LA TROBE UNIVERSITY

LIVING WITH DISABILITY RESEARCH CENTRE

2018 Annual Report

Contents

Message from the Deputy Vice Chancellor (Research)

The Living with Disability Research Centre is one of La Trobe's leading research centres. It plays a key role in bridging the gap between academic research and the application of its research findings in practice. The Centre has an excellent reputation within the University and the broader community based on its excellent track record of engagement with, and delivery of research that has a transformational impact within the disability sector. The Centre's work is increasingly important in the context of the revolutionary change being driven by the roll out of the National Disability Insurance Scheme (NDIS).

The Centre demonstrates a bi-directional exchange between industry partners and academic researchers, and is an exemplar of how La Trobe University does things differently to shape the future of our communities. The Centre is connected to its communities via an impressive number of partnerships and exchanges that enable a high level of involvement with the beneficiaries of its research. This creates impact far greater than the Centre's size would suggest.

The Living with Disability Research Centre continues to work across our Research Focus Areas delivering ambitious programs of scale and depth, as well as trialling innovative ideas and approaches. The Centre's research sees collaborations across our many campuses and by working with the Schools of Rural Health in Bendigo, and Allied Health in Bundoora, it brings great diversity to its research projects.

I am pleased to see that continued University investment, such as internal grants to support Early Career Researchers, have contributed to the success of Professor Bigby and the Centre. The Centre's output of high quality research publications and its success in attracting research grants demonstrates La Trobe University's commitment to research excellence and community impact.

I am also pleased to report that the Living with Disability Research Centre continues to work across an exceptionally varied array of disciplines and research areas. From History to Management and Law, the reach of the Centre reflects the totality of the lives of those we research. Professor Bigby has managed to draw several common threads that form a substantial framework across her research themes and maintain a consistent appeal to the needs of industry and other partners.

The Living with Disability Research Centre also provided one of the successful case studies submitted by La Trobe University for the Australian Research Council Impact and Engagement assessment exercise for 2018. The work of the Centre in improving the lives of people with intellectual disabilities in group homes was used by La Trobe to illustrate the way in which our research engages with industry and communities and delivers real impacts. Researchers in the centre were major contributors to the above world standard rating for the discipline of social work in the 2018 Excellence in Research Assessment by the ARC and to the high rating for Engagement with research end users gained by the Studies in Human Society field of research at La Trobe University.

The Centre should be congratulated for its continued excellent work. I look forward to an exciting 2019, and the contribution the Living with Disability Research Centre will continue to make in producing research with real impact and meaning for individuals and communities.

**Professor Russell Hoye
Acting Deputy Vice Chancellor
(Research and Industry Engagement)**

Message from the
Director

2018 marked five years since the establishment of the first pilot NDIS sites. It was a year of extraordinary activity in the disability sector. Public interest in the social inclusion of people with cognitive disabilities is growing and mainstream services are increasingly trying to find ways of delivering high quality service to people with disabilities.

The Living with Disability Research Centre continues to make a major contribution in three core areas of knowledge to improve the quality of life of people with cognitive disabilities: delivering effective specialist disability services, building the evidence base for participation and enabling mainstream services to be inclusive. Our work increasingly combines publication of high quality academic research and dissemination of evidence in forms that are useable and available to those delivering, designing or funding services or who are advocating to effect social change.

We started off the year with a panel discussion reflecting on lessons learned from the roll out of the NDIS, and interviews on the Stan Grant show and Life Matters. We ended the year with the graduation of 6 PhD students and one masters student whose research makes a significant contribution to the disability sector (see page 24 for more details). During the year we collectively published

53 articles, 7 reports, and 4 book chapters. We also launched a new set of online training resources about Enabling Risk, disseminated the first edition of a new Quarterly Digest of Administrative Appeals Tribunal (AAT) decisions, funded by the Brotherhood of St Laurence, and commenced 9 new research projects. Our staff and PhD students presented research at conferences and industry forums around the world. Professors Bigby and Douglas each received prizes for the most outstanding papers published during 2018 in the *Journal of Intellectual and Developmental Disability* and *Brain Injury* respectively.

During 2018 we consolidated much of our research into a suite of new online postgraduate courses on Disability Practice. These courses will be offered for the first time in 2019 and can be taken as short professional development courses, or a Graduate Certificate, Graduate Diploma or Masters in Disability Practice. We will also be offering a series of master classes in key areas of disability practice during 2019. Our monthly seminars are now open to the public to attend either in person or remotely.

This report describes some of our major projects, summarises key findings and provides easy links to articles, reports and training resources. You can join our mailing list to receive regular updates of publications and events during the year. We continue to work with key partners across the disability sector and the University. I thank all our partners for their continuing support for our work during this year.

Director, Living with Disability Research Centre, Professor Christine Bigby

About the Living with Disability Research Centre

Mission

The mission of the Centre is to improve the social inclusion and participation of people with cognitive disability through research, education and knowledge transfer by strengthening the evidence base that informs practices, programs and policies that further social inclusion.

Expertise

Unique among research centres in Australia is our focus on social inclusion and participation of people with cognitive disabilities – mainly those with intellectual disabilities or acquired brain injury. The Centre has an outstanding track record of delivering rigorous high quality research that adds to the academic literature, as well as significant strengths in translating research findings into formats and resources that are accessible to stakeholders across the disability sector and mainstream service providers.

Research Programs

Our research is characterised by three broad themes:
- Improving the effectiveness of disability services;
- Building the evidence base for community, social and political participation; and
- 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. The Centre partners in different ways with more than 40 different 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 or government funding bodies. The Summer Foundation co-funds the Summer Foundation Chair, Living Well with Brain Injury, held by Professor Jacinta Douglas and the research program associated with this chair. As well as having dedicated research staff, the Centre works with staff from across La Trobe University giving us a strong multi-disciplinary perspective.

Governance

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

The Living with Disability Research Centre Director and 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 PVC (College of SHE) and the Deputy Vice-Chancellor (Research).

During 2018 members of the Advisory Committee were:

Internal members:
• The Centre Director - Professor Christine Bigby
• The Pro Vice-Chancellor (College of SHE) Professor Rob Pike
• Nominee of Head of School (School of Allied Health) Professor Anne Holland
• Staff member of the Centre - Professor Jacinta Douglas

External members:
(from organisations within the sector)
• Daniel Leighton - Brotherhood of St Laurence
• Dr Christine Fyffe - Consultant
• Dr Di Winkler - Summer Foundation
• Dr Jane Tracy - Centre for Developmental Disability Health Victoria

Personnel

Professor Christine Bigby
Director of the Living with
Disability Research Centre

Professor Jacinta Douglas
Summer Foundation Chair,
Living Well with Brain Injury

Professor Teresa Iacono
La Trobe Rural Health School

Senior Research Fellows

- Dr Emma Bould
- Dr Suzane Vassallo

Research Fellows

- Dr Sian Anderson
- Dr Nadine Cameron (left during 2018)
- Dr David Henderson
- Dr Lucy Knox
- Dr Elizabeth Smith
- Dr Jo Spong
- Ms Rebecca Leeson
- Dr Megan O'Neil (left during 2018)

Research Officers

- Dr Sandy Barry
- Ms Michelle Collins
- Dr Lincoln Humphreys
- Ms Chantelle Hutchinson
- Ms Jen Jackson-Hall
- Ms Talia Lipschitz
- Dr Bronwyn Moorhouse
- Ms Becky Thiele
- Ms Sophia Tipping
- Ms Megan Topping
- Ms Yuki Wakamatsu
- Mr Andrew Westle

Adjuncts

- Luke Bo'sher – Adjunct Research Fellow
- Professor Lauren Clark - Adjunct Professor
- Dr Jennifer Clegg - Adjunct Professor
- Dr Stacy Clifford Simplican - Adjunct Associate Professor
- 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
- Dr Jane Tracy - Adjunct Associate Professor
- Dr Di Winkler - Adjunct Associate Professor

Associated La Trobe University staff

- Dr Tal Araten-Bergman – Social Work
- Dr Anoo Bhopti – Occupational Therapy
- Professor Leanne Carey – Occupational Therapy
- Dr Jillian Cavanagh - Management
- Ms Kate D'Cruz – Occupational Therapy
- Dr Michael Dillon – Prosthetics & Orthotics
- Dr Pam Kappelides – Sport & Tourism
- Dr Tessa Keegal - Public Health
- Dr Alicia Malika - Audiology
- Dr Darren O'Donovan - Law
- Dr Robyn O'Halloran – Speech Pathology
- Dr Jodi Oakman – Public Health
- Professor Jennifer Oates – Speech Pathology
- Dr Tanya Serry – Speech Pathology
- Dr Andrea Simpson – Audiology
- Dr Ruth Stuckey – Public Health

The Living with Disability Research Centre is proud to acknowledge our international partnership with the University of Kent, England.

Professor Julie Beadle Brown
Living with Disability Research Centre &
The Tizard Centre, University of Kent, UK

Higher Degree by Research students

- Kate D'Cruz
- Kate Fitt
- Amy Ford
- Susan Jackson
- Yeptain Leung
- Kristy Logan
- Jenna MacNab
- Jade McEwen
- Margaret Mealings
- Margaret Pozzebon
- Claire Quillam
- Gail Ritchie
- Bojana Sarkic
- Kellie Stagg
- Sophia Tipping
- Rahila Ummer Christian
- Elizabeth Williams

Higher Degree students completing in 2018

- William Crisp PhD
- Melanie Drummond PhD
- Lincoln Humphries PhD
- Michelle Browning PhD
- Barbara Wolfenden PhD
- Michelle Attard PhD
- Danielle Ashley MAOT

Research Programs

1 Effectiveness of disability services

Research in this theme aims to improve the design and delivery of specialist disability support services. It includes two large research programs that have multiple strands.

Effective decision making support for people with cognitive disability

Professors Bigby and Douglas have been leading a program of research on support for decision making for people with cognitive disabilities for a number of years. They focus on understanding the practice necessary to provide good support that enables all people with cognitive disability to participate in decision making. Good support means that decisions reflect the will, preferences and rights of a person with cognitive disability, irrespective of their capacity to make independent decisions.

The evidence based La Trobe Support for Decision Making Practice Framework forms the basis of training and a set of resources aimed at developing the skills of those providing decision support for people with cognitive disabilities. Supporters may be parents, support workers, support coordinators, friends or other family members. With funding from an ARC Linkage grant, we are in the final stages of a randomised control trial to test the impact of this training on the quality of decision support and the experiences of the person being supported. By the end of 2018, more than 60 people with intellectual disabilities or acquired brain injury and their supporters were participating in the study. The results will be available at the end of 2019. The evidence base and process for developing the framework is now published in Rehabilitation and Society and is available from our website along with other information about this project.

http://bit.ly/LiDs-SfDM-framework

Other parts of this program of research have involved, training Local Area Coordinators and Ability Linkers from St Vincent de Paul Society in NSW in support for decision making, training advocates at 'Leadership Plus' in support for decision making, and designing a set of online training resources which will be available by mid 2019. A new part of this research - funded by the TAC - commences in 2019.

Professor Christine Bigby
Director of the Living with Disability Research Centre

Embedding active support and practice leadership in supported accommodation services

Led by Professor Bigby, this research builds on her earlier studies about the closure of Kew Cottages and the culture in group homes in Victoria. It also builds on significant evidence from the UK that if staff use Active Support the people they support are more engaged and have a better quality of life. Funded by an ARC Linkage grant and Industry Partners, the study commenced in 2009. The impetus for the study was the variable quality of Active Support in services for people with intellectual disabilities, despite organisations claiming to use Active Support. The study aimed to understand 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 observational data 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.

Whichever way the data are cut, the results are similar. This provides significant new knowledge about where organisations should focus attention to ensure good Active Support practice. In a nutshell, if organisations want to embed good Active Support and deliver high quality support to people with intellectual disabilities they need to:

- Train all staff in Active Support, and ensure they are skilled in tailoring their practice to the level of ability of each person they support.

- Ensure every individual support worker and team receives strong Practice Leadership. This means the practice of support workers is regularly observed and they receive feedback and coaching, have the chance to discuss Active Support in team meetings and individual supervision, and understand what is expected of them on every shift. Finally, at the core of everything they and their managers do should be a focus on the quality of life of the people they support.

- Organise Practice Leadership so practice leaders are close to front line practice, the tasks are not split between different positions in the organisation and practice leaders

have a good rapport with all the support workers and knowledge of the support needs of the people they support.

- Ensure support workers are motivated and have confidence in the management of the organisation.

- Design services that are small and do not support more than 6 people.

- Ensure the optimal mix of people in any service, i.e. people whose supports needs are not too different, but who do not all have challenging behaviour.

- Ensure that all senior managers in the organisation understand Active Support and recognise the value of high quality practice.

These finding are important for service providers, boards of organisations, NDIS pricing schedules, the Quality of a Standards Commission, and people with intellectual disabilities and their families who are making choices about the services they use.

Interim results of the Embedding Active Support and Practice leadership study were presented as a part of the Research Week event.

View the poster online:

http://bit.ly/LiDs-ASposter

Research Programs

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Building the evidence base for participation

Many people with cognitive disabiliies are socially isolated and participate in few community or political activities. The research in this theme identifies challenges, promising practices and strategies to facilitate participation and social inclusion.

Transport Accident Commission (TAC) Research Panel (2018-2020)

The Living with Disability Research Centre's researchers led the La Trobe University competitive application for appointment to the Transport Accident Commission's (TAC) Research Panel for the next 3 years. The appointment provides La Trobe with opportunities to support the TAC in world leading health, disability and compensation research to meet the TAC's strategic objectives. The panel tender was led by Prof Jacinta Douglas with A/Prof Natasha Lannin and Prof Christine Bigby. The Research Panel contract has an estimated value of approximately $5M per year.

Grants resulting from the TAC Research Panel

Building capability to support client decision making

The aim of this project is to translate existing evidence on the La Trobe Support for Decision Making Practice Framework (Douglas & Bigby, 2018) to support practice within the Transport Accident Commission. The project will involve training a cohort of the TAC's independence claims employees to apply the strategy to their client planning interactions and deliver services consistent with contemporary disability practice. Following training we will assess the training-specific impact on the capability of independence claims employees to be effective supporters of decision making. The project is led by Professors Douglas and Bigby and funded by the TAC.

Contemporary disability practice: Ongoing horizon scanning program

The Horizon Scanning Program is designed to identify emerging and innovative advances in contemporary disability practice across the national and international disability sector. Our findings will assist the TAC to remain aware of developments in the definition, principles, and characteristics of contemporary disability practice and support their aim to be a world leading social insurer. Professors Douglas and Bigby are leading this TAC funded project.

Supporting people with intellectual disabilities to vote

Voting is an important part of political citizenship. The first part of this study aimed to explore the barriers to voting for people with intellectual disabilities in order to understand how to best support their participation. The findings showed that some people with intellectual disabilities do have political opinions, are interested in voting and have had experiences which help them understand voting processes.

Only around half of all the people with intellectual disabilities had voted and many were unclear about their enrolment status. Barriers to voting were limited support, low expectations, and uncertainty about provision of support by staff in disability support services and family members.

The study is funded by the Victorian Electoral Commission with support from Inclusion Melbourne and a consortium of other Australian Electoral Commissions. Based on the findings, the Victorian Electoral Commission designed a capacity building initiative which targeted 2 disability support organisations in the lead up to the 2018 November State election. The initiative is being evaluated by our team of researchers and a final report wil be prepared by March 2019. Interim reports are available in the University Research Repository.

View the report online:

www.bit.ly/LiDs-VotingReport

Maximising social connection and building relationships in the community

The goal of this project is to implement and evaluate innovative strategies to support social activity, social relationships and community inclusion for people with severe brain injury who live in a range of different environments. The intervention program is tailored to each individual and evaluated using single case experimental design methods. Many adults who sustain severe traumatic brain injury experience difficulties developing and maintaining connections within the community. They report having few, if any, friends and having little social or no community involvement.

The project is funded by the Institute of Safety Compensation and Research Recovery (ISCRR). All participants have been recruited and results to date show positive outcomes for those who have completed a cycle of intervention. We anticipate that the project will be concluded by the end of 2019. We will begin progressively publishing the results of the series of single case experimental design studies throughout 2019.

Designing effective support for community participation for people with intellectual disabilities

This study, conducted in collaboration with NDS was completed at the end of 2018. Community participation has been a long held but seldom realized aim of disability policy. It is an ill-defined and slippery concept. The aim of this study was to develop conceptual clarity about, and a typology of, different types of community participation and interventions to support it. The project then sought to present exemplar case studies of interventions illustrating the different approaches, as well as the resource and skills necessary to deliver good support for community participation to people with intellectual disabilities.

We identified 3 types of community participation and interventions. Community participation as:

- Social relationships and interventions to develop social relationships.

- Convivial encounters and interventions that supported social interactions where there is a shared identity or activity with others and a sense of pleasantness or warmth.

- Belonging and interventions to support a sense of belonging.

The full report has 5 detailed case studies that provide a blueprint for designing programs that provide individualized support for these different types of community participation.

During 2019, we will be working with NDS to produce more accessible versions of this material in the form of a guide to good practice and design of support for community participation.

Research Programs

2

Building the evidence base for participation

Many people with cognitive disabilities are socially isolated and participate in few community or political activities. The research in this theme identifies challenges, promising practices and strategies to facilitate participation and social inclusion.

Summer Foundation Partnership

This three million dollar partnership between La Trobe University and the Summer Foundation began in 2014 and was made possible by a generous donation from a private philanthropic trust. The Summer Foundation is Australia's leading organisation on research regarding young people with acquired brain injury in nursing homes. This pioneering research program focuses on developing interventions that work for people with acquired brain injury and bring them back into mainstream society.

In 2018, Professor Jacinta Douglas and the Summer Foundation Research Team led by Dr Di Winkler continued their collaborative work with a number of active projects focussing on a wide range of issues, including; evaluation of tenant outcomes for people with disability living in new housing options, understanding the NDIS from the perspective of people with disability and complex needs, development and evaluation of participant led videos to train support workers and evaluation of support, technology and built design in housing for people with disability and complex needs. Two of our current projects are described briefly on the next page.

Development and evaluation of participant led videos to train support workers of people with severe acquired brain injury

Participant Led Videos (PLV) give people with disability the opportunity to self-direct the training of their support workers. The process of creating PLV includes supporting a person to think about and express their personal goals and translate them into constructive approaches to inform support workers about how the person wants to be supported. Throughout the process, the choices, thinking and where possible, the language, are that of the person with disability. This project set out to co-design, pilot and evaluate a process for producing PLV with people with acquired brain injury and cognitive and communication impairments. Qualitative and quantitative methods were used to document the experience and measure satisfaction from multiple perspectives: primary participants, close supporters and facilitators. Primary participants had severe ABI and high support needs.

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

Integrating housing for people with disability into mainstream housing provides the opportunity for young people with acquired brain injury and complex needs to live in the community with the support of services through the National Disability Insurance Scheme (NDIS). The aim of this project is to understand the individual experiences and outcomes of people who move into appropriately designed housing in the community. The project involves collection of information using interviews and questionnaires completed by people with acquired brain injury who move into new housing designed for people with disability.

Professor Jacinta Douglas
Summer Foundation Chair,
Living Well with Brain Injury

Research Programs

3 Enabling mainstream services to be more inclusive

This theme identifies strategies for making mainstream services more inclusive and responsive to the needs of people with cognitive disabilities.

Supporting the inclusion of people with cognitive disabilities in the health system

Previous reports suggest that the health system stands out as being unresponsive to the particular requirements of people with disabilities and their families as a consequence of their needs and circumstances being poorly understood within a healthcare context. We take people with cognitive disability (intellectual disability and traumatic brain injury) as the exemplar group of service users with disability. Their healthcare outcomes are poor and resource use is high. Key to redressing this problem is that staff and service delivery processes make the adjustments required to accommodate their needs.

This study, funded by the National Disability Research Agenda, has been conducted across three hospital systems from metropolitan and rural locations. Findings for 60 adults with cognitive disability show that they are high end users of Emergency Departments (with 179 encounters documented over a period of 35 months). There was no evidence of systematic problem practices; rather, hospital staff applied good practice and often made accommodations to meet the needs of this patient group. The findings indicated the longer than benchmark time of 4 hours required to provide quality care for people with cognitive disabilities in Emergency Departments.

The study also showed that when problems did occur, they often stemmed from a lack of collaboration between the health and disability sectors. There was also poor understanding about their respective roles together with family members in supporting hospital encounters for people with cognitive disabilities who found it difficult to express or explain their own needs.

The full report is available online together with a series of check lists for delivering high quality care for people with disabilities in hospital

View the report online:

http://bit.ly/LiDs-HospitalReport

Professor Teresa Iacono
La Trobe Rural Health School

Developing options to enable specialist schools to become "Centres of Expertise" to support inclusion in mainstream schools

This project resulted from the recent review of the Victorian Government's Program for Students with Disabilities. It addresses a recommendation that options be developed for how specialist schools can support inclusive mainstream education. Funding for this project was awarded by the Victorian Principals' Association of Specialist Schools. The project brought together researchers from across the Living with Disability Research Centre and La Trobe Rural Health School (Teresa Iacono, Amanda Kenny and Carol McKinstry), and the School of Education (Mary Keeffe). A forum was used as a key mechanism to develop options, which were informed by policy and research literature reviews and interviews with 20 stakeholders from across specialist and mainstream school communities. The options were then prioritised for preference and acceptability through a survey of specialist and mainstream schools and were included in a report to the Department of Education and Training.

View the report online:

http://bit.ly/LiDs-SchoolReport18

Co-designing online modules to strengthen inclusive educational supports for children with disability though collaboration with allied health

This project was funded by an Information, Linkages, and Capacity building (ILC) Readiness grant (2017). It brings together allied health (Teresa Iacono, Carol McKinstry, Nerida Hyett, Oriane Landry, Kerryn Bagley) and education (Mary Keeffe) researchers, in partnership with mainstream and special education schools, and an allied health practice in Bendigo. A co-design group comprising parents of children with disability, education staff, and allied health practitioners developed the content for an online package to support the development of reasonable adjustments within mainstream schools to support the inclusion of students with disability. The package demonstrates how these supports can maintain a child-focus, while meeting requirements under the NDIS and The Program for Students with Disability funding.

View the resource online:

http://fea-inclusiveschools.org.au

Building healthy communities with the Social Model of Disability: a randomized controlled trial of shifting perceptions to enhance inclusive school education

This project has been funded by a Building Healthy Communities Research Focus Area grant (2018-2019). Building on their previous work, the team comprises Teresa Iacono, Nerida Hyett, Jo Spong, Kerryn Bagley (La Trobe Rural Health School), Oriane Landry (Psychology) and Michael Arthur-Kelly (University of Newcastle). The team is developing 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 disability.

Research Translation & Resources for Practice

The Living with Disability Research Centre has produced three sets of training resources designed for direct support workers and front line practice leaders. These free online resources are used widely across the disabilty sector.

Risk Enablement Training and Resources

This new resource, launched in late 2018, was developed for disability support workers. Enabling people to take risks is an integral part of disability support work. It is also important that practice leaders, frontline managers, 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.

www.enablingriskresource.com.au

PAGEVIEWS
13,050
Since May 2018

Person-centred Active Support: Every Moment has Potential

This resource provides an introduction to Person Centred Active Support - a way of working that enables everyone, no matter what their level of intellectual or physical disability, to make choices and participate in meaningful activities and social relationships. This resource was developed specifically for disability support staff.

www.activesupportresource.net.au

PAGEVIEWS
135.5k
During 2018

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.

http://supportinginclusion.weebly.com

PAGEVIEWS
15,594
During 2018

Front-line Practice Leadership

Front-line Practice Leadership is an online learning program for front-line managers and other staff responsible for guiding the practice of disability support workers. All support workers need to receive good Front-line 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 Front-line Practice Leadership. It covers topics such as the purpose of Front-line Practice Leadership, the five tasks of Front-line Practice Leadership, the skills needed to be a good Front-line Practice Leader and how Front-line Practice Leadership should be organised.

The La Trobe Support for Decision Making Practice Framework

This resource is designed for supporters, including: frontline managers, disability support workers, team leaders, clinicians, guardians, friends, spouses, parents and other family members.

Decision making is a fundamental human right. For people with cognitive disabilities, particularly people with severe and profound disabilities, decisions are often made for them by others, on their behalf. This online resource will demonstrate how to apply the Latrobe Support for Decision Making Practice Framework when supporting a person with cognitive disability to make or participate in decisions that affect their life.

Administrative Appeals Tribunal (AAT) Quarterly Digest

This digest is prepared by the Living with Disability Research Centre. It summarises a selection of Administrative Appeals Tribunal (AAT) decisions about the NDIS published in the preceding three months and highlights overarching themes.

By drawing out the implications of AAT decisions and interpreting the provisions of the scheme, the digest will help 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.

View the digest online:

https://www.latrobe.edu.au/lids/resources/aat-ndis-decision-digest

Notable Achievements

Henry Stonnington Award for Best Review Article published in Brain Injury in 2018

In recognition of Brain Injury's Founding Editor, Henry Stonnington, the journal gives two annual awards for the best review articles published. Our Centre's researchers Professor Jacinta Douglas and Dr Lucy Knox received the Henry Stonnington Award in 2018 for their article: 'A scoping review of the nature and outcomes of extended rehabilitation programs after very severe brain injury', *Brain Injury*, 32(8). For those of you familiar with brain injury research, Jacinta and Lucy join an impressive group of previous winners including Mark Ylvisker, Roger Wood, Robert Teasell, Mathilde Chevignard and Erin Bigler.

2018 Best Australasian Article published in the Journal of Intellectual and Developmental Disability

Professor Christine Bigby, Dr Emma Bould & Professor Julie Beadle-Brown were awarded the 2018 prize for the article: 'Conundrums of supported living: the experiences of people with intellectual disability'. *Journal of Intellectual and Developmental Disability* 42(4).

This is the third time that Christine Bigby has won this prize. In 1992 she won the prize for the paper: 'Access and linkage: Two critical issues for older people with an intellectual disability in utilising day activity and leisure services' 18(2), and in 2010 with 'Reflections on doing inclusive research in the 'Making Life Good in the Community' study' 35(2).

View the award winning paper online:

http://bit.ly/LiDs-Conundrums

ARC College of Experts appointment

In 2018, Professor Christine Bigby served as a member on one of the Research Evaluation Committees for the Excellence in Research for Australia assessment conducted by the ARC. She was also appointed as a member of the ARC College of Experts in November 2018.

New Courses

During 2018 our research and practice knowledge was used to develop a new suite of disability practice courses to be offered for the first time in 2019

The courses are designed to be flexible and offered in a fully online mode. They are taught by the leading researchers from the Centre, ensuring relevant and current knowledge of trends in the sector. They cater to the diverse range professionals who are currently involved in or entering the disability sector and offer contemporary knowledge and skills, to enhance professional practice

The table below shows the different paths to a Graduate Certificate, Graduate Diploma or a Master of Disability Practice. For specific information about each subject, visit the website: **www.latrobe.edu.au/courses/disability**

Study online at a time that suits you. Enrol in 1, 4, 8 or 11 subjects in Disability Practice. Flexible full time, part time or single subject options are available.

Featured Academics: L to R: Sian Anderson, Pam Kappelides, Suzane Vassallo, Nicholas Barry, Tal Araten-Bergman, Lucy Knox, Teresa Iacono, Christine Bigby, David Henderson.

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	Semester 2	Research Thesis

Entry & 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.

During 2019 the Centre will be offering monthly seminars, short courses and master classes to interested staff and students across the sector which will complement these courses.

Find out more online: www.latrobe.edu.au/courses/disability or call 03 9479 3826

Research Centre Seminar Series

During 2018, nine seminars were held with invited guests as well as higher degree by research students and staff from the Living with Disability Research Centre. The seminars covered a broad range of disability research from storytelling, to law and eugenics. For the first time, the seminars were opened to a wider audience and through remote access they are now available to practitioners, advocates and managers across the disability sector.

	PRESENTERS	TOPIC
FEB	Dr Piers Gooding	19 Stories of social inclusion: Lessons from the lives of everyday Australians on belonging, disability and community contribution
MAR	Dr Hilary Johnson	Speaking up and being safe: Providing a safety net
	Prof. Magnus Tideman	Disability support and research in Australia: Through the eyes of a Swedish observer
APR	Dr Anoo Bhopti	Research on 'family quality of life when there is a child with disability'
	Prof. Teresa Iacono	Strengthening mainstream school capacity to support students with disability
MAY	Rahlia Christian	Access to dental services for children with intellectual and developmental disabilities
	Dr Caroline Ellis-Hill	Exploring a lifeworld approach to working with people with acquired disability
JUN	Prof. Robert A. Wilson	Eugenics and disability
	Dr Natalie Araujo, Dr Pam Kappelides & Associate Professor Tonya Stebbins	Research on information accessibility, CALD communities, and the NDIS
AUG	Prof. Nora Shields	Increasing participation in exercise among youth with disability
	Dr Pam Kappelides	Barriers and facilitators of sport participation for people with disabilities from culturally and linguistically diverse (CALD) backgrounds
SEP	Jasvinder Sekhorn	A review of counseling training to enable speech-language pathologists to address the psychological wellbeing of people affected by post-stroke aphasia
	Claire Quilliam	Understanding how staff use paperwork in group homes for people with intellectual disability
OCT	Dr Amanda Pagan	Local Area Coordination (LAC), planning and where the community fits in
	Dr Darren O'Donovan	An update on NDIS appeals decided by the Administrative Appeals Tribunal (AAT)
	Prof. Jan Tøssebro	Delivering intensive support services to people with disability and complex support needs in Norway: findings from a recent study
DEC	Prof. Christine Bigby	Organisational structures and processes associated with the successful implementation of Active Support
	Prof. Lisa Brophy	Efforts to reduce coercive practice in mental health service delivery in Victoria

Events

The NDIS 5 Years on

La Trobe's Bold Thinking events throughout 2018 challenged the audience to broaden their minds and do as the title suggests – think boldly. The first event of the year was titled the NDIS 5 Years On and featured Professor Christine Bigby. A panel of experts explored what is working and what is failing with the marketisation, individualisation and insurance principles that underpin the NDIS. What has the NDIS meant for the people the system has been set up to support? Is life any better for them? Is the system actually delivering on the ambitious targets set by policy makers and politicians?

The panel was chaired by broadcaster, journalist and writer Francis Leach. Joining Professor Bigby on the panel were Dr Jane Tracy, Director for the Centre for Developmental Disability Health Victoria (CDDH), Monash Health and an external member of the Living with Disability Research Centre at La Trobe, Dr Lisa Chaffey, paralympian, elite athlete, academic and occupational therapist and Rick Morton, the social affairs writer at *The Australian* who more than any other journalist has monitored the implementation of the NDIS.

This event was live streamed and the recording is available on the Living with Disability Research Centre website:

http://bit.ly/LiDs-Videos

Panel speakers at the State Library for La Trobe's Bold Thinking events series

La Trobe University Research Week, 2018

The Showcase held on 28 August 2018, took 'Research Impact' as its theme. Staff from the Living with Disability Research Centre displayed 5 posters demonstrating the industry engagement and impact of our research programs. The program of research about Active Support and Practice Leadership was also featured.

Professor Christine Bigby was joined by two of our industry partners, Scott Sheppard, House with No Steps and Cathy Gauci, Unisson Disability Services. Christine talked about the annual review of practice quality for organisations conducted as part of the research and the value of independent observations of practice. She presented some key findings from the study, which demonstrate the significance of training in Active Support and strong Front-line Practice Leadership to the quality of practice of staff in group homes.

Industry partners Scott and Cathy talked about the way their organisations had used the research findings to drive changes to the management of group homes. They also highlighted the value of the open-access on-line learning materials developed by the research team that have significantly improved access of training about Active Support for staff across the disability sector.

Watch the video online:

http://bit.ly/LiDs-Videos

Annual Conference of the Australasian Society for Intellectual Disability – November 2018, Queensland

The annual ASID conference is a valuable chance to share research from the Living with Disability Research Centre with other academics, staff from the disability sector, families and people with intellectual disabilities. Seven staff from the Centre presented papers (details on page 32).

Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, May 2018, Adelaide

Professor Jacinta Douglas gave the 2018 ASSBI Presidential Address. She spoke on, 'The things that help, the things that get in the way': Working together to improve outcome following acquired brain injury. She and other researchers and PhD students from the Centre presented posters and papers during the conference.

Summary of LiDs research, given to all attendees at the ASSID conference

Higher Degree by Research Graduations

Lincoln Humphreys PhD

Does organisational culture matter in group homes for people with intellectual disabilities?

This thesis examined organisational culture in group homes for people with intellectual disabilities. A quantitative measure of group home culture was developed, named the Group Home Culture Scale. Using this measure, associations between dimensions of group home culture and residents' quality of life outcomes were examined. The results showed that some dimensions were associated with certain quality of life outcomes.

http://bit.ly/LiDs-CultureScale

William Crisp PhD

"She proudly announced she has a boyfriend from her day placement and wants him to sleep over": the grounded theory of the process of guiding self-determination

Dr Crisp's study investigated the way parents and their like-minded allies supported people with intellectual disabilities to be self-determined. He developed the concept of guided self-determination which details the significance of relationships in building a good life.

http://bit.ly/LiDs-SelfDetermine

Michelle Browning PhD

Developing an understanding of supported decision-making practice in canada: the experiences of people with intellectual disabilities and their supporters

Dr Browning explored how people with intellectual disabilities were supported with their decision making in the context of two legal mechanisms that allow for supported decision making in Canada. The highly individualised, contextually dependent process she discovered has implications for the development of supported decision-making legislation, policy and practice.

http://bit.ly/LiDs-DecisionCA

Michelle Attard PhD

The efficacy of an interdisciplinary community aphasia group model for living well with aphasia

The aim of Dr Attard's thesis was to determine the efficacy of an interdisciplinary community aphasia group model for living well with aphasia. A comprehensive 12-week program was tested with four people with aphasia and their spouses. Quantitative and qualitative results reflected positive outcomes for members with aphasia. The members and staff perceived the interdisciplinary facilitation to be important, with the program considered to be acceptable and of value overall. The thesis contributes to our understanding of the way in which community aphasia group quality may be conceptualised and realised to best address consumers' needs.

http://bit.ly/LiDs-AphasiaGroup

Melanie Drummond PhD

Olfactory impairment following traumatic brain injury; the incidence, recovery and consequences over time

Dr Drummond's thesis presents the rationale and findings of a consecutive admission longitudinal study which set out to investigate the incidence, recovery and predictive factors of outcome relating to Olfactory Impairment (OI) following Traumatic Brain Injury (TBI). Results found that OI occurred in 66% of all individuals following TBI and was an enduring problem with a significant impact on family life. Clinical recommendations for rehabilitation professionals have been developed.

http://bit.ly/LiDs-Olfactory

Barbara Wolfenden PhD

Measurement of activity participation and related factors in younger stroke survivors aged 18-64 years

Dr Wolfenden examined participation in everyday activities of working-aged stroke survivors. Activity areas included social and educational, household, and leisure. Work and child caring were also included. At 12 months post-stroke, younger survivors retained more activities than older survivors. Survivors' activity increased with younger age, increasing autonomy, improving ability to participate in work and social adjustment, and physical function.

A bi-directional recovery model addressing themes of Coping, Environment, and Challenges was developed.

http://bit.ly/LiDs-StrokeActivity

Danielle Ashley MAOT

Time use and occupational engagement of adults with intellectual disability in supported living

Ms Ashley explored the time use and occupational engagement of people with intellectual disabilities in supported living and their perceptions of engagement in daily occupations. This study suggested that being under occupied and living in home environments with limited occupational demands characterise the lives of people with intellectual disability in supported living. Individualised support addressing the occupational needs of people with intellectual disabilities could improve their engagement in valued occupations. Occupational Therapists could have a consultative role in building the capacity of support workers to enable occupational engagement.

Dr Michelle Browning with Professor Christine Bigby at La Trobe's graduation ceremony

Dr William Crisp (left) and Dr Lincoln Huphreys (right) at La Trobe's graduation ceremony

Funded Projects

New in 2018

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

Bigby, C., Bould, E., **Using person centred active support in the community;** E W Tipping Foundation

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

Bigby, C. **Quality support in supported accommodation;** Yooralla, Annecto, House with No Steps, Identitywa, GenU, Unisson Disability, Jewish Care

Kappelides, P. **Be prepared: Sport and active recreation resource kit for staff and volunteers;** Victorian Department of Health and Human Services

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;** House with No Steps

Bigby, C., Douglas, J. **Network and assistance services icare project: Evaluation;** St Vincent de Paul Society

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

Douglas, J.,Bigby, C. **Contemporary disability practice: ongoing horizon scanning program;** Transport Accident Commission

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

Projects continuing from 2017

Bigby, C. **Embedding active support and practice leadership in supported accommodation services;** ARC Linkage grant and additional Industry partners

Bigby, C. **Research to action guides;** National Disability Services

Bigby, C., Douglas, J. **Training in support for decision making training for ability linkers and building capacity to undertake future training within St Vincent de Paul Society NSW;** St Vincent de Paul Society

Bigby, C., Douglas, J., **Delivering and monitoring the impact of training local area coordinators in support for decision making and building the capacity of St Vincent de Paul Society;** St Vincent de Paul Society

Wells, Y., Bould, E., Teshuva, K. **Evaluation of hand-in-hand model of residential aged care;** Jewish Care

Bigby, C., Henderson, D., Araten-Bergman, T. **Models for forming and supporting circles of support for people with intellectual disabilities;** Inclusion Melbourne

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.

Duff, G., Bigby, C. **Models for facilitating community participation of adults with cognitive impairment; National Disability Research and Development grants.**

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

Bigby, C., Douglas, J. **Effective decision making support for people with cognitive disability;** ARC Linkage Projects

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

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

Bigby, C., Douglas, J. **Supporting decision making resources for community workers and peer to peer programs;** St Vincent de Paul Society

Tilbury, C., Bigby, C., Hughes, M., Fisher, M. **The production, use and effect of social work research;** ARC Discovery

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.

Publications

Refereed Journal Articles

Barry, S., Knox, L., & Douglas, J. M. (2018). **"Time's up": The experience of entering residential aged care for young people with acquired neurological disorders and their families. Brain Impairment.** www.doi.org/10.1017/BrImp.2018.13

Beadle-Brown, J., Wilkinson, D., Richardson, L., Shaughnessy, N., Trimingham, M., Leigh, J., . . . Himmerich, J. (2018). **Imagining autism: Feasibility of a drama-based intervention on the social, communicative and imaginative behaviour of children with autism.** Autism, 22(8), 915-927. www.doi.org/10.1177/1362361317710797

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Chaffey, L., & Bigby, C. (2018). **'I feel free': The experience of a peer education program with Fijians with spinal cord injury.** Journal of Developmental and Physical Disabilities, 30(2), 175-188. www.doi.org/10.1007/s10882-017-9578-5

Chaffey, L., & Bigby, C. (2018). **Health education by peers with spinal cord injury: A scoping review.** Journal of Developmental and Physical Disabilities, 30(1), 141-154. www.doi.org/10.1007/s10882-017-9569-6

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Reports

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Presentations

Keynotes and invited presentations

Bigby, C. (2018). **What does research say about diagnosing and supporting people with Down syndrome and Alzheimer's disease.** Down Syndrome Victoria, invited presentation.

Bigby, C. (2018, April). **What makes a good group home.** ASID and NDS, One day seminar series, Hobart and Perth.

Bigby, C. (2018, February). **Using research evidence to identify and measure quality in supported accommodation services.** Delivering quality in the NDIS, Criterion conference, Sydney.

Bigby, C., Tilbury, C., Hughes, M. (2018, September). **Advancing social work research: Pathways to impact.** ANZSWWER, national conference, Adelaide.

Douglas, J. (2018, May). ASSBI Presidential Address: Prof Jacinta Douglas, **'The things that help, the things that get in the way': Working together to improve outcome following acquired brain injury.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Douglas, J. (2018, September). **Rehabilitation of cognitive-communication problems: Getting on with living.** International Symposium in Cognitive-communication Disorders, London, United Kingdom.

Douglas, J. (2018, July). **Understanding friendship following severe traumatic brain injury: A mixed methods study.** International Neuropsychological Society, Mid-Year Meeting, Prague, Czech Republic

Selected other presentations

Bigby, C. (2018, November). **Quality of staff support in group homes.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Beadle-Brown, J., Bradshaw, J., Bigby, C., Richardson, L. (2018, July). **Understanding the culture of supported accommodation services: Staff views.** Fifth International IASSIDD Europe Congress.

Bigby, C., Anderson, S. (2018, July). **Creating and supporting convivial encounters as a means of community participation for people with intellectual disabilities.** Fifth International IASSIDD Europe Congress.

Bigby, C., Anderson, S. (2018, November). **Reframing day programs: Supporting convivial encounters for people with severe intellectual disabilities as a means of social inclusion.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Bigby, C., Bould, E., Iacono, T., Beadle-Brown, J. (2018, November). **Organisational structures and processes associated with the successful implementation of active support.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Bigby, C., Douglas, J. (2018, July). **Developing an evidence-based practice framework to guide support for decision making.** Fifth International IASSIDD Europe Congress.

Bigby, C., Wiesel, I., Bredewold, F. (2018, July). **Encounters as a means of social inclusion.** Fifth International IASSIDD Europe Congress.

Bould, E., Bigby, C., Bennett, C., Howell, T. (2018, July). **Demonstrating the potential of dogs to facilitate social encounters for people with intellectual disabilities.** Fifth International IASSIDD Europe Congress.

Bould, E., Bigby, C., Iacono, T., Beadle-Brown, J. (2018, November). **Factors that support and sustain good active support over time in shared supported accommodation services.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Bradshaw, J., Beadle-Brown, J., Bigby, C., Richardson, L., Whelton, B. (2018, July). **Dimensions of support: Can we get the best of both worlds?** Fifth International IASSIDD Europe Congress.

D'Cruz, K., Douglas, J., Serry, T. (2018, May). **Narrative storytelling: A collaborative therapeutic relationship.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Douglas, J. (2018, July). **Olfactory impairment following traumatic brain injury: Consequences for everyday life.** Oral and Poster presentation given at the 15th Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (WNFR), Prague, Czech Republic.

Douglas, J., Knox, L. (2018, May). **Using an evidence-based practice framework to guide support for decision making of adults with acquired cognitive and communication disability.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Douglas, J., Knox, L. (2018, July). **"It's not our job to hold people back": Strategies to support decision-making participation after acquired brain injury.** Oral and Poster presentation given at the 15th Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (WNFR), Prague, Czech Republic.

Drummond, M., Douglas, Douglas, J., Olver, J. (2018, May). **New findings in olfactory impairment following traumatic brain injury.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Drummond, M., Douglas, J., Olver, J. (2018, July). **Olfactory impairment following traumatic brain injury: Consequences for everyday life.** Oral and Poster presentation given at the 15th Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (WNFR), Prague, Czech Republic.

Humphreys, L., Bigby, C., Iacono, T., Bould, E. (2018, November). **Dimensions of group home culture as predictors of quality of staff support.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Iacono, T. (2018, July). **A scoping review of research into supporting educational inclusion for children using AAC.** International Association of Augmentative and Alternative Communication Conference, Gold Coast.

Iacono, T., Hyett, N., Bagley, K., McKinstry, C., Keeffe, M., Landry, O. (2018, July). **Co-designing on-line modules to strengthen the capacity of mainstream schools to support students with disability.** Fifth International IASSIDD Europe Congress.

Iacono, T., Keeffe, M., McKinstry, C., Kenny, A., Wilson, E., Landry, O. (2018, July). **The potential role of special schools in supporting inclusive education for students with disabilities.** Fifth International IASSIDD Europe Congress: Journal of Applied Research in Intellectual Disabilities.

Johnson, H., Burn, G., Lyon, K. (2018, November). **Creating communication accessibility for people with intellectual and communication disabilities within Victoria Police services.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Knox, L. (2018, July). **"It's not our job to hold people back": Strategies to support decision-making participation after acquired brain injury (Datablitz).** Oral and Poster presentation given at the 15th Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (WNFR), Prague, Czech Republic.

Knox, L., Barry, S., Douglas, J. (2018, May). **"It was worse than being in jail": The experience of living in residential aged care for young people with acquired neurological conditions.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Logan, K., Iacono, T., & Trembath, D. (2018, July). **Aided enhanced milieu teaching to develop use of varied communication functions in children with ASD who use AAC.** International Association of Augmentative and Alternative Communication Conference, Gold Coast.

Presentations

McVilly, K., Anderson, J., Koritsas, S., Johnson, H., Wiese, M., Stancliffe, R. (2018, July). **Accessible written information resources for adults with intellectual disability: compiling the evidence to inform good practice.** Fifth International IASSIDD Europe Congress.

Mealings, M., Douglas, J., Olver, J. (2018, May). **'I think part of going through the accident is, the challenge to your own identity': Thoughts about identity arising from students' participation in education following TBI.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Moorhouse, B., Mainprize, E., Douglas, J., Fisher, C. (2018, May). **Impact of group art therapy on an individual with complex communicative, cognitive and behavioural needs following acquired brain Injury.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Richardson, L., Turnpenny, A., Whelton, B., Beadle-Brown, J. (2018, July). **Care managers' use of quality information to promote choice in decision making about services for people with intellectual and developmental disabilities.** Fifth International IASSIDD Europe Congress.

Šarkić, B., Douglas, J., Simpson, A. (2018, May). **Peripheral auditory dysfunction secondary to traumatic brain injury: A systematic review of literature.** Presentation given at the 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Siska, J., Beadle-Brown, J., Kanova, S. (2018, July). **Active citizenship through community living: The experience of people with intellectual disabilities.** Fifth International IASSIDD Europe Congress.

Symmons, M., Douglas, J., Winkler, D. (2018, May). **Avoiding unnecessary discharge to residential aged care: The case for a holistic community based bridging solution for young adults with complex disability.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Tipping, S., Bigby, C., Douglas, J. (2018, November). **Australian democracy and the perceptions and experiences of voting by people with intellectual disabilities.** Annual conference of the Australasian Association for Intellectual Disability, Gold Coast, Australia.

Vassallo, S., & Douglas, J. (2018, May). **Variability in visual dysfunction following severe traumatic brain injury (TBI): Consideration of compensatory approaches.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Vassallo, S., Douglas, J. (2018, July). **Re-positioning the visual scan path to emotional facial expressions following severe traumatic brain injury: Evaluation of a training intervention using a single case experimental design.** Oral and Poster presentation given at the 15th Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (WNFR), Prague, Czech Republic.

Williams, L., Douglas, J., Serry, T. (2018, May). **Getting on the same wavelength: Clinicians' perspectives of the therapeutic alliance in community brain injury rehabilitation.** 41st Annual Conference of the Australian Society for the Study of Brain Injury and Brain Impairment, Adelaide.

Media

Researchers from the Centre featured in various media in 2018

Professor Christine Bigby contributed to an article in **The Conversation** titled How the NDIS will impact our cities (May 7, 2018).

Professor Christine Bigby appeared as part of a panel on **ABC TV – Matter of Fact** with Stan Grant (May 3, 2018).

Professor Christine Bigby appeared on **ABC Radio National Life Matters** discussing the progress of the NDIS (March 27, 2018).

Sophia Tipping was interviewed by **the Sunraysia Daily** after visiting Mildura for the Voting project (October 2, 2018).

Professor Jacinta Douglas contributed to the article 'Time's Up: Issues Faced by Young People in Residential Aged Care' in **Pro Bono Australia** (October 30, 2018).

Professor Christine Bigby and Dr Lisa Chaffey on ABC TV Matter of Fact with Stan Grant

Our Reports in Detail

Developing and maintaining person centred active support: a demonstration project in supported accommodation for people with neurotrauma

This project explored the introduction of Active Support in supported accommodation services for people with neurotrauma. Three supported accommodation services in metropolitan Melbourne for people with neurotrauma participated in the study. Mixed methods were used to collect data about staff practice and service user outcomes before and after staff were trained in Active Support, and perceptions about Active Support. Some good examples of Active Support were found. There was strong support for its use from staff, managers, service users and families, who felt Active Support encouraged service users to do many more things for themselves and for staff to interfere less. The study demonstrated the viability of Active Support as a preferred practice for front line staff in services for people with neurotrauma. It identified the need for:

- adaptation training materials to illustrate possibilities of Active Support for people with neurotrauma;
- leadership by senior and front line managers to reinforce and reward changed practice;
- class room training and hands on mentoring for all direct support and front line managers;
- strengthening of practice leadership (coaching, modelling, team work, supervision and focus on direct practice) by front-line managers;
- involvement of the Allied Health professionals who form part of the support team for each individual in the service.

www.bit.ly/LiDs-NeuroRpt

Overview of literature about enabling risk for people with cognitive disabilities in the context of disability support services

This report summaries a review of the peer reviewed and grey literature on risk and the practice of front-line staff in supporting service users with cognitive disability. Consistent themes about risk are; risk forms a key part of supporting decision making; risk is often perceived negatively; perceptions of risk are subjective; risks are contextually situated and dynamic; rule based or procedural approaches can be restrictive; support workers often fear blame and retribution doubting that organisations will support risk taking when outcomes do result in harm; organisational approaches to risk may not be coherent, as imperatives to avoid risk to reputation may not align with positive risk taking for service users.

There was consensus that risk enablement processes should be person centred - reflective of individuals' wishes, their context, the particular circumstances of the risk, and minimise any changes to the preferred action. This suggests it is preferable for staff to have a set of principles as a reference point to inform their judgements rather than prescriptive procedures. The use of such principles can help to identify what is important in a specific decision, the process of weighing up positive and negatives of the risk, and in finding ways to enable choice without imposing restrictions. As well as being person centred, the literature suggests that risk enablement plans should be collaborative.

An outcome of this review was the development of the online Enabling Risk resources to guide disability support worker practice and the inclusion on a risk enablement approach into the LaTrobe Support for Decision Making Practice Framework.

www.bit.ly/LiDs-RiskLit

Raising the voices of people with intellectual disabilities and changing systems: the contribution of the NSW Council for Intellectual Disability to social change

The NSW Council for Intellectual Disability (CID) leads advocacy to ensure the NDIS, mainstream services and the broader community take account of the lived experiences and issues unique to people with intellectual disabilities. This study explored CID's approach to systemic advocacy and the value of its work, using key informant interviews and document review. The findings detailed in the report capture the outstanding reputation of CID among senior government and service personnel and its contribution to lasting social change for people with intellectual disabilities. This is an organisation that models inclusion of people with intellectual disabilities in everything it does. CID has driven a NSW state and, to some extent, a national agenda to ensure issues specific to people with intellectual disabilities are not ignored. The researchers concluded that if this organisation were to fold, governments would lose an organisation that has held them to account and also a critical and effective means of involving people with intellectual disabilities in service design. Governments would therefore lose a key way of understanding whether policy intentions and service design reflected needs on the ground. As one national policy leader said of CID, 'we need organisations that are … looking at the big-picture outcomes. We need them'.

www.bit.ly/LiDs-NSWCIDRpt

Enabling mainstream systems to be more inclusive and responsive to people with disabilities: hospital encounters of adults with cognitive disabilities

The aim of this study was to provide evidence about the processes and practices that enable hospital services to identify and respond to the particular needs of people with cognitive disabilities as a matter of course. Mixed methods were used to understand the hospital journeys of 60 people with cognitive disabilities, through their own eyes and those of family, and staff from disability services and the hospitals. Three hospital networks were involved. The research identified many promising pratices by staff to adjust the needs of people with cognitive disabilities, but these often went unrecognized and were not included in a system wide approach. Both the support needs of people with cognitive disabilities and the information needs of hospital staff were best met when health care practices were underpinned by a positive attitude towards collaboration between hospital staff members, the person with cognitive disability and family members, and disability support workers who knew them well and accompanied them during the hospital encounter. A lack of reciprocal knowledge across the hospital and disability systems acted as a barrier or could be seen to have a negative influence throughout the hospital experience having an effect on the ease of collaboration, the flow of information, the provision of support, and ultimately the outcome of the hospital encounter for the person.

http://hdl.handle.net/1959.9/563685

Hospital discharge planning for young people with complex disability: literature review

This review sought to explore the current evidence base for hospital discharge planning for young adults (aged 18-64) with disability and complex support needs. Successful discharge planning for this group is complex and requires effective cooperation between health and disability services. Based on the findings of this review, suggestions were made for change, including both a set of guiding design principles and a complementary set of specific recommendations about possible discharge planning interventions. Through this work, the Summer Foundation plans to work in a partnership to create a multi-sectorial approach for hospital discharge planning, which will assist people with disability and their families to connect with the National Disability Insurance Scheme (NDIS), and improve health professionals' NDIS knowledge.

https://www.summerfoundation.org.au/resources/hospital-discharge-planning-literature-review/

Partners

The Living with Disability Research Centre works with a variety of funders, partners and other universities

- annecto Inc
- Australian Research Council
- Bayley House
- Brotherhood of St Laurence
- Civic Disabilities Services
- E W Tipping Foundation
- GenU
- House With No Steps
- Identitywa
- Inclusion Melbourne
- Jewish Care
- National Disability Insurance Agency - Community Inclusion Capacity Development (CICD) Program
- National Disability Research and Development grants. (joint State Commonwealth Initiative)
- National Disability Services
- National Institute for Health Research School for Social Care Research, UK
- NSW Trustee and Guardian
- 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
- St Vincent de Paul Society
- Summer Foundation
- The Public Advocate of Victoria
- The Public Advocate Queensland
- The Public Trustee of Queensland
- The University of Sydney
- Transport Accident Commission
- Unisson Disability Services
- University of Melbourne
- Victorian Electoral Commission
- Yooralla