Internal members:

- Centre Director – Professor Christine Bigby
- Pro Vice-Chancellor (College of SHE) – Professor Rob Pike
- Dean, School of Allied Health, Human Services and Sport – Professor Russell Hoyer
- Staff member of the Centre – Em. Professor Jacinta Douglas
- Research Fellow, Living with Disability Research Centre – Dr William Crisp

External members:

(from organisations within the sector)

- Daniel Leighton – NDIS
- Dr Christine Fyffe – Consultant
- Dr Di Winkler – Summer Foundation
- Dr Jane Tracy – Centre for Developmental Disability Health Victoria
- Rod Carracher – Yooralla



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Personnel

Executive Committee

Professor Christine Bigby (Director)
Em. Professor Jacinta Douglas
Professor Teresa Iacono

Administrative Staff

Ms Melanie Hayes

Staff Research Fellows

Dr Sian Anderson
Dr Ana Garcia-Melgar
Dr David Henderson
Dr Lincoln Humphreys
Ms Rebecca Leeson
Dr Elizabeth Smith
Dr William Crisp

Research Officers and Casual Staff

Dr Sandy Barry
Ms Jane Bowden-Dodd
Ms Michelle Collins
Ms Lauren De Losa
Ms Chantelle Hutchinson
Ms Talia Lipschitz
Dr Bronwyn Moorhouse
Ms Tessa-May Zirnsak
Ms Yuki Wakamatsu

Adjuncts

Dr Glenda Bishop – Adjunct Research Fellow
Dr Em Bould – Adjunct Research Fellow
Dr Mark Brown – Adjunct Research Fellow
Professor Lauren Clark – Adjunct Professor
Dr Jennifer Clegg – Adjunct Professor (UK)
Dr Stacy Clifford Simpican – Adjunct Associate Professor (USA)
Professor Ellie Fossey – Adjunct Professor
Dr Chris Fyffe – Adjunct Professor
Dr Hilary Johnson – Adjunct Associate Professor
Dr George Taleporos – Adjunct Senior Research Fellow
Professor Magnus Tideman – Adjunct Professor (Sweden)

Dr Jane Tracy – Adjunct Associate Professor
Dr Di Winkler – Adjunct Associate Professor

Associated La Trobe University Staff

Dr Tal Araten-Bergman – Social Work
Dr Kerry Bagley – La Trobe Rural Health School
Dr Anoo Bhojti – Occupational Therapy
Dr Pam Kappelides – Sport & Tourism
Dr Darren O'Donovan – Law
Dr Robyn O'Halloran – Speech Pathology
Professor Nora Shields – Physiotherapy
Dr Jo Spong – La Trobe Rural Health School
Dr Ruth Stuckey – Public Health

Higher Degree by Research Students

Amy Ford
Yeptain Leung
Kristy Logan
Jenna MacNab
Jade McEwen
Gail Ritchie
Bojana Sarkic
Cara Schofield
Charity Sims-Jenkins
Joanna Shoreland
Kellie Stagg
Megan Topping
Rahila Ummer Christian
Elizabeth Williams
Kangwei Xun

Higher Degree students completed in 2019

Kathleen Fitt, PhD
Margaret Mealings, PhD
Margaret Pozzebon, PhD
Claire Quillam, PhD

Higher Degree students completed in 2020

Kate D'Cruz, PhD



Professor Christine Bigby



Emerita Professor Jacinta Douglas



Professor Teresa Iacono



Living with Disability Research Centre staff 2020

Research Themes

The Living with Disability Research Centre conducts research that can help improve practices, programs and policies that support the social inclusion of people with cognitive disabilities. It is organised into three Themes. Each theme has several programs of research which encompass various projects.

Essentially, our research is concerned with building a robust evidence base for the disability sector and the broader community to address the complex and multifaceted problems facing people with cognitive disability, their families, and carers.

Our research is interdisciplinary and translational, and it aims to capitalise on our extensive partnerships throughout the disability sector.



Theme 1: Effectiveness of Disability Services

Research in this theme aims to improve the design and delivery of specialist disability support services. The most important program has been measuring and evaluating the quality of support in supported accommodation services for people with intellectual disabilities.

Since 2009 we have been conducting research to identify the most significant factors associated with good quality staff support in such services. We have published a significant body of work about staff practice, including the challenges of implementing Active Support, the nature and impact of Practice Leadership, and the impact of culture, organisational structures and values of senior managers.

All publications can be found on our website. See for instance: [Report Active Support.pdf](#), [articles-reports, C Bigby/publications](#). We have also developed the Group Home Culture Scale, a valid and reliable measure of culture in group homes, which is being used in Germany and the UK. DOI: [10.1111/jar.12693](#).

More recently in partnership with the Summer Foundation this program has expanded to include research about new NDIS funded Specialist Disability Accommodation.



Theme 1: Effectiveness of Disability Services

Selected Projects

Project Title:

Living the good life: Embedding Active Support and Practice Leadership in supported accommodation services

Research Team: Professor Christine Bigby, Professor Teresa Iacono, Professor Julie Beadle-Brown, Dr Emma Bould, Dr Lincoln Humphreys, Jane Bowden-Dodd

Project Aim: Led by Professor Bigby, this study commenced in 2009 and concluded in 2019. It is the largest study about Active Support in Australia, and it was funded by an ARC Linkage Grant and Industry Partners. The study was essentially concerned with understanding the individual, service and organisational factors necessary to embed Active Support in services and thus to deliver higher quality staff support to people with intellectual disabilities.

Every year, data collection included observations about the quality of Active Support in services, the strength of Practice Leadership, and an array of other data. By 2017, three data sets were compiled about the quality of Active Support: (1) data from a sample of the same 51 services for periods of between 2-7 years; (2) data about a total of 134 different services between 2009-2017; and (3) data about 71 services collected in 2017 included organisational data from interviews with senior managers and organisational documents from 14 organisations.

In 2019 we released a summary report, *Enabling engagement and inclusion: Organisational factors that embed Active Support in*

accommodation services for people with intellectual disabilities, which outlines findings from the study.

The summary report highlights the significance of practice leadership to the quality of Active Support and identifies the importance of key organisational factors associated with the values and actions of senior leaders and the structuring of practice leadership. These factors are pivotal to delivering good Active Support to address poor and variable quality support and therefore improving the quality of life of people with intellectual disabilities in services.

The findings from this study provide the first rigorous evidence about the factors that predict the delivery of good Active Support and delivers a blueprint of the design features that disability service organisations should incorporate in order to provide good quality support to people with intellectual disabilities. These findings also provide a guide to families and people with disability about what to look for in good services, to the NDIA about what should be funded to ensure good quality support, and to the NDIS Quality and Safeguarding Commission about what it should be monitoring.

Funding: Australian Research Council (Linkage Grant)

Partners: annecto, Aruma, Bayley House, CARA, Civic, Sydney, Endeavour Foundation, GenU, Golden City Support Services, Greystanes Disability Services, Help Enterprises, Identitywa, Jewish Care, Melba Support Services, Unisson Disability Services, Yooralla

Date: 2009-2018

Project Title:

Active Support, Practice Leadership and organisational culture in supported accommodation services for people with intellectual disabilities: A longitudinal study

Research Team: Professor Christine Bigby, Dr Lincoln Humphreys, Jane Bowden-Dodd

Project Aim: The overarching aim of this project is to improve the quality of frontline staff practices and practice leadership in services and thus the quality of life of people with intellectual disabilities using those services. The project builds on an ARC Linkage study that identified the factors that predicted good Active Support in supported accommodation services. See: [Report Active Support.pdf](#). This project continues the longitudinal and multi organisational approach of the original ARC Linkage study, but it widens the focus to explore the impact of culture, teamwork and other organisational features that have an impact on the quality of support. The project is funded by industry partners, who also gain access to an annual independent report on the quality of support in their services. Data are collected annually from a sample of services in each participating organisation, and include observations of the quality of staff practice, and of the strength of Practice Leadership, completion of the Group Home Culture Scale by staff, and interviews with senior managers. Data collection was paused during 2020 due to COVID-19 restrictions and will recommence in March 2021.

Partners and Funding: annecto, Dundaloo Services, Focus Individualised Support Services, GenU, Golden City Support Services, Help Enterprises, Identitywa, Jewish Care, Oak Possibility, Rocky Bay, Unisson Disability Services, Yooralla.

Date: 2018-2022

Project Title:

Identifying quality: Resources for delivering and monitoring quality of evidence-informed practice

Research Team: Professor Christine Bigby, Professor Teresa Iacono, Dr Lincoln Humphreys, Dr Tal Araten-Bergman, Dr David Henderson, Dr Werner Vogels, Charity Sims-Jenkins

Project Aim: This project aims to develop resources to build NDIS service providers' capacity to deliver high quality evidence-informed practice to people with intellectual disabilities in supported accommodation services. Essentially, the project is concerned with embedding practices that support people with intellectual disabilities to exercise choice and control, and to be engaged and active participants in their own lives. The project draws on ten years of practice quality research in supported accommodation services and aims to increase the capacity of NDIS providers to deliver high quality evidence-informed practice. We will develop a new training program on Frontline Practice Leadership, update an online resource outlining the key tenets of Active Support, develop a new easy to use Tool for Observing Practice, and produce Guides on what makes a difference to service quality tailored for organisations, families and people

with intellectual disabilities. The first online training resource from this project on Frontline Practice Leadership will be launched in February 2021 and others will follow in the latter half of the year.

See: [Frontline Practice Leadership](#)

Funding: NDIS, Quality and Safeguards Commission

Date: 2019-2022

Project Title:

Culture and quality in group home services

Research Team: Dr Lincoln Humphreys, Professor Christine Bigby

Project Aim: This study aims to enhance understanding of organisational culture in supported accommodation services for people with intellectual disabilities. High scores on some subscales of the Group Home Culture Scale (GHCS) are predictive of better quality of life outcomes for the people supported. This study will use the GHCS to measure the culture in group homes and other types of supported accommodation services at one disability organisation in Victoria and explore further the different cultures that may coexist in services with an organisation and relationships between culture and quality of life outcomes. The project was delayed due to COVID-19 and data collection will commence in early 2021.

Partners and Funding: Melba Support Services

Date: 2019-2022

PHD Projects:

Jade McEwen

Quality systems or quality services? Exploring how service quality is and could be measured across the disability sector

Gail Ritchie

Keeping people with an intellectual disability safe: A case study of sexual abuse

Megan Topping

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

Kangwei Xun

Services for older people with intellectual disabilities in Hong Kong



Theme 2: Building the evidence base for community participation and inclusion

Participation in communities and in decision making about one's own life are key principles of the United Nations Convention on the Rights of People with Disabilities.

Research in this theme falls into two programs. One program is about supported decision making and the other is about strategies to enable participation in community groups, sport, and physical activity.

Disability reform has generated imperatives to develop supported decision making options for people with cognitive disabilities that respect their right to participate in decision making, give primacy to their will and preference, and provide mechanisms that safeguard against undue influence by supporters.

Professors Bigby and Douglas are leading a program of research that aims to build an evidence base about supported decision making practice. The La Trobe Support for Decision Making Practice Framework DOI: [10.1080/09638288.2018.1498546](https://doi.org/10.1080/09638288.2018.1498546), and associated training materials supportforddecisionmakingresource.com.au, were published in 2018. Since then, various projects have explored the effectiveness of the Framework in building the capacity of decision supporters.

Professor Nora Shields leads a program of research about the participation of people with intellectual disabilities in physical activity. This includes work with specific groups such as people with Down syndrome, the Fitskills program, and people with Prader Willi syndrome, the Presto trial. A third program is focussed more broadly on community participation and includes the M-Corn Connect study with people with acquired brain injury. This study is in its final stages.



Theme 2: Building the evidence base for community participation and inclusion

Selected Projects

Project Title:

Support for decision making: Effective decision making support for people with cognitive disabilities

Research Team: Professor Christine Bigby, Em. Professor Jacinta Douglas, Em. Professor Terry Carney (University of Sydney), Dr Shih-Nhing Then (Queensland University of Technology), Dr Ilan Wiesel (University of Melbourne), Dr Elizabeth Smith

Project Aim: This project is now in its final phase. It aimed to 1) understand the relevance of the evidence based La Trobe Support for Decision Making Practice Framework to decision supporters and capture their experience of using it, 2) assess the impact of training in the Framework on capacity of supporters to enable the person to participate in decision making and use processes of effective support, and 3) understand more about the processes of decision support.

The study was conducted across 3 States, Vic, NSW and QLD and recruited 83 decision support dyads, comprising a person with either intellectual disability or acquired brain injury and a regular supporter, as well as 6 supporters of people with severe intellectual disabilities. Supporters were randomly selected to be trained and mentored in the Framework, and all participants interviewed at regular intervals over a 12-month period about their experiences of providing or receiving support. A measure of decision support, the Decision Support Questionnaire (DSQ), was developed to measure changes in decision support strategies.

During 2019 and 2020, initial findings from the Support for decision making project were presented at various national and international

conferences and three interlinked papers were presented in session 3 at the conference of the Australian Guardianship and Administration Council in March 2019.

Findings: We have demonstrated the validity and the sensitivity to change of the DSQ as a tool for measuring changes in supporters' strategies. This will provide a key means for tracking the extent to which supporters' strategies reflect the elements of effective decision support practice and is aligned with supported decision making principles.

We have demonstrated the efficacy of the La Trobe Support for Decision Making Framework and found it to be a useful and relevant tool for parents of adults with cognitive disabilities to build their capacity for decision making support.

As part of the project we have also explored further the issues that parents grapple with in providing support and the strategies they use, and reviewed the evidence that emerged from the series of pilot support for decision making programs between 2010- 2015. And we have analysed NDIS planning mechanisms and the concepts embedded in 'will rights and preferences'. Published papers from the study can be found below.

Partners: Endeavour, Melbourne City Mission, Inclusion Melbourne, Summer Foundation, Victorian Office of the Public Advocate, NSW Department of Family and Community Services (FaCS), NSW Office of the Public Guardian, NSW Trustee and Guardian, Queensland Public Advocate, Queensland Mental Health Commission, Queensland Public Trustee, Queensland Office of the Public Guardian.

Funding: ARC Linkage Grant

Date: 2015-2021

Project Title:

Evaluation the implementation of the La Trobe Support for Decision Making Practice Framework by Queensland Public Trustee

Research Team: Professor Christine Bigby, Em. Professor Jacinta Douglas

Project Aim: The Queensland Public Trustee (QPT) resolved to adopt the La Trobe Support for Decision Making Practice Framework for use by its frontline and supervisory staff in mid 2019. This project has supported the training unit to adapt the existing training to the context of the QPT and it is evaluating the impact of the training and it's value from the perspectives of staff. Data will be collected from staff pre and post training through surveys completed by staff which include the Decision Support Questionnaire, and semi structured interviews with staff.

Findings: The project is still in progress, but early findings suggest the Framework was successfully adapted to the QPT context and that frontline staff found it useful and shifts occurred in their practice following the training.

Funding: Queensland Public Trustee

Date: 2019-2021



Project Title:

Building capability to support client decision making

Research Team: Em. Professor Jacinta Douglas, Professor Christine Bigby

Project Aim: As part of implementing the new Service Model Framework, the Transport Accident Commission (TAC) engaged the Living with Disability Research Centre to build the capability of independence claims employees to apply the La Trobe Support for Decision Making Practice Framework. The project aimed to translate existing evidence on the Support for Decision Making Practice Framework by training a small cohort of independence claims employees to apply the Framework in their interactions with clients and assess the impact of training on their capability to be effective supporters of decision making.

Nine independence claims employees participated in two face to face training sessions about the Framework followed by individual mentoring to assist them in applying it to their day to day work. Data about confidence and strategies

for decision making were collected prior to and following training using measures including the Decision Support Questionnaire.

Findings: Both the measures and the qualitative data from the mentoring showed training in the Framework had a significant and measurable positive impact on the participants' support for decision making practice. Their confidence increased significantly, and they showed improved use of supported decision making steps and principles and a significant increase in their use of strategies that clearly supported the client's right to participate in decision making. They also showed a substantial increase in self-reflective practice. The TAC is planning to roll out training in the Framework more widely for staff across the organisation and will work with La Trobe to develop further examples of applying the Framework in this specific context. A report of this project is available from the University Repository. See: [Report_Capability.pdf](#)

Funding: Transport Accident Commission (TAC)

Date: 2019-2021

PHD Projects:

Yeptain Leung

Pitch, resonance, and their contributions to listener perceptions of speaker's gender

Jenna MacNab

Supported decision making and guardianship practice

Bojana Sarkic

Peripheral auditory dysfunction following traumatic brain injury: A consecutive cohort study

Cara Schofield

Using focussed ethnography to understand the social context of exercising in a community gym for people with Prader-Willi syndrome

Joanna Shoreland

Profiling cognitive-communication difficulties in older adults following new onset traumatic brain injury (TBI)

Charity Sims-Jenkins

How self-advocates' stories change frontline staff's perceptions of service user self-determination

Kellie Stagg

Communication impairment and the working alliance in stroke rehabilitation



Theme 3: Enabling mainstream services to be more inclusive

Despite the implementation of the National Disability Insurance Scheme, mainstream services will continue to provide the vast majority of services required by people with cognitive disabilities. Inclusion of people with cognitive disabilities in the mainstream is at the heart of human rights and disability policy.

This theme of our research is concerned with finding ways to make mainstream services more accessible and responsible to people with disabilities. This theme includes programs of research about on Education, Health Systems and Cities. Professor Teresa Iacono and her team of disability researchers from the Rural Health School have worked in collaboration with schools and parents to develop an evidence-based tool that identified the types of reasonable adjustments necessary to for inclusive education. A cross-school group has been funded by an NDIS grant to translate findings from our research on quality care in hospitals into a set of resources for hospital staff, disability support services and families of people with cognitive disabilities.

Meanwhile, Professor Bigby is working with long term collaboration partner, Dr Ilan Wiesel, School of Geography, University of Melbourne on an ARC Linkage grant examining the accessibility of cities and mainstream services for people with intellectual disabilities.



Theme 3: Enabling mainstream services to be more inclusive

Selected Projects

Project Title:

Increasing the quality of hospital care for people with cognitive disabilities

Research Team: Professor Teresa Iacono, Em. Professor Jacinta Douglas, Professor Christine Bigby, Dr Jo Spong, Dr Ana Garcia Melgar, Dr William Crisp

Project Aim: The aim of this project is to translate research evidence from a previous study conducted by the Living with Disability Research Centre, *Enabling mainstream services to be more inclusive*. The project is concerned with understanding what is necessary to ensure quality hospital care for people with cognitive disabilities in Victoria. This project brings together regional and metropolitan hospitals and disability services. Key activities include the trial and evaluation of multi-media training for patients, families, disability support workers and hospital staff to improve hospital care and the experiences of adults with cognitive disabilities. This work is timely in light of the particular health vulnerabilities of people with life-long or long-term disabilities in the current COVID-19 environment.

Work, to this point, has focused on further developing a framework for good quality hospital care developed from the research findings of our completed study into hospital encounters of adults with cognitive disability. This framework and data from the study are being used to develop content for the multi-media web-based resources for hospital and disability sectors, and families and others who support people with cognitive disabilities through their hospital journeys. A Reference Committee has been formed with members from our participating organisations of Eastern Health,

Bendigo Health, Golden City Support Services and Yooralla. The multimedia company, Maitree, that will assist preparing videos and other media, has been engaged.

Funding: NDIS Information, Linkages and Capacity Building

Date: 2020-2023

Project Title:

Exploring the current preparedness and training needs of a regional rural public mental health workforce for the provision of care to people with intellectual disabilities and mental illness

Research Team: Dr Jo Spong, Professor Teresa Iacono, Dr Janelle Weise (UNSW), Professor Julian Trollor (UNSW), Lisa Spong (Bendigo Health), Tim Lenten (Bendigo Health)

Project Aim: This project was developed in response to a national recommendation to upskill the mental health workforce in the provision of care to people with intellectual disabilities and mental ill-health. The aim of the project was to identify the current preparedness, training needs, resources and supports of a regional rural public mental health workforce in the provision of care and services to people with intellectual disability and mental ill-health. Data was collected in 2019 via survey, interviews and a forum and is providing insight from participating mental health service staff regarding attitudes, confidence, education and experience, as well as barriers and enablers in caring for a person with intellectual disabilities and mental ill-health. This information can assist in the future design of a targeted mental health workforce development plan which can be

implemented to progressively build staff competencies. The manuscript for publication of this research project is in preparation.

Funding: Building Healthy Communities Research Focus Area (La Trobe University)

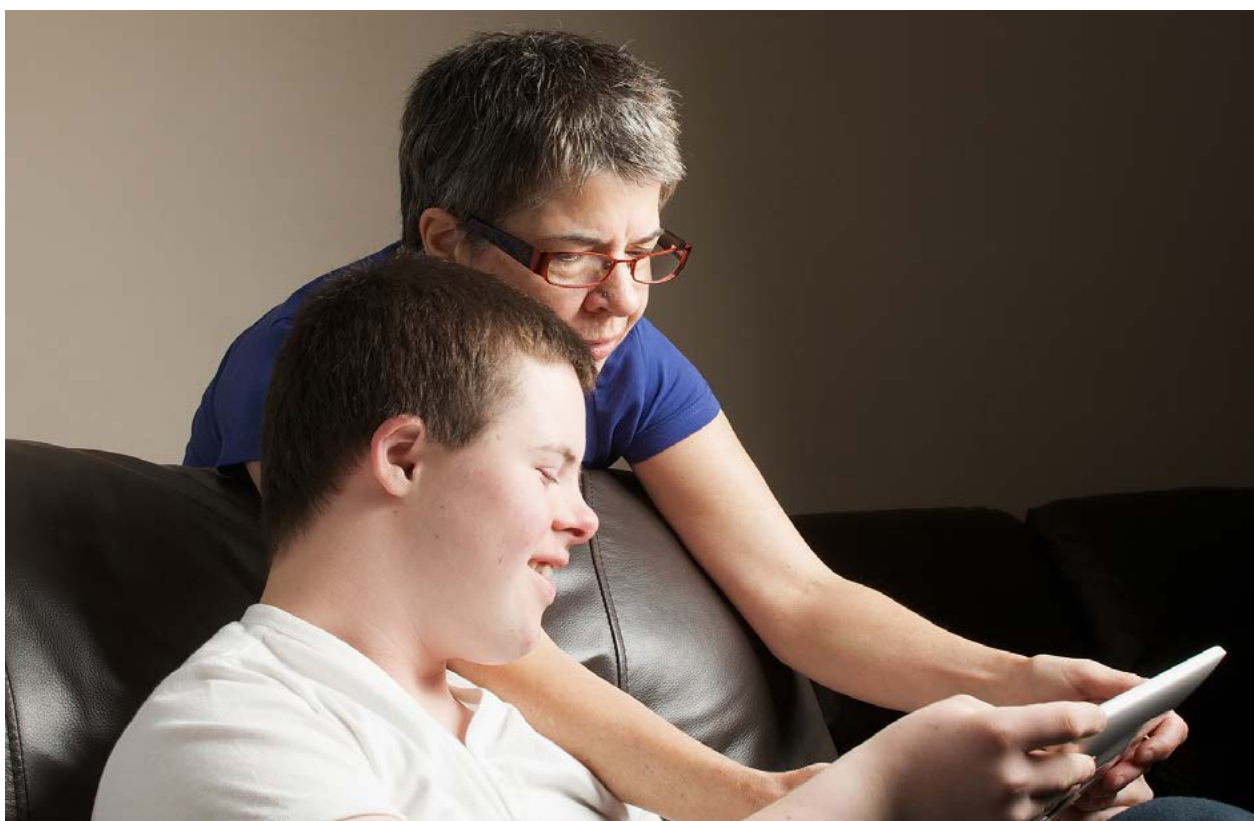
Date: 2019

Project Title:

Building healthy communities with a social model of disability: A randomised controlled trial

Research Team: Professor Teresa Iacono, Dr Jo Spong, Dr Kerry Bagley, Dr Nerida Hyett, Assoc. Professor Carol McKinstry, Dr Ana Garcia-Melgar, Dr Oriane Landry, Professor Michael Arthur-Kelly (University of Newcastle)

Project Aim: Within the social model of disability, inclusion occurs when reasonable adjustments are made to enable access to mainstream processes and structures to address needs arising from a person's impairment. Expectations that schools will implement reasonable adjustments for students with disabilities are embedded within legislation and policy. The aim of this study was to test the premise that embedding the social model of disability into training, which also addresses the provision of real and authentic learning opportunities, will improve the quality of reasonable adjustments designed by stakeholders in the education of students with disabilities. The key component of this project is the development of a Reasonable Adjustments for Inclusive Education rating scale and using it to test the efficacy of an educational intervention on designing supports for school students with disabilities.



A Randomised Control Trial was implemented and data collection was completed in 2019. Thirty-one participants selected across school staff, allied health professionals providing supports to school students, and parents of children with disabilities attending primary schools were randomly allocated to intervention and control (no intervention) groups. Scenarios were prepared about students with varied disabilities and education needs. Participants responded to each scenario by suggesting reasonable adjustments during interviews conducted pre- and post-intervention (two student scenarios), and at 2-month follow-up (a third scenario was added to evaluate generalisation). The intervention group completed online modules. Reasonable adjustments described by participants were rated by two independent assessors who had been trained to use the newly developed and trialled tool, the La Trobe Reasonable Adjustments for Inclusive Education (LT-RAIE).

Approximately 170 reasonable adjustments were generated at each of the pre- and post-intervention data collection points, and about 250 at the 2-month follow-up. Analyses of these data are enabling evaluation

of the intervention in terms of improving the quality of reasonable adjustments. Preliminary evidence shows that some participants had difficulty with designing them, and variation in the extent to which they addressed five key dimensions assessed using the LT-RAIE: authenticity, support for real learning, incorporating learner strengths, learner agency, and social inclusion. The findings from this research are currently being prepared for publication. The online modules from this study and the student scenarios are now freely available as a resource for parents and professionals working towards the educational inclusion of students with disability. reasonableadjustmentsinschools.org.au/

Funding: Building Healthy Communities Research Focus Area (La Trobe University)

Date: 2018

PHD Projects:

Kristy Logan

Aided enhanced milieu teaching to increase symbolic communication in children with autism spectrum disorder

Research Translation & Resources for Practice

At the end of 2019, the Living with Disability Research Centre added the La Trobe Support for Decision Making Practice Framework Learning Resource to its growing suite of online training resources. The Research Centre developed and supports four online training resources for direct support workers and frontline practice leaders. All of these training resources are free, and they are used widely across the disability sector. A fifth resource, for frontline managers, will be launched in 2021.

New in 2019

The La Trobe Support for Decision Making Practice Framework Learning Resource

This resource was launched in October 2019. It was developed to guide supporters of people with cognitive disabilities through the process of supporting them to make a decision. Decision making is a fundamental human right and people with cognitive disabilities are likely to need ongoing support with making decisions. The La Trobe Support for Decision Making Practice Framework is the first evidenced based guide to supporting people with cognitive disabilities to make decisions. It can be used by frontline managers, disability support workers, team leaders, clinicians, guardians, friends, spouses, parents and other family members to enable people with cognitive disabilities to exercise choice and control in their own lives supportforddecisionmakingresource.com.au/

Figures: 1,682 page views October 2019 – December 2019. 4,492 page views in 2020.

Online Training Resources Person-centred Active Support: Every Moment has Potential

This resource provides an introduction to Active Support – a way of working that enables everyone, no matter their level of intellectual or physical disability, to make choices and participate in meaningful activities and social relationships. The resource was developed in 2015 for disability support staff. As part of our Identifying Quality project, we are updating this resource. The new, updated version of this resource will be launched in the second half of 2021. activesupportresource.net.au/

Figures: 74,520 page views in 2019. 88,400 page views in 2020.

Supporting Inclusion

The purpose of this resource is to create a space where disability support workers can think about what social inclusion means for people with intellectual disabilities and learn or refresh some useful tools and strategies to support people with intellectual disabilities in ways that will promote their social inclusion. supportinginclusion.weebly.com/

Figures: 9,935 page views in 2019. 10,975 page views in 2020.

Enabling Risk: Putting Positives First

This resource was launched in late 2018. It was developed for disability support workers. Enabling people to take risks is an integral part of disability support work and it is important that practice leaders, frontline managers, and senior managers are aware of the essentials of enabling risk – as outlined in this resource – as they play a significant role in creating the right environment for support workers to put risk enablement into practice. enablingriskresource.com.au

Figures: 681 page views in 2019. 12,400 page views in 2020.



Other Resources

Administrative Appeals Tribunal (AAT) Digest

This digest is prepared by the Living with Disability Research Centre. It summarises a curated selection of Administrative Appeals Tribunal (AAT) decisions and offers an overview of some important themes arising from those decisions about the NDIS. By exploring recent AAT decisions, the Digest aims to capture the way the Tribunal is dealing with some common issues raised in appeals against NDIS decisions.

By drawing out the implications of AAT decisions and interpreting the provisions of the scheme, the digest helps to inform scheme participants, supporters, advocates and those involved in its administration. The primary intended audience of the Digest is people who have some familiarity with the scheme, including Partners in Community organisations, advocacy organisations, peak bodies and disability service providers.

[aat-ndis-decision-digest](#)

Forthcoming online training resources

Frontline Practice Leadership

This resource is currently under construction, as part of Identifying Quality Project, and will be launched at the beginning of 2021. The Frontline Practice Leadership resource is an online learning program for frontline managers and other staff responsible for guiding the practice of disability support workers. Support workers need to receive good Frontline Practice Leadership to deliver quality Active Support to the people they support. By completing this program, support workers will learn the tasks and skills essential to Frontline Practice Leadership. The program covers topics such as the purpose of Frontline Practice Leadership, how Frontline Practice Leadership should be organised, the five tasks of Frontline Practice Leadership, and the skills needed to be a good Frontline Practice Leader.

[practiceleadershipresource.com.au](#)

Notable Achievements

Distinguished Achievement Award for Research

Professor Bigby's sustained and enduring contribution to research in the field of intellectual disability was acknowledged at the 2019 IASSIDD World Congress in Glasgow. Bigby was presented with the Distinguished Achievement Award for Research. The award recognises a significant contribution to the sciences related to intellectual and developmental disabilities through a sustained and important contribution over time. Bigby said she was honoured to receive an award that acknowledged her body of work aimed at enhancing the inclusion of people with intellectual disability in society.

Disability Worker Registration Board of Victoria

In 2019, Professor Christine Bigby was appointed to the Disability Worker Registration Board of Victoria. The Registration Board is responsible for setting the standards for registration and accreditation of approved programs of study. The Board works closely with the Victorian Disability Worker Regulation Scheme to oversee the regulation of registered and unregistered disability workers in Victoria. The Regulation Scheme applies to all disability workers in Victoria. Registration is voluntary for disability workers and the conduct of registered workers will be regulated.

2020 Fetal Alcohol Syndrome Disorder Research Australia – Mid-Career Researcher Award

In 2020, Dr Kerry Bagley, was awarded the FASD Research Australia Mid-Career Research Award. Dr Bagley, a specialist in fetal alcohol spectrum disorders (FASD), is a researcher at the Living with Disability Research Centre and lecturer in social work, social policy and rural health in the La Trobe Rural Health School, Bendigo. Her research investigates health and human service sector responses to FASD. Dr Bagley helped to develop one of the first best-practice FASD diagnostic clinics in Australia and was the inaugural co-chair of the Australian FASD Clinical Network.

Life Membership – Speech Pathology Australia – Associate Professor (Honorary) Hillary Johnson

In 2020, long time Living with Disability Research Centre member and Honorary Associate Professor Hillary Johnson was awarded life membership of Speech Pathology Australia. The award is the highest public professional honour the association awards to its members. Over the course of her career, Hillary Johnson has been an exemplary clinician, advocate and researcher. Her work has been driven by a firm commitment to improving the lives of people with the most severe disabilities and it is wonderful to see her sustained and multifaceted contribution to the profession - and to people with disabilities - being recognised in such an award.

Disability Practice

Online Courses

In 2019, the Living with Disability Research Centre and La Trobe University launched its online Disability Practice Courses. The flexible, fully online courses draw on our Centre's research and practice knowledge and are taught by leading researchers from the Centre. Our Disability Practice Courses cater to a diverse range of professionals who are currently involved in, or entering, the disability sector and offer contemporary knowledge and skills to enhance professional practice.

The first two years have been a resounding success and in spite of the interruptions wrought by the COVID-19 pandemic, enrolments have steadily increased across all subjects. The feedback from our 2019 and 2020 students has been really positive and our course coordinator, Sian Anderson, received the 2019 Vice Chancellor's Teaching Award for her work with the team teaching social policy.

"The course has really opened my eyes to a lot of issues. I've been a support worker for years and I've never read any research or thought about some of those great big issues we have covered".

Student, 2020.

We look forward to welcoming successive cohorts of students. Flexible full time, part time or single subject options are available. Study online at a time that suits you. Enrol in 1, 4, 8 or 11 subjects in Disability Practice. The table below shows the different pathways to a Graduate Certificate or a Master of Disability Practice. For specific information about each subject, visit:

latrobe.edu.au/courses/disability

Course Structure

Year One (8 subjects)				
Semester 1	The Contemporary Disability Landscape**	Enhancing Social Inclusion	Support Planning with People with Disabilities	Translating Evidence into Disability Practice
Semester 2	Ethical Issues in Disability Practice	Disability and the Law	Advocacy in Contemporary Disability Practice	Understanding Complex and Challenging Needs
Year Two (3 subjects)				
Semester 1	Foundations of Graduate Research	Scoping Reviews in Disability Research	Research Thesis	

Exit Options

Graduate Certificate in Disability Practice

(choose any 4 subjects from Year One)
6 months full time or part time equivalent*

Graduate Diploma in Disability Practice

(all 8 subjects from Year One)
1 year full time or part time equivalent

Master of Disability Practice

(all 11 subjects from Year One and Year Two)
1.5 years full time or part time equivalent

* Graduate Certificate in Disability Practice is able to be completed in 6 months full time provided subjects are chosen within the same semester. For those wishing to choose subjects from different semesters, the completion time would be longer.

** The Contemporary Disability Landscape is offered in both Semester 1 and Semester 2 of Year One.



Research Seminar Series

2019-2020

During 2019, eleven seminars were held with invited guests (local and international), higher degree by research students and staff from the Living with Disability Research Centre. And despite the significant interruptions wrought by the global pandemic in 2020, the Research Centre continued to run its monthly research seminar series largely uninterrupted.

The Research Seminar Series has always attracted a good audience and since it pivoted to an online format in early 2020, our audience has grown significantly. The seminars attract a wide range of service providers from across the disability sector, as well as academics and professionals each month.

The seminars showcase the research of the Centre, our higher degree by research students and our collaborative work with researchers at other universities. For more information about our Research Seminar Series, you can subscribe to our mailing list. You can also access recordings or PowerPoint slides from all of our seminars on our website.

latrobe.edu.au/lids/resources/conferences



Research Seminar Series

2019

	Presenter	Topic
February	Dr David Henderson , Research Fellow, Living with Disability Research Centre, La Trobe University	<i>'The boy tied to a stake': The Tipping campaign and reform at the Kew Cottages in the 1950s</i>
	Gail Ritchie , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>A case study of a perpetrator: Abuse in a service for young people with intellectual disabilities</i>
March	Dr Nicola Grove , Tizard Centre, University of Kent (UK)	<i>Story webs: Anecdotal narrative and the fabric of being</i>
April	Em. Professor Pavla Millar , School of Global, Urban and Social Studies, RMIT	<i>"The age of entitlement has ended": NDIS and path dependence</i>
	Dr Sian Anderson , Lecturer, Living with Disability Research Centre, La Trobe University	<i>Writing the script: The overt and hidden contradictions of supporters' work in independent self-advocacy groups</i>
May	Jade McEwan , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>What is good service quality? Frontline day service staff's perspectives on what it is and how it should be measured</i>
	Tessa May-Zirnsak , PhD Candidate, Gender, Sexuality and Diversity Studies, La Trobe University	<i>Understanding systemic and cultural violence against the cognitive disability community: A new theoretical model</i>
June	Dr Tal Araten-Bergman , Lecturer, Social Work, La Trobe University	<i>Models for forming and supporting circles of support for people with intellectual disabilities</i>
	Dr Robyn O'Halloran , Lecturer, Speech Pathology, La Trobe University	<i>Why don't hospitals measure the patient experience of people with communication disabilities?</i>
July	Dr Ilan Wiesel , Lecturer, School of Geography, University of Melbourne	<i>Finding the mainstream city: The ambiguities of 'mainstream participation' by people with intellectual disabilities</i>
	Associate Professor Karen Soldatic & Dr Michelle Fitts , Western Sydney University & James Cook University	<i>Sorting myself out of the system: Social sorting & the disability income support system for Indigenous Australians with disabilities</i>
August	Dr Nastaran Doroud , Lecturer, Occupational Therapy, La Trobe University	<i>Recovering through everyday life activities: A participatory photovoice study with people experiencing mental health issues</i>
	Kellie Stagg , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Communication impairment and the working alliance in stroke rehabilitation</i>
September	Professor Christine Bigby, Director , Living with Disability Research Centre, La Trobe University	<i>Developing an evidence-based practice framework to guide support for decision making</i>
	Dr Elizabeth Smith , Research Fellow, Living with Disability Research Centre, La Trobe University	<i>Support for decision making: The rights of people with cognitive disability to decision making support</i>
October	Professor Ellie Fossey , Head of Department, Occupational Therapy, Monash University	<i>How are consumers involved in mental health education in Australian and New Zealand? Barriers and facilitators</i>
	Anne Williams , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Using e-mental health resources together: A qualitative study of consumer & worker experiences in mental health practices</i>
November	Professor Jacinta Douglas , Summer Foundation Chair, Living with Disability Research Centre, La Trobe University	<i>Maximising community connection for people with acquired brain injury: A multi-component program</i>
	Rebecca Leeson , Research Fellow, Living with Disability Research Centre, La Trobe University	<i>Finding the missing shoe: The effectiveness of M-Com Connect for Suzie</i>
December	Assistant Professor Phyllis Wong , Visiting Scholar, Department of Social Work, Chinese University, Hong Kong	<i>ICF-based practice on staff competency and satisfaction: A pioneer project</i>
	Dr Mark Feigan , Office of the Public Advocate, Victoria	<i>Systemic advocacy: Changing what happens</i>

Research Seminar Series

2020

	Presenter	Topic
February	Dr Lincoln Humphreys , Research Fellow, Living with Disability Research Centre, La Trobe University	<i>Frontline Practice Leadership: what it is and how to do it</i>
	Per Arvidsson , Visiting Scholar, PhD Candidate, Malmö University, Sweden	<i>Implementing Practice Leadership in a community setting, examples from Malmö, Sweden</i>
March	Charity Sims-Jenkins , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Do warm feelings, rather than negative feelings, obstruct support for self-determination from support workers?</i>
	Dr Sian Anderson , Lecturer, Living with Disability Research Centre, La Trobe University	<i>Social media responses to evidence presented by researchers to the Disability Royal Commission</i>
May	Dr Claire Spivakovsky , Senior Lecturer in Criminology, University of Melbourne	<i>Concerns about 'risk' in group homes: When reputational risks meet OHS concerns and result in restrictive practices</i>
	Professor Christine Bigby , Director, Living with Disability Research Centre, La Trobe University	<i>Dedifferentiation and people with intellectual disabilities in the Australian National Insurance Scheme</i>
June	Professor Teresa Iacono , Living with Disability Research Centre, La Trobe University	<i>Development of the La Trobe Reasonable Adjustments for Inclusive Education rating scale</i>
	Dr Jo Spong , Lecturer, La Trobe Rural Health School, La Trobe University	<i>A randomised control trial of shifting perceptions to enhance inclusive school education of students with disabilities</i>
July	Megan Topping , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Understanding the factors that influence the quality of paid support for adults with acquired neurological disabilities</i>
	Professor Christine Bigby , Director, Living with Disability Research Centre, La Trobe University	<i>Factors that influence the quality of staff support for people with intellectual disabilities in supported accommodation services</i>
August	Dr Kate D'Cruz , Lecturer, Occupational Therapy, La Trobe University	<i>Understanding the transformative potential of sharing personal stories: A process model of narrative storytelling</i>
	Dr David Henderson , Research Fellow, Living with Disability Research Centre, La Trobe University	<i>Stories from the Wild West frontier: The NDIS experiences of people with severe and profound intellectual disabilities</i>
September	Dr Alan Hough , Director, Purpose at Work	<i>The NDIS Quality & Safeguarding Scheme in context</i>
	Jade McEwen , PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Administrative compliance or personal outcomes? Exploring service quality of frontline staff in day services</i>
October	Em. Professor Jacinta Douglas , Summer Foundation Chair, Living with Disability Research Centre, La Trobe University	<i>Living well with acquired neurological disability: The things that help, the things that get in the way</i>
	Dr Kerry Bagley , Lecturer, Social Work, La Trobe Rural Health School, La Trobe University	<i>Perceptions of health and social service professionals of Fetal Alcohol Spectrum Disorder</i>
November	Professor Christine Bigby , Director, Living with Disability Research Centre, La Trobe University	<i>The La Trobe Support for Decision Making Practice Framework</i>
	Em. Professor Jacinta Douglas , Summer Foundation Chair, Living with Disability Research Centre, La Trobe University	<i>The La Trobe Support for Decision Making Practice Framework</i>
December	Daniel Leighton , Strategic Advisor, Intellectual Disability, Policy, Advice and Research Division, NDIS	<i>The role of the Strategic Advisor, Intellectual Disability, within the policy setting landscape of the NDIS</i>
	Dr Janice Biggs , Branch Manager, Research and Evaluation, NDIA	<i>The NDIS Research and Evaluation Branch</i>
	Professor Bruce Bonyhady , Director, Melbourne Disability Institute	<i>The National Disability Research Partnership (NDRP)</i>
	Dr Di Winkler , CEO Summer Foundation, and Adjunct Associate Professor, La Trobe University	<i>The partnership between the Summer Foundation and the Living with Disability Research Centre</i>

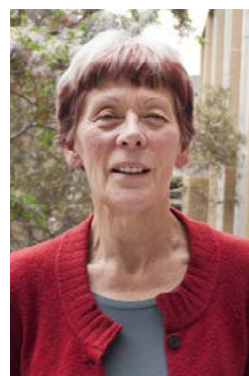
Other Events

Story webs: Anecdotal narrative and the fabric of being. A workshop with Dr Nicola Grove (UK)

In March 2019, Dr Nicola Grove (Tizard Centre, University of Kent, Canterbury) held a one-day workshop at the Living with Disability Research Centre that explored story webs and the way in which stories are intimately connected to the fabric of being. In this fantastic workshop, Dr Grove outlined how human beings spend a lot of their time together exchanging stories about their lives and how these so-called “small stories” can be regarded as critical in building a sense of personal identity, relationships and communities. The workshop illustrated some of the mechanisms whereby the exchange of stories can help to break down barriers and stigma in the lives of people with severe and profound intellectual disabilities.

Marking claims that matter. A workshop with Professor Jennifer Clegg (UK)

In November 2019, Professor Jennifer Clegg (University of Nottingham, UK) delivered a wonderful, one-day workshop: Making claims that matter: non-behavioural approaches to supporting people with intellectual disabilities. The workshop, co-hosted by the Living with Disability Research Centre and ASID, was a great success. More than forty people from various professions attended the workshop and delved into the latest research and practice around attachment and Trauma Informed care. The workshop explored non-behavioural approaches to people with intellectual disabilities and provided participants opportunities to view videos that show how interactions reveal attachment; to examine instruments that assess emotional development and levels of distress, and to discover new research and practice into attachment and Trauma-Informed Care. Professor Clegg designed and taught the *Understanding Complex and Challenging Needs* online module in the La Trobe University Graduate Certificate of Disability Practice last year. Her workshop explored some of the material that she covered in the course.



Professor Jennifer Clegg, University of Nottingham, UK.



Dr Nicola Grove, Honorary Senior Lecturer at the Tizard Centre, University of Kent, UK.



Higher Degree by Research Graduations

2019

Kathleen Fitt, PhD.

Encounters with child welfare discourses: Beginning practitioners working with mothers with intellectual disability

Abstract: Both beginning child and family welfare practitioners and mothers with an intellectual disability experience difficulties within the child protection system. Beginning practitioners experience high attrition rates in the first year of practice. Mothers with an intellectual disability are overrepresented in applications to remove children from the family home. This thesis explores discourses within the child welfare field and how, when and where those encountered by beginning child welfare practitioners influence practice when working with mothers with an intellectual disability. Findings revealed five key discourse themes: ecology, bureaucratic processes, knowledge, resources and definitions of harm/risk. These discourses came together as a framework that was implicit in child protection action. The framework provided an explanation for how beginning practitioners were influenced in terms of their functioning in their own professional and personal environments, and responses to the mother with intellectual disability. There is a need to consider the supports and knowledge beginning practitioners require to manage the five elements of the framework when working with vulnerable groups, such as mothers with intellectual disability.

Margaret Mealings, PhD.

Participating in education: The student perspective. Understanding the experiences of students returning to secondary and tertiary education following traumatic brain injury

Abstract: Participating in education following traumatic brain injury (TBI) provides a pathway for returning to important aspects of a student's pre-injury life. However, ongoing challenges in supporting students persist with variations in access, provision and length of support across rehabilitation and educational settings. This thesis explores the experience of secondary and tertiary students participating in education following TBI through exploring themes related to adjustment and wellbeing. Findings suggest that students' experiences were unique, with varied timelines and outcomes. However, they shared many critical points and the thesis showed that moving along the pathway was not always straightforward. The themes arising from this study provide clinicians and educators with suggestions for improving practice and show that students need to be supported in complex process of adjusting and reshaping identity through the use of holistic, comprehensive approaches that can be adapted in response to changing needs. Using the concept of a student journey provides a framework to explore broad approaches for supporting a range of academic and non-academic factors influencing students' participation over time.

Articles:

Students' perspectives on adjusting to life after traumatic brain injury through participation in study.

Margaret Pozzebon, PhD.

The spousal experience of primary progressive aphasia

Abstract: Primary Progressive Aphasia (PPA) is a neurocognitive-degenerative disorder, characterised by early and ongoing decline of language-communication abilities. Despite the pivotal role that spouses play in supporting their partner diagnosed with PPA, little is known about how they deal with and face the challenges associated with this progressive condition. This thesis explores the personal experiences of spouses living with this condition. The investigation yielded four published papers, and collectively the studies revealed the complex interpersonal and relational implications faced by spouses across the illness trajectory. This body of research makes a unique contribution to contemporary PPA literature. The research findings also enabled the development of a conceptual model which captured key aspects of the spousal experience of PPA. It emphasises the importance for clinicians to consider and address the relationship consequences of living with PPA from the perspective of spouses, specifically managing their sense of self in the context of changing relational connectivity with their partner and social world. These research findings have substantial potential to inform speech pathology therapeutic interventions and approaches to best support spouses to do the tough work of spousal caregiving.

Articles:

Facing the challenges of primary progressive aphasia

Claire Quillam, PhD.
Group home bureaucrats?
Understanding how staff
use paperwork in group
homes for people with
intellectual disability

Abstract: Paper tools, the paper or electronic documents that staff use in doing paperwork, are prominent in group homes for people with intellectual disability in Australia. Paperwork forms a significant part of staffs' work and is expected to serve many functions by disability service organisations, including guiding practice and capturing information for evaluating service quality. Little research has explored staffs' perspectives of their paperwork, although such research could reveal how staff use paperwork and offer strategies to support staff to complete paperwork in ways that lead to good resident support. This thesis explores how staff use paperwork in group homes for people with intellectual disability. The findings illustrate how staff draw on their frontline experiences and critical reflections to manage paperwork so they can remain focused on supporting residents, and revealed that staffs' paperwork is complex and possibly discretionary in nature. The findings suggest paper tools may be somewhat useful for meeting staffs' day-to-day practice requirements, but inadequate for capturing information to evaluate service quality.

Articles:

How frontline staff manage paperwork in group homes for people with intellectual disability.

Being a valuable contributor on the frontline.

Staff perspectives on paperwork in group homes for people with intellectual disabilities.

2020

Kate D'Cruz, PhD.
Narrative storytelling
following acquired brain
injury: Creating connections
and exchanging wisdom
through sharing stories of
lived experience

Abstract: Adapting to life following acquired brain injury (ABI) is a complex process of adjustment and community reintegration. While narrative storytelling is recognised as an approach to supporting coherence following trauma or disruption to the life narrative, there is limited direct research into narrative approaches in ABI. This thesis explores the subjective experience of narrative storytelling following ABI. The study was conducted in the context of a storytelling advocacy program, in which personal stories are shared to advocate for the rights of young people with disabilities residing in nursing homes. Narrative storytelling was found to be a humanising experience and central to this finding was the advocacy context of the storytelling, in which sharing stories of lived experience held meaningful occupational purpose for the storytellers, and their lived experiences were valued. This is the first study to investigate the use of narrative storytelling for adults with ABI in an advocacy context, and from the perspective of both storytellers and facilitators. The findings contribute new insights, with practice recommendations considered in the context of holistic ABI rehabilitation.

Articles:

Personal narrative approaches in rehabilitation following traumatic brain injury.

Sharing stories of lived experience.

Narrative storytelling as both an advocacy tool and therapeutic process.



Dr Margaret Pozzebon (left) with supervisor Professor Jacinta Douglas at the La Trobe graduation ceremony.



Dr Margaret Mealings (centre) with principal supervisor Professor Jacinta Douglas and co-supervisor Professor John Oliver, Medical Director, Rehabilitation, Epworth HealthCare, Victor Smorgon Chair of Rehabilitation, Monash University Epworth HealthCare at the La Trobe graduation ceremony.

Funded Projects

New in 2019 and 2020

Araten-Bergman, T., Bigby, C. **Aging with intellectual disability. Exploring the impact of the NDIS on service provision**; School of Allied Health, Human Services and Sport, La Trobe University.

Bigby, C., Douglas, J. **Support for decision making. Adapting the La Trobe Support for Decision Making Practice Framework for the Queensland Public Trustee**; Queensland Public Trustee.

Bigby, C., Crisp, W. **V/Line and passengers with communication difficulties**; Scope.

Bigby, C., Humphreys, L. **Measuring culture in supported accommodation services**; Melba Support Services.

Bigby, C., Iacono, T., Humphreys, L., Araten-Bergman, T. **Identifying quality. Resources for delivering and monitoring quality of evidence informed practice**; NDIS Quality and Safeguards Commission.

Bigby, C., Iacono, T., Humphreys, L., Araten-Bergman, T. **Identifying quality. Quantifying features of organisation structures and leadership that contribute to sustained quality of Active Support practice in supported accommodation services**; Lorna Hodgkinson Foundation.

Bigby, C., Sheehan, M., Douglas, J. **Promoting equal rights under the Victorian Medical Treatment Planning and Decisions Act 2018. Supporting the rights of Victorians with cognitive disability**; La Trobe University.

Douglas, J., Bigby, C. **Building capacity to support client decision making**; Transport Accident Commission.

Iacono, T., Bigby, C., Douglas, D., & Spong, J. **Increasing hospital access and quality of care for people with cognitive disability**; National Disability Insurance Scheme – Mainstream Capacity Building (MCB) Grant Round 2019-202.

Lanin, N., Douglas, J., et al. **Early vocation intervention for people who have experienced a stroke. A randomised pilot trial**; Stroke Foundation.

Linehan, C., Araten-Bergman, T., Bigby, C., Beadle-Brown J., et al. **Impact of Covid-19 on individuals with intellectual and developmental disabilities and caregivers**; Health Research Board, Ireland (COV19-2020).

Shields, N., Bennell, K., Taylor, N, Rice, L., Markovic, T., Bigby, C., Watts, J., Prendergast, L. **Improving muscle strength in young people with Prader-Willi syndrome**; Medical Future Fund.

Smith, E., Bigby, C., Lyons, A., Power, J. **Rainbow me! Inclusion of LGBTQI and gender diverse adults with intellectual disability in social and support services**; Building Healthy Communities Research Focus Area, La Trobe University.

Continuing from 2018

Beadle-Brown, J., Bigby, C., Bradshaw, J. **Uncovering staff culture of good quality supported accommodation for people with intellectual disabilities**; National Institute for Health Research, School for Social Care Research, UK.

Bigby, C. **Living the good Life: Embedding Active Support and Practice Leadership in supported accommodation services**; Australian Research Council (ARC) Linkage Grant and additional industry partners: Yooralla, annecto, Aruma, Identitywa, GenU, Unisson Disability, Jewish Care.

Bigby, C. **Using person centred active support in the community. A study of the quality of support and service user outcomes in supported living and drop in services**; Aruma.

Bigby, C., Douglas, J. **Effective decision making support for people with cognitive disability**; Australian Research Council (ARC) Linkage Grant.

Bigby, C., Iacono, T., Douglas, J., Troller, J., Tracy, J, Sheilds, N. **Enabling mainstream systems to be more inclusive and responsive to people with disabilities**; National Disability Research and Development grants.

Bigby, C., O'Donovan, D., Douglas, J. **Accessible summaries and digest of AAT decisions about the NDIS**; Brotherhood of St Laurence.

Bigby, C., Tideman, M. **After school job project**; National Disability Services.

Bigby, C., Tipping, S. **Strategies to support people with intellectual disabilities to vote**; Victorian Electoral Commission.

Douglas, J. **Summer Foundation Research Chair**.

Douglas, J., Bigby, C. **Building capacity to support client decision making**; Transport Accident Commission.

Douglas, J., Bigby, C., Iacono, T. **Maximising social connection and building relationships in the community: Evaluation of a multi-component community connection program (M-ComConnect) for people with severe TBI**; Institute for Safety, Compensation and Recovery Research.

Iacono, T., McKinstry, C., Keeffe, M., Hyett, N., Landry, O. **Strengthening the capacity of mainstream schools to meet the functioning, developmental, educational and psychosocial needs of children with disability**; National Disability Insurance Agency - Community Inclusion Capacity Development (CICD) Program.

Tilbury, C., Bigby, C., Hughes, M., Fisher, M. **The production, use and effect of social work research**; Australian Research Council (ARC) Discovery Grant.

Weisel, I., Gleeson, B., Bigby, C., Whitzman, C. **The disability inclusive city**; Australian Research Council (ARC) Discovery Grant.



Publications

2019

Articles

Ashley, D., Fossey, E., & Bigby, C. (2019). The home environments and occupational engagement of people with intellectual disabilities in supported living. *British Journal of Occupational Therapy*.
DOI: [10.1177/0308022619843080](https://doi.org/10.1177/0308022619843080)

Barry, S., Knox, L., & Douglas, J. (2019). 'Time's up': The experience of entering residential aged care for young people with acquired neurological disorders and their families. *Brain Impairment*, 20(1), 37-48.
DOI: [10.1017/BrImp.2018.13](https://doi.org/10.1017/BrImp.2018.13)

Bigby, C., Bould, E., & Beadle-Brown, J. (2019). Implementation of Active Support over time in Australia. *Journal of Intellectual and Developmental Disability*, 44(2), 161-173.
DOI: [10.3109/13668250.2017.1353681](https://doi.org/10.3109/13668250.2017.1353681)

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019). Quality of practice in supported accommodation services for people with intellectual disabilities: What matters at the organisational level. *Journal of Intellectual and Developmental Disability*.
DOI: [10.3109/13668250.2019.1671965](https://doi.org/10.3109/13668250.2019.1671965)

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019). Predicting good Active Support for people with intellectual disabilities in supported accommodation services: Key messages for providers, consumers and regulators. *Journal of Intellectual and Developmental Disability*.
DOI: [10.3109/13668250.2019.1685479](https://doi.org/10.3109/13668250.2019.1685479)

Bigby, C., Bould, E., Iacono, T., Kavanagh, S., & Beadle-Brown, J. (2019). Factors that predict good Active Support in services for people with intellectual disabilities: A multilevel model. *Journal of Applied Research in Intellectual Disabilities*.
DOI: [10.1111/jar.12675](https://doi.org/10.1111/jar.12675)

Bigby, C., Johnson, H., O'Halloran, R., Douglas, J., West D., & Bould, E. (2019). Communication access on trains: A qualitative exploration of

the perspectives of passengers with communication disabilities. *Disability and Rehabilitation*, 41(2), 125-132.
DOI: [10.1080/09638288.2017.1380721](https://doi.org/10.1080/09638288.2017.1380721)

Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support of decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability*, 44(4), 396-409.
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Submissions

Bigby, C. (2020). Parliamentary Inquiry into the NDIS Workforce. Written Submissions April 2020. Written and oral Submission, July 2020.

Bigby, C. (2020). Parliamentary Inquiry into the NDIS Quality and Safeguards Commission. Written submission, July 2020.

Presentations

Keynotes and invited presentations 2019

Bigby, C. (2019, February). **Understanding community participation for people with intellectual disabilities. Keynote.** Hong Kong network on intellectual disability, Hong Kong.

Bigby, C. (2019, May). **What is necessary to embed active support in supported living services.** British Learning Disabilities Conference, Birmingham, UK.

Bigby, C. (2019, May). **Using convivial encounter to create social inclusion for people with more severe intellectual disabilities: What does practice look like?** Utrecht University of Humanities - Conference on Social Inclusion. Utrecht, Netherlands.

Bigby, C. (2019, June). **Understanding types of community participation and designing effective support for people with intellectual disabilities. Plenary.** Asia Pacific Autism Conference, Singapore.

Bigby, C., (2019, November). **Why is research evidence important? What does it say about social inclusion of people with intellectual disabilities?** Festival of Inclusion, Sydney, Australia.

Bigby, C., (2019, November). **Perspectives of people with intellectual disabilities about voting.** Electoral Regulation Research Network, Adelaide, Australia.

Bigby, C. (2019, November). **What does the evidence say?** Having a Home Forum, ACT Office Disability, Canberra, Australia.

Bigby, C., Douglas, J., & Iacono, T. (2019, March). **Enabling mainstream systems to be more inclusive of people with cognitive disabilities.** Victorian Allied Health Conference, Melbourne.

Clegg, J. Adjunct Professor (2019). **Helping damaged people manage their chaotic emotions.**

Clifford-Simplican, S. Adjunct Associate Professor (2019). **Critiquing approaches to community participation of people with intellectual disabilities.**

Douglas, J. Winkler, D., D'Cruz, K., Buculo, C., & Finis, C. (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.

Selected other presentations

Anderson, S., & Bigby, C. (2019, November). **Writing the script: The overt and hidden contradictions of supporters' work in independent self-advocacy groups.** Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

Araten-Bergman, T. (2019, November). **Models for forming and supporting circles of support for people with intellectual disability.** Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

Bigby, C. (2019, August). **'Glossing over issues in the rush to have everybody under the disability banner': A case study of a dedifferentiated reform in the Australian National Disability Insurance Scheme.** The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow, Scotland.

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019, August). **Identifying factors that predict good Active Support in group homes for people with intellectual disabilities using multi-level modelling.** The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow, Scotland.



Professor Christine Bigby presenting the keynote at the Hong Kong Network on Intellectual Disability 2019.



Dr Lincoln Humphreys presenting at the International Association for the Scientific Study of Developmental Disabilities Conference, Glasgow, Scotland in 2019.



William Crips presenting at the Annual conference of the Australasian Association for Intellectual Disability, Adelaide, 2019.

Bigby, C., Bould, E., Iacono, T., & Beadle-Brown, J. (2019, August).

Organisational structures and processes associated with good Active Support. The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow, Scotland.

Bigby, C., & Douglas, J. (2019, March). **Developing an evidence-based support for decision making practice framework.** Australian Guardianship and Administration Council Conference, Canberra, Australia.

Bigby, C., & Douglas, J., & Smith, E. (2019, March). **The La Trobe Support for Decision Making Practice Framework: Preliminary analysis.** Australian Guardianship and Administration Council Conference, Canberra, Australia.

Bigby, C., & Humphreys, L. (2019, August). **Patterns of staff culture in Australian group homes.** The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow, Scotland.

Bigby, C., Douglas, J., & Iacono, T. (2019, August). **Enabling hospitals to be more inclusive and responsive to people with intellectual disabilities.** The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow, Scotland.

Crisp, W., Bigby C., & Whiteside, M. (2019, November). **Strategies for supporting people with intellectual disability to have choice and control over their lives.** Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

D'Cruz, K., Douglas, J., & Serry, T. (2019, May). **Humanising healthcare: Understanding the potential of narrative storytelling.** Australasian Society for the Study of Brain Impairment/New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

D'Cruz, K., Douglas, J., & Serry, T. (2019, July). **A grounded theory study of narrative storytelling following acquired brain injury: An altruistic occupational opportunity to help others through story sharing.** Occupational Therapy Australia, National Conference and Exhibition, Sydney, Australia.

D'Cruz, K., Douglas, J., & Serry, T. (2019, July). **Narrative storytelling following acquired brain injury: A collaborative therapeutic relationship between storytellers and facilitators.** Occupational Therapy Australia, National Conference and Exhibition, Sydney, Australia.

Douglas, J., Bigby, C., & Iacono, T. (2019, May). **Enabling hospitals to be more inclusive and responsive to people with cognitive disabilities.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Douglas, J., Bracy, C., Snow, P., Knox, L., & De Maio, C. (2019). **Understanding and treating cognitive-communication deficits that impact on success in the workplace following traumatic brain injury.** International Brain Injury Association's 13th World Congress.

Humphreys, L., Bigby, C., & Iacono, T. (2019, August). **The Group Home Culture Scale: Validation and use in predicting quality of staff support in group homes.** The International Association for the Scientific Study of Intellectual and Developmental Disabilities Conference, Glasgow.

Iacono, T., Hyett, N., Spong, J., Bagley, K., Landry, O., McKinstry, C., Arthur-Kelly, M., & Garcia Melgar, A. (2019, December). **A randomised controlled trial of shifting perceptions to enhance inclusive school education of students with disability through reasonable adjustments.** Australian Association for Research in Education Conference, Brisbane.

Iacono, T., Hyett, N., Spong, J., Bagley, K., Landry, O., McKinstry, C., Arthur-Kelly, M., & Garcia Melgar, A. (2019, December). **Development of a reasonable adjustments for inclusive education rating scale.** Australian Association for Research in Education Conference, Brisbane.

Iacono, T., Bigby, C., Douglas, J., & Spong, J. (2019, August). **A prospective study of hospital encounters by people with intellectual and developmental disability and a comparison group.** Association for the Scientific Study of Intellectual and Developmental Disabilities European Regional Congress, Glasgow.

Iacono, T., Hyett, N., Spong, J., Bagley, K., Landry, O., Arthur-Kelly, M., McKinstry, C., & Garcia Melgar. (2019, August). **Development of a reasonable adjustments for inclusive education rating scale.** Association for the Scientific Study of Intellectual and Developmental Disabilities European Regional Congress, August, Glasgow.

Knox, L. & Douglas, J. (2019). **"If there's an official term called supported decision making, I have no clue": Experiences of community-based rehabilitation professionals in supporting decision-making participation for adults after ABI.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Mealings, M., Douglas, J., & Olver, J. (2019, May). **The student journey: Living and learning following traumatic brain injury.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

McEwan, J. (2019, November). **What is good service quality? Frontline day service staff's perspectives on what it is and how it should be measured.**

Presentations

Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

McNabb, J. (2019, November). **Article 12 and the NSW guardianship framework: A case study highlighting barriers for people with intellectual disability regarding legal capacity and autonomy of decision-making.**

Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

Pozzebon, M., Douglas, J., & Ames, D. (2019, May). **The spousal experience of Primary Progressive Aphasia.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Ritchie., Bigby, C., & Douglas, J. (2019, November). **Keeping people with an intellectual disability safe: A case study of sexual abuse.** Annual conference of the Australasian Association for Intellectual Disability, Adelaide, Australia.

Stagg, K., Douglas, J., & Iacono, T. (2019, May). **Communication impairment and the working alliance in stroke rehabilitation.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Tipping, S., Bigby, C., & Douglas, J. (2019). **The perceptions and experiences of voting by people with intellectual disability: Implications for Australian democracy.**

Van Nierop, M., Johnson, H., Heppell, A., Rezzani, N., Iacono, T. (2019). **Empowering families to use and obtain augmentative and alternative**

communication (AAC) Resources for children with intellectual and developmental disability.

Williams, L., Douglas, J., & Serry, T. (2019, May). **"I really try to plug into the person": Strategies used by clinicians to build and nurture the therapeutic alliance in community brain injury rehabilitation.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Winkler, D. & Douglas, J. (2019, May). **Integrated apartments for people with disability: Individual experience and outcomes.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Winkler, D., & Douglas, J. (2019, May). **Co-design, pilot and evaluation of participant led videos to train support workers.** Australasian Society for the Study of Brain Impairment/ New Zealand Rehabilitation Association Conference, Wellington, New Zealand.

Winkler, D., Douglas, J., D'Cruz, K., Buccolo, C., & Finis, C. (2019, July). **Outcomes of participant-led videos: Supporting people with severe brain injury to have choice and control, set goals and direct their supports.** Occupational Therapy Australia, National Conference and Exhibition, Sydney, Australia.

Keynotes and invited presentations 2020

Bigby, C. (2020, February). **Convivial encounter as a means of social inclusion for all ages.** Invited presentation, Deakin University Seminar, Australia.

Bigby, C. (2020, July). **What makes a difference to quality of life and quality of services: Some evidence from research.** Queensland Disability Network, Australia.

Bigby, C. (2020, September). **Enabling hospitals to be more inclusive and responsive to people with intellectual disabilities.** ASID Webinar.

Bigby, C. (2020, October). **An evidence-based support for decision making practice framework.** Invited presentation, Disability Summit.

Bigby, C. (2020, October). **Dedifferentiation and people with intellectual disabilities in the NDIS.** Invited presentation, Possibility, Australia.

Bigby, C. (2020, October). **Identifying difference in culture between poor performing and better group homes.** Tizard Centre, seminar in conjunction with CQC, UK.

Humphreys, L. (2020, October). **The Group Home Culture Scale: Development and findings.** Tizard Centre, seminar in conjunction with CQC, UK.

Partners

The Living with Disability Research Centre works in partnership with government and non-government organisations and other universities. Our Centre also continues to work in partnership with the Summer Foundation, Australia's leading organisation on research regarding young people with acquired brain injury in nursing homes. This partnership continues to facilitate pioneering research that focuses on developing interventions that work for people with acquired brain injury and brings them back into mainstream society.



Our Partners

- annecto Inc
- Aruma
- Australian Research Council
- Civic Disabilities Services
- Dundaloo Support Services
- Endeavour Foundation
- Epworth Health
- GenU
- Golden City Support Services
- Greystanes Disability Services
- Help Enterprises
- Identitywa
- Inclusion Melbourne
- Institute for Safety, Compensation and Recovery Research
- Jewish Care
- Melba Support Services
- Melbourne Health
- NDIS Information, Linkages and Capacity Building
- NDIS Quality and Safeguards Commission
- National Disability Services
- NSW Trustee and Guardian
- Oak Possability
- Office of Public Advocate Victoria
- Office of the Public Guardian QLD
- Principals' Association of Specialist School Victoria Inc
- Queensland Mental Health Commission
- Queensland Office of the Public Guardian
- Queensland University of Technology
- Rocky Bay
- Summer Foundation
- The Public Advocate Queensland
- The Public Trustee of Queensland
- Transport Accident Commission
- Unisson Disability Services
- Yooralla

Contacting Us

If you want to talk to us about our research, be included on our mailing list, or partner with us, please contact us.

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