



# Living with Disability

RESEARCH CENTRE



# ANNUAL REPORT 20 16

<b>HOW WE OPERATE</b>	<b>3</b>
<b>MESSAGE FROM THE DEPUTY VICE-CHANCELLOR</b>	
<b>RESEARCH</b>	<b>4</b>
<b>MESSAGE FROM THE DIRECTOR</b>	<b>5</b>
<b>OVERVIEW</b>	<b>6</b>
<b>PERSONNEL</b>	<b>8</b>
<b>RESEARCH ACTIVITIES</b>	<b>10</b>
<b>EVENTS</b>	<b>15</b>
<b>RESEARCH OUTPUTS AND IMPACT</b>	<b>19</b>

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Mission  
Vision  
Expertise  
Research and Translation  
Governance

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Academic Staff  
Research Fellows  
Adjuncts  
Research Officers  
La Trobe University Staff associated with LiDs  
Students

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

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Advanced Masterclass in Person Centred Active Support  
Annual Roundtable - Policy and Practice of Support for Decision making Workshop

Putting Rights into Practice: Political Citizenship for People with Intellectual

Slow Stream (Extended Rehabilitation Roundtable

LiDs Seminar Series

IASSIDD 15th World Congress 2016

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Funded Projects  
Publications  
Presentations  
Media

# HOW WE OPERATE

La Trobe University continues to provide the core funding for the Living with Disability (LiDs) Research Centre. Staff are either teaching and research academics or funded entirely from research grants.

The LiDs research partnership with 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.

LiDs partners with an evolving range of collaborators who work with us to design and implement research and (at times) provide funding. They are also important in helping LiDs to trial education and training packages developed through our research, as well as frequently assisting with dissemination of our findings to stakeholders to increase the impact of our research.

Our university collaborators come from across Australia including the University of Melbourne, the University of Queensland, University of Sydney, Queensland University of Technology and the University of New South Wales.

This report provides snapshots of some of our projects, impacts and successes. Below are some of the achievements made in collaboration with partners in 2016 which

include:

- A joint seminar with ASID and Inclusion Melbourne on political participation and people with intellectual disabilities
- The annual roundtable on supporting the decision making of people with cognitive disabilities
- Papers on support for decision making at the Australian Council of Guardianship Conference in November
- Joint roundtable on slow stream rehabilitation with the Summer Foundation
- Papers at two major international conferences held in Melbourne, one which focussed on people with Brain Injury and the other on people with Intellectual Disability
- Presentations and keynotes at national and international academic conferences, organisational AGM's and industry forums.
- Hosting international visitors, Jan Killeen, Churchill Fellow from Scotland and Professor Lauren Clark from The University of Utah

LiDs research is funded by national and international competitive grants from the ARC (Australian Research Council), NHMRC (National Health and Medical Research Council) and other industry or government funding bodies, including The UK School for Social Care Research, Department of Business Innovation, Epworth Health, Transport Accident Commission, James

McDonald Foundation, National Disability Research and Development Grants, Principals' Association of Specialist Schools Victoria Inc, NSW Family and Community Services, Institute for Safety, Compensation and Recovery Research, National Disability Services and Speech Pathology Australia.

## Who We Work With

Government (State and Commonwealth)

Industry - Disability Services

Mainstream services such as health, education and transport

Industry Peak or Advocacy Bodies

For a full list see page 27.

# MESSAGE FROM THE DEPUTY VICE- CHANCELLOR RESEARCH

As we look back on this second full year of the LiDs Research Centre we can agree that their research is ever more important, more valued and more relevant as Australia engages with the largest change to how disability funding operates in a generation.

The research centre has continued to deliver high-quality research and to translate that into real impact on our society. Just as La Trobe as a whole strives to do.

Some of the most exciting research in this area is being led by LiDs and looks at how we engage with the new National Disability Insurance Scheme, a multi-billion dollar system that will change the lives of hundreds of thousands of people. We are working closely with governments and disability services to provide evidence to inform the major changes that are happening in the disability sector and beyond.

The relevance of the research conducted by Professor Bigby and her LiDs team is reflected in their continued ability to attract significant grant funding with an income in 2016 totalling \$2.2 million including new grants to the value of \$1.7 million in 2016. This is matched by a similarly impressive record of scholarly outputs, including 69 separate journal articles during 2016.

Equally important are the strong links they forge with the disability industry, government departments, not-for-profits and peak bodies, an area of work that we are pleased to have seen increase during 2016.

The research output of the LiDs team continues to make a significant contribution to our university research standing, contributing to La Trobe having the highest ranking for Social Work research in Victoria and judged as being above world standard in the last Excellence in Research for Australia assessment.

LiDs is a strong partner and collaborator with our Research Focus Areas, (RFA's), helping us deliver research excellence in pursuit of our refreshed Future Ready strategy. The LiDs Research Centre continues to be a significant member of the Building Health Communities RFA, which brings together La Trobe's expertise in research that attacks disadvantage, builds health and wellbeing, and advocates access to high-quality systems and services. LiDs' work within the RFA has been a model for how we would like others to operate - receiving small internal grants that are leveraged into larger grants and industry engagement opportunities. With an interdisciplinary team that work across both Colleges of La Trobe University, it is no surprise that LiDs crosses RFA boundaries, bringing together research projects with relevance to Building Healthy Communities as well as Transforming Human Societies.



I hope you once again enjoy reading about the achievements of LiDs in 2016, and join me in celebrating their successes. I look forward to what is already in progress in 2017 and the contribution LiDs will continue to make to La Trobe University life and Australian society.

Deputy Vice Chancellor (Research)  
Professor Keith Nugent

# MESSAGE FROM THE DIRECTOR



2016 was a momentous year for people with cognitive disabilities as the roll out of the NDIS gathered pace across Australia. LiDs research and training materials are playing an important part in building the evidence base and skilled workforce needed by disability support services to deliver on the promise of the NDIS of not only more, but more effective services to improve the quality of life

## and community participation of people with disability.

In 2016 LiDs research continued to be funded by highly competitive grants from the ARC and NHMRC as well as key partnerships with Industry. The total value of all grants held at the end of 2016 was \$7,954,771 and total income for 2016 as \$2,122,340. In 2016, the value of new grants was \$1,704,317. The research undertaken by the centre is playing a major role in adding to knowledge particularly around support and services for people with cognitive disability with the publication of 69 articles in peer reviewed journals.

Increasingly our publications are being complemented by easier to access shorter reports, resources for practice and newsletter items. All of our published work is available in the La Trobe University research repository.

The Centre is helping to build the future capacity of disability research and practice through its PhD program, seminars and open events held with Industry partners. LiDs has also supported early and mid-career researchers to apply for internal funding to build their own research capacity. Dr Emma Bould, Dr Robyn O'Halloran and Dr David Henderson were all successful in RFA or School research grants.

Significantly the work of the 'little LiDs' group that focussed on supporting tertiary students with disability came to fruition with the publication of a series of articles and a webinar hosted by NCVET on what

works for students and staff. This has paved the way for a new strand of work on inclusive education led by Professor Iacono to complement existing strong programs in the effective design of disability services and evidence to support community participation led by Professors Bigby and Douglas.

Reflecting the revised strategic directions for La Trobe University, LiDs is increasingly becoming the partner of choice for disability service organisations, as our collaborations have expanded to include the St Vincent de Paul Society of NSW, IdentityWA and the Victorian Electoral Commission to name but a few.

This year our long-term collaboration with Professor Magus Tideman and Halmstad University in Sweden came to a good end with Professor Tideman's appointment to a position at La Trobe to lead the discipline of Social Work and to join LiDs. We were also very fortunate to welcome Dr Tal Araten-Bergman, a seasoned disability researcher from Israel who also took up a position with the discipline of Social Work.

I would like to thank all those who have made our research and impact possible. We look forward to building on our successes during 2017.

Director, Living with Disability  
Research Centre  
Professor Christine Bigby

# OVERVIEW

## Mission

Our mission remains to improve the social inclusion and participation of people with cognitive disability through research, education and knowledge transfer. We will improve the evidence base to facilitate the development of practices, programs and policies in order to enable participation of people with cognitive disability and promote their social inclusion.

## Vision

To be recognised as a national and international centre of excellence for research about the social inclusion and participation of people with cognitive disability and its translation to policy, practice, advocacy and social programs.

To continue to be the focal point for researchers in the area of social inclusion and participation of people with cognitive disability.

To be the recognised source of expertise in the translation of research about living with disability into policy and practice outcomes.

## Expertise

The LiDs Research Centre is one of the pre-eminent centres 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 quality research outcomes.

Importantly, it is extremely effective at research translation - that is, working with the disability sector, its people and organisations, to implement projects that are evidence-based, as well as including people with a disability in research.

## Research and Translation

People with disabilities and their families comprise one of the most disadvantaged and socially excluded groups in Australian society. Our purpose is to promote the social participation and inclusion of people living with disability.

Research activities are conducted across three broad themes.

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

As a result of our research, we aim to improve the effectiveness of health and community services for this disadvantaged group. We focus particularly on people with cognitive disabilities such as intellectual disability or acquired brain injury, but also people who have mental health problems, physical disabilities, aphasia or other language problems.





## Governance

LiDs activities are overseen by an Executive Committee comprising the Director (Professor Christine Bigby) and theme leaders, Professors Jacinta Douglas and Teresa Iacono. Each executive member heads a specific research theme of LiDs:

- Effectiveness of disability services;
- Building the evidence base for participation and inclusion; and
- Enabling mainstreams services to be inclusive.

### The LiDs 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; and,
- Receive and endorse the Annual Report of the Centre, and submitting it to the Academic Board through the PVC (College of SHE) and the Deputy Vice-Chancellor (Research).

### Current Advisory Committee Members are:

#### Internal members

- The Centre Director - Professor Christine Bigby
- Theme leaders - Professors Teresa Iacono and Jacinta Douglas
- The Pro Vice-Chancellor (Research) Nominee - Professor Russell Hoye
- The Pro Vice-Chancellor (College of SHE) Nominee - Professor Rob Pike
- University Members - Professors Patrick Keyzer and Katie Holmes
- Staff member of Centre - Dr Emma Bould (Research Fellow LiDS)

#### External members

(from organisations within the sector)

- Daniel Leighton - Brotherhood of St Laurence
- Dr Christine Fyffe - Consultant
- Dr Di Winkler - Summer Foundation
- Dr Gerry Naughtin - Mind Australia
- Dr Jane Tracy - Centre for Developmental Disability Health Victoria

# PERSONNEL

## Academic Staff



Professor Christine Bigby - Director



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



Professor Teresa Iacono - Rural and Regional Allied Health



Professor Julie Beadle Brown - LiDs and The Tizard Centre, University of Kent, England



Professor Magnus Tideman - Head of Social Work discipline and member of LiDs

## Research Fellows

- Dr Sian Anderson
- Dr Emma Bould
- Dr Nadine Cameron
- Dr Lisa Chaffey
- Dr Hilary Davis
- Dr David Henderson
- Dr Ruth Quibell
- Dr Elizabeth Smith
- Dr Jo Spong

- Dr Kristina Szönyi - Honorary Research Fellow
- Dr George Taleporos - Adjunct Senior Research Fellow
- Dr Jane Tracy - Adjunct Associate Professor
- Dr Di Winkler - Adjunct Associate Professor

## Research Officers

- Ms Emma Caruana
- Ms Caitlin Farmer
- Ms Belinda Green
- Ms Lisa Hamilton
- Mr Lincoln Humphreys
- Ms Emma Hunter
- Dr Lucy Knox
- Ms Bronwyn Lacey
- Ms Rosa Solá Molina
- Ms Claire Quilliam
- Ms Sophia Tipping
- Mr Andrew Westle
- Ms Erin Wilson

## Adjuncts

- Luke Bo'Sher - Adjunct Research Fellow
- Dr Jennifer Clegg - Adjunct Professor, University of Nottingham
- Dr Chris Fyffe - Adjunct Professor
- Dr Hilary Johnson - Adjunct Associate Professor
- Professor Ellie Fossey - Monash University
- Dr Natasha Layton - Honorary Research Fellow

**The LiDs Research Centre is proud to acknowledge our international partnerships with the University of Kent, England, Halmstad University, Malmö University and Karolinska Institute, Sweden.**



## La Trobe University Staff associated with LiDs

- Dr Tal Araten-Bergman – Social Work
- Professor Tim Bartram – Management
- Mrs Anoo Bhojti – Occupational Therapy
- Professor Leanne Carey – Occupational Therapy
- Dr Marcella Carragher - CCRE
- Dr Jillian Cavanagh - Management
- Ms Kate D’Cruz – Occupational Therapy
- Dr Michael Dillon –Prosthetics & Orthotics
- Dr Shane Erickson – Speech Pathology
- Dr Pam Kappelides – Sport & Tourism
- Dr Maureen Long – Social Work
- Dr Darren O’Donovan - Law
- Dr Robyn O’Halloran – Speech Pathology
- Dr Jodi Oakman – Public Health
- Dr Jennifer Oates – Speech Pathology
- Dr Miranda Rose – Speech Pathology
- Dr Tanya Serry – Speech Pathology
- Dr Andrea Simpson – Audiology
- Dr Ruth Stuckey – Public Health
- Dr Mary Whiteside – Social Work

## Students

- Riham Abdullah
- Danielle Ashley
- Michelle Attard
- Michelle Browning
- Christopher Bruce
- Michelle Caldwell
- Rahila Christian
- Michelle Cimoli
- William Crisp
- Kate D’Cruz
- Nastaran Doroud
- Melanie Drummond
- Gemma Duffield
- Maya Menahemi Falkov
- Kate Fitt
- Abby Foster
- Isobel Hubbard
- Lincoln Humphreys
- Susan Jackson
- Adam Kauchki
- Lucie Lanyon
- Yeptain Leung
- Kristy Logan
- Essie Low
- Claire Lynch
- Caitlin McDowell
- Jade McEwen
- Belinda Mclean
- Jenna MacNab
- Margaret Mealings
- Elspeth Mitchell
- Amy Muir
- Michaela Pascoe
- Elizabeth Pearson
- John Pierce
- Margaret Pozzebon
- Claire Quillam
- Karen Roberts
- Gail Ritchie
- Priscila Rocha
- Bojana Sarkic
- Jasvinder Sekhon
- Kristy Smith
- Kellie Stagg
- Sophia Tipping
- Russell Ullah
- Barbara Wolfendon
- Elizabeth Williams

# RESEARCH ACTIVITIES

The research of LiDs is broadly undertaken in three themes:

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

The work in these themes is necessarily complementary and overlapping, with projects often covering two themes.

The following pages present snapshots of some of our projects. A full listing of our current projects starts on page 25.

Professor Bigby continued to edit the journal **Research and Practice in Intellectual and Developmental Disabilities** during 2016, producing a virtual special issue on Supported Decision Making on the occasion of the 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.

## Effectiveness of disability services

Any service - government or non government - should be on a constant search for more effective service design and ways to improve quality. This is true for the disability sector as much as any other. With new operational and funding paradigms - such as the National Disability Insurance Scheme - it is particularly important that disability services operate effectively. Professor Christine Bigby leads the work in this theme which aims to create an evidence base on which disability services can be built and continue to grow. Working closely with people with a disability and disability services, researchers are investigating new models of services, such as supported living, new practices such as supported decision making, and how to improve outcomes in group homes through embedding active support and practice leadership.



Professor Christine Bigby - Research Theme Leader for Effectiveness of Disability Services



**Every  
moment  
has  
potential**

### **Embedding Active Support and Practice Leadership in supported accommodation services**

Person Centred Active Support is a way of working that enables everyone with intellectual disability to make choices and participate in meaningful activities and social relationships. Quality of life of people with intellectual disabilities improves if staff consistently practice active support.

Active support is hard to embed in services and LiDs research aims to find out what are the most important organisational factors to pay attention to. Our ARC funded study is the first longitudinal study of active support in Australia with 14 industry partners across all States.

We have demonstrated the importance of Practice Leadership to good active support and the significance of culture. PhD student Lincoln Humphreys is in the final stages of developing a measure of culture in group homes for use by organisations to assess culture.

After final data collection and analysis in 2017, our findings will provide a guide for organisations to improve the quality of staff practice.

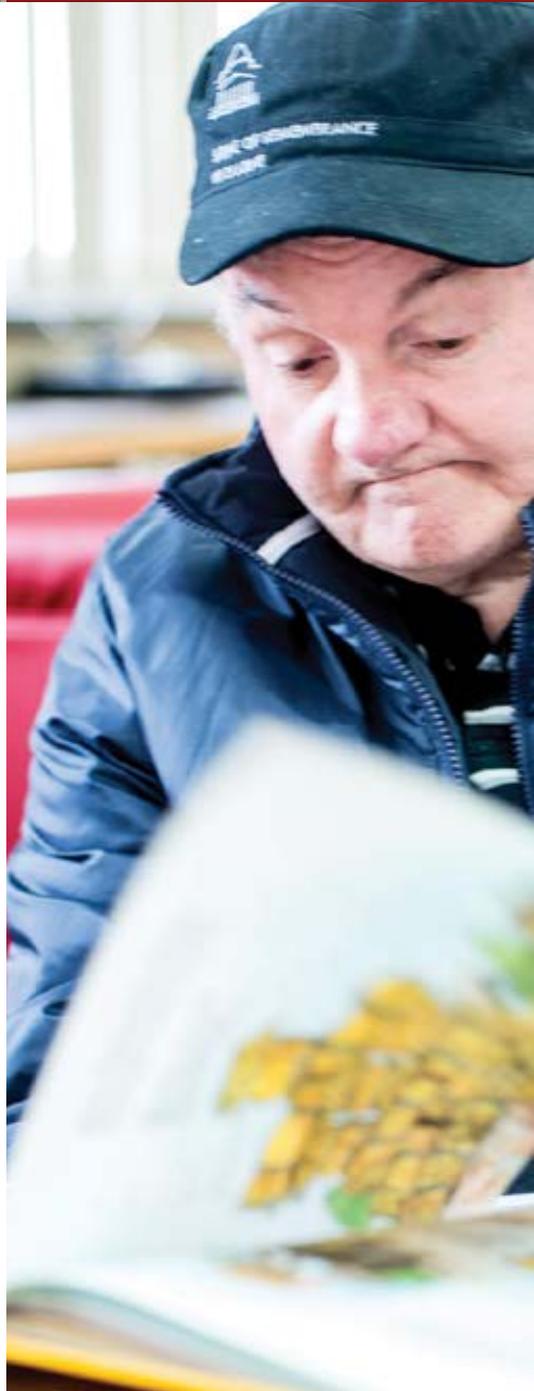
Interim findings are available ([www.bit.ly/CBigbyPapers](http://www.bit.ly/CBigbyPapers)) and we continue to provide training in active support and practice leadership to complement the online training resource 'Every Moment has Potential' produced in collaboration with Greystanes Disability Services ([www.activesupportresource.net.au](http://www.activesupportresource.net.au)).

### **Effective Decision Making Support for People with Cognitive Disability**

Ensuring that all people with cognitive disability have support for decision making that respects their will, preference and rights is fundamental to the NDIS.

This ARC Linkage project is testing evidence-based education resources that boost the ability of supporters of people with cognitive disability to put the supported person's own desires and values at the centre of decisions. The resources were developed from previous projects investigating support for decision making led by Professors Bigby and Douglas. They include a practice framework and illustrative film clips. These clips are tailored either to people with intellectual disability or those with acquired brain injury, made by professional actors working with people with cognitive disabilities.

We are investigating the impact of the resources on the practices of decision-making supporters and the person being supported. A randomised control trial (the most powerful type of research possible) is being conducted in three jurisdictions (NSW, QLD and VIC). The project involves 12 Industry partners as well as three researchers from other universities (Dr Shih-Ning Then, Queensland University of Technology; Emeritus Professor Terry Carney, University of Sydney; and Dr Ilan Wiesel, University of Melbourne).





## Building the evidence base for participation

Many people with a disability continue to be unnecessarily excluded from participating in wider society or activities that most of us take for granted. Led by Professor Jacinta Douglas, the projects in this theme make use of academic research to identify challenges, promising practices and strategies to facilitate participation and social inclusion of people with cognitive disability.



Professor Jacinta Douglas - Research Theme Leader for Building the evidence base for participation

## M-COMMConnect

**M-COMMConnect or Maximising Social Connection and Building Relationships in the Community: Evaluation of a Multicomponent Community Connection program for people with severe traumatic brain injury (TBI) is a research program whose focus is community connection amongst adults with TBI.**

This project aims 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. The improvements that result from this intervention program are expected to facilitate well-being and enhance community integration of individuals with severe brain injury, thus making a significant contribution to improving their long-term outcomes.

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 community involvement.

The project is funded by the Institute of Safety Compensation and Research Recovery (ISCR) and participants are currently being recruited for inclusion in the program.

## Understanding 'encounter' as a dimension of social inclusion for people with intellectual disability

This ARC Linkage project was a partnership between Professor Bigby, Dr Ilan Wiesel, Professor Julie Beadle Brown from the Tizard Centre at the University of Kent and the late Professor Jim Mansell. Industry partners were Jewish Care and Yooralla.

It has helped create new connections between urban geography and disability studies, with numerous potential research directions to explore.

People with intellectual disabilities are the largest group of disability service users and remain one of the most socially excluded groups in society. Enhancing the social inclusion of people with disability is a primary goal of the National Disability Strategy and the National Disability Insurance Scheme. By challenging existing concepts of 'community participation', and offering new more nuanced ideas about the meaning and forms of social inclusion, as well as the practical steps to achieve it, this study provided new knowledge and a more promising new direction towards the attainment of this goal. It has directly informed the study 'Models for facilitating community participation'.

Another exciting future research direction arising from this project is the expansion of the Active Support framework beyond the confines of people's homes, to engage more directly with the challenges of

# People with intellectual disabilities are the largest group of disability service users and remain one of the most socially excluded groups in society.

supporting people with intellectual disability in community settings. This study provides some of the foundations for this approach, through its publications and an online resource package 'Supporting Inclusion' designed for disability support workers. See the resources here: [www.bit.ly/LiDsInclusion](http://www.bit.ly/LiDsInclusion)

This work has been noticed by international researchers who are taking up its ideas in further studies and is having an impact on disability studies and urban geography.

## Models for facilitating community participation of adults with intellectual disability

**This study is a collaboration with NDS (National Disability Services) the peak industry body for disability services in Australia.** It aims to bring conceptual clarity to the diverse manifestations of community participation for people with cognitive disability. From an extensive review of the literature a typology of interventions to support community participation for people with intellectual disability has been developed and published. An assessment of the program models reported in the literature showed that little was known about the effectiveness or cost of these.

(<http://bit.ly/LiDsParticipationScoping>)

In the second stage of the study LiDs researchers have identified best practice programs for each of the three types of programs: 1) relationships building programs 2) programs that support

convivial encounters in community groups, volunteer settings or commercial places in the community, and 3) arts, sports or other cultural programs for people with intellectual disability that aim to build a sense of identity and belonging for their members. Case studies of each are underway that will identify the staff practices and organisational strategies that underpin successful programs for supporting community participation.

## Dogs as Catalyst for inclusion of people with intellectual disability in the community

**Building social relationships in the community is difficult for anyone, let alone for a person with an intellectual disability.**

There is little evidence about effective models to increase social relationships or enable people to connect with peers, places or activities in the community. With the heightened awareness of the importance of social relationships for health and wellbeing as well as for strengthening local communities investigating catalysts for these could not be timelier.

So we raised the question... What might be a catalyst for social interaction with others in the community for a person with an intellectual disability?

Our answer: Cute, adorable, friendly dogs.

The project which was conceived by Dr Emma Bould, received funding from the

Building Healthy Communities Research Focus Area has led to a new collaborative partnership with Dr Pauleen Bennett and Dr Tiffani Howell from the Anthrozoology Research Group, in Bendigo.

The study is piloting a visiting dog walking program for dog lovers with intellectual disability who for whatever reason do not have a dog of their own. It is run in collaboration with Righteous Pups Australia, a national NGO based in Bendigo. Each participant will take a dog for a walk in their local community over a 3 month period with a trained dog handler from Righteous Pups. The research will provide valuable information about the social connections that dog walking helps to facilitate for people with intellectual disability. If the concept works then it will be used to design a larger and more rigorous study.



**Jimmy and two human participants in the Catalyst for inclusion project.**

# Mainstream organisations will continue to provide the vast majority of services and supports required despite the implementation of the National Disability Insurance Scheme.

## Enabling mainstream services to be more inclusive

Led by Professor Teresa Iacono, this theme identifies cost-effective opportunities for mainstream services to better account for the needs of people with a disability. Our research has focused on health, education services as well as electoral processes. These institutions will continue to provide the vast majority of services and supports required despite the implementation of the National Disability Insurance Scheme.



Professor Teresa Iacono - Research Theme Leader for Enabling mainstream services to be more inclusive

## Supporting the inclusion of people with disability 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, is being conducted at Eastern Health, Bendigo Health and Northern Health. The aims are to understand the barriers to responding appropriately to people with disabilities and delivering them quality healthcare services; and Identifying promising ad hoc and systematic processes and practices that facilitate inclusion and responsiveness.

## 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, which showed that students with disabilities continue to experience unequal access to quality education in mainstream schools. A recommendation of the Review was to explore options for how the expertise in Specialist Schools could be harnessed to support mainstream schools to be inclusive of students with disabilities. Funding for this project was awarded by the Victorian Principals’ Association of Specialist Schools (PASS) to a team lead by Professor Teresa Iacono. The project brought together researchers from across LiDs and La Trobe Rural Health (Teresa Iacono, Amanda Kenny and Carol McKinstry), and the School of Education (Mary Keeffe). The project also brings together stakeholders from across specialist and mainstream school communities to co-design options informed by policy, research evidence, and interview data to develop options for how specialist schools can become “Centres of Expertise” to support inclusive education.

# EVENTS

## Advanced masterclass in Person Centred Active Support

Delivered again by Professor Julie Beadle-Brown, this one-day masterclass (29 July, 2016) was once more in high demand. Building on the resources provided in the **Every Moment has Potential** online program, ([www.activesupportresource.net.au](http://www.activesupportresource.net.au)).

The masterclass helped participants grow their knowledge of active support to a higher level, facilitating participants to become trainers in active support. Of course, many attendees were practice leaders, keen to deepen their knowledge as well as those interested in monitoring the quality of services and support provided both from within organisations and externally.

## Annual Roundtable: Policy and Practice of Support for Decision Making Workshop

The annual roundtable on disability policy and practice has been a feature of disability research at La Trobe since 2006. This year we hosted international visitor Jan Killeen, Churchill Fellow from Scotland.

Information was shared about Australian and international developments that are furthering the rights of people with cognitive disabilities to participate in decision making about their own lives. Participants discussed the policy and practice issues that have arisen as new approaches to support their decision making have been trialled. Answers were sought to the question: What has been learned and what are the pressing issues to be resolved?

Speakers included:

Colleen Pearce & John Chesterman - Perspectives from the Office of the Public Advocate in Victoria

Jan Killeen - Scottish experiences supporting decision making of people with dementia

Rhonda Galbally AO - Perspectives from the Independent Advisory Committee and the Intellectual Disability Reference Group

Dr Deirdre Featherstonehaugh - Supporting people with dementia, their carers and surrogate decision-makers.

Dr Lucy Knox - Issues for practitioners in supporting people with acquired brain injury to make decisions.

Professor Magnus Tideman - Swedish God man - A unique supported decision-making system - but does it work?

Professor Christine Bigby - What has been learned from the pilot projects in Australia between 2010-2015

Professor Jacinta Douglas - A Practice framework to build capacity of supporters of people with cognitive disabilities.

Emeritus Professor Terry Carney - Meeting the challenge of moving from capacity to capacity-building?

Dr Shih-Ning Then - How proposals for law reform have fared in different jurisdictions

Presentations are available online: [www.bit.ly/LiDs2016Roundtable](http://www.bit.ly/LiDs2016Roundtable)



Roundtable Attendees after the event, Melbourne.

# There is a need for enhanced access to Slow Stream Rehabilitation (SSR) programs for young people with high and complex needs in nursing homes.

## Putting Rights into Practice: Political Citizenship for People with Intellectual Disability

A collaborative event presented by Australasian Society for Intellectual Disability, Inclusion Melbourne and the Living with Disability Research Centre.

This seminar explored local and global strategies to facilitate the greater exercise of political citizenship by people with intellectual disability - especially through participation in voting during democratic elections.

The seminar led to an exciting new partnership between LiDs, Inclusion Melbourne and the Victorian Electoral Commission which is investigating strategies to support people with intellectual disability to vote.

The seminar was podcast, which can be accessed online.

[www.bit.ly/2016CitizenshipPod](http://www.bit.ly/2016CitizenshipPod)

## Slow Stream (Extended) Rehabilitation Roundtable

In partnership with La Trobe University, the Summer Foundation held a roundtable on Slow Stream Rehabilitation in Melbourne on 31 August 2016. The roundtable was facilitated by Rosemary Calder, Director of the Australian Health Policy Collaboration.

There is a need for enhanced access to Slow Stream Rehabilitation (SSR) programs for young people with high and complex needs in nursing homes, as well as a greater consistency in service delivery across Australia.

The roundtable event was attended by experts with a wide range of perspectives including government, clinical, advocacy, compensation, research and people with disability and families. Discussion was based on the information from a scoping review created specifically for the event. The review summarised the current state of knowledge regarding Slow Stream Rehabilitation from the perspective of people with direct experience and existing research evidence. The scoping review will be used to inform the continued advocacy by the Summer Foundation to support people with severe brain injury to achieve improvement in function.



Mary Nolan AM, Inability Possibility co-founder, Rosemary Calder, Director of the Australian Health Policy Collaboration & Professor Jacinta Douglas at the rehabilitation roundtable.

# LiDs Seminar Series

In 2016, eleven more LiDs Seminars were held from February to December; covering the broad range of disability research within LiDs. Supporting the development of early career researchers, as well as the exchange of ideas between academia and industry.

## MONTH PRESENTERS TOPIC

MONTH	PRESENTERS	TOPIC
<b>FEB</b>	Rwth Stuckey	The psychosocial impact of a riding for disabled program on children with autism
<b>MAR</b>	Teresa Iacono	Taking Risks to Embed Disability into Undergraduate Curricula
	Lauren Clark	A measure of Health Related Quality of Life for people with intellectual disability
<b>APR</b>	Anne Williams	Using online tools to promote personal recovery in users of mental health services
<b>MAY</b>	Dani Ashley	Time use and occupational engagement of people with mild intellectual disability
	Sue Jackson	Investigating the making of the National Disability Insurance Scheme
<b>JUN</b>	Lincoln Humphries	Development of a Scale to Measure Organisational Culture in Group Homes
	Professor Chris Bigby	Factors that impact on person centred practice for residents with complex needs
<b>JUL</b>	Michelle Browning	The process of supported decision making: a Canadian Model
	Sophia Tipping	The political participation of people with intellectual disability: A mapping review
<b>SEP</b>	Jade McEwen	Safeguards for people with intellectual disability during the NDIS transition
	Hilary Johnson	Supporting train travel for people with communication disabilities
<b>OCT</b>	Georgia Dacakis	The Transsexual Voice Questionnaire
	Michael Dillon & Matt Quigley	Shared decision making to inform decisions about partial foot amputation
<b>NOV</b>	Various, see pg 15	Roundtable - Policy and Practice of Support for Decision Making Workshop
	Various, see pg 16	Putting Rights into Practice: Political Citizenship for People with Intellectual Disabilities
<b>DEC</b>	Caitlin McDowell	The perspectives of front-line staff in supporting clients with mental illness
	Jade McEwen	Quality systems measuring both process and outcomes within disability services



## IASSIDD 15th World Congress 2016, 15 - 19 August

Every four years the **International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD)** holds a World Congress. This provides a global community of intellectual disability stakeholders the opportunity to come together and share knowledge.

In 2016 Melbourne was the host city and a sizable contingent of LiDs members were in attendance. Thirteen members presented on topics as diverse as their disciplines and roles in LiDs. All levels of the LiDs team were represented from areas as diverse as history, social work and speech pathology.

There were a number of speakers with lived experience of intellectual and developmental disability who shared their efforts to create change in the sector and the community more broadly. Representatives from government departments, service providing agencies and advocacy organisations shared innovative policy and service provision strategies from around the globe.

Researchers from physical, human and social sciences shared unique disciplinary perspectives on varied issues related to disability - often in dialogue with each other leading to rich discussion enjoyed by all.



From left to right: Michelle Browning (PhD candidate), Professor Jacinta Douglas (LiDs), Professor Christine Bigby (LiDs) & Professor Julie Beadle-Brown, (LiDs).



Professor Teresa Iacono (LiDs)



Aine Healy (former director of Advocacy at NSW Council for Intellectual Disabilities), Robert Strike (Self Advocacy NSW) & Christine Bigby (LiDs).



Dr Hilary Johnson (right) Adjunct Associate Professor (LiDs) presenting a poster of a Communication Access project.



William Crisp (PhD candidate), presenting on the complexity of self-determination for people with intellectual disabilities.

# RESEARCH OUTPUTS, OUTCOMES & IMPACT

## Funded Projects

### Led by LiDs and new in 2016

- Bigby, C. & Duff, G. Models of facilitating community participation for adults with cognitive impairments; National Disability Research & Development Data Working Group
- Bigby, C. Research to action guides; National Disability Services
- Bigby, C. NDIS evaluation subcontract, Flinders - Older persons study; Department of Social Security National Insurance Disability Scheme
- Bigby, C. & Douglas, J. Evaluation of clinical care coordination model trial; Hunter Primary Care
- Bigby, C. & Bould, E. Embedding Active Support and Practice Leadership; Civic Disability Services Limited
- Bigby, C. Experiences of involvement in Circles of Support; Inclusion Melbourne
- Bigby, C. & Douglas, J. Risk enablement project; National Disability Services and NSW Department of Family and Community Services
- Bigby, C., Douglas, J. & Knox, L. Review of contemporary third party insurance models; Transport Accident Commission
- Iacono, T., Keeffe, M., Snow, P., Kenny, A., McKinstry, C. Develop options to enable specialist schools to become "Centres of Expertise" to support local mainstream schools to implement inclusive

education; Principals' Association of Specialist School Victoria Inc

- Douglas, J., Bigby, C., Iacono, T., Knox, L., Winkler, D. & Callaway, L. 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
- Bigby, C. Embedding Active Support and Practice Leadership in supported accommodation services; IdentityWA
- Bennet, P., Howell, T. & Shiell, A. Reviewing assistance dog effectiveness: Literature review, interviews with participants, and health economics analysis; Commonwealth Government

### Led by LiDs and continuing from 2015

- Bigby, C. Inclusion of CARA in Embedding Active Support and Practice Leadership in supported accommodation services; CARA
- Bigby, C., Iacono, T., Douglas, J., Troller, J., Tracy, N. & Shields, N. Enabling mainstream systems to be more inclusive and responsive to people with disabilities; National Disability Research and Development Grant
- Bigby, C., Douglas, J., Carney, T., Wiesel, I., Shih-Ning, T., Chesterman, J., & Cook, J. Effective decision making support for people with cognitive disability;

Australian Research Council Linkage Grant

- Rose, M. Multi-modal aphasia therapy: A computerised extension (Maya Menehemi-Falkov); Department of State Development, Business and Innovation
- Bigby, C. Embedding Active Support; House with No Steps
- Bigby, C. Embedding Active Support; EW Tipping Foundation
- Bigby, C. Embedding Active Support; Bayley House
- Bigby, C., & Bartram, T. Post-Doctoral Fellowship (Employment and Health); La Trobe University Building Healthy Communities, Research Focus Area
- Rose, M., Copland, D., Nickels, L., Togher, L., Meinzer, M., Rai, T., & Godecke, E. COMPARE - Constraint induced or multi-modal aphasia rehabilitation: An RCT of therapy for stroke related chronic aphasia; National Health and Medical Research Council Program Grant
- Bernhardt, J., Nilsson, M., Carey, L., van Vliet, P., Cadilhac, D., Parsons, M., Bladin, C., Middleton, S., Levi, S., & Donnan, G. NHMRC Centre of Research Excellence in Stroke Rehabilitation and Brain Recovery; National Health and Medical Research Council
- Bigby, C., Iacono, T., Douglas, J., Beadle-Brown, J., Winkler, D., & Callaway, L. Developing and maintaining person centred active support (PCAS): A demonstration project in supported accommodation for people with neurotrauma; Institute of Safety,



#### Compensation and Recovery Research.

- Bigby, C., Iacono, T., Bould, E. & Beadle-Brown, J. Enabling engagement and inclusion: Organisational factors that embed Active Support in accommodation services for people with intellectual disability; ARC Linkage grant
- Bigby, C., & Douglas, J. Evaluation of the launch of the National Disability Insurance Scheme; Department of Families, Department of Families, Housing and Community Services (sub-contract via Flinders University)

#### Led by LiDs and completed in 2016

- Chaffey, L., & Bigby, C. Peer-to-peer training for people with SCI in Pacific Island Countries; La Trobe University Institute for Human Security and Social Change and La Trobe University Asia
- Long, M., Venville, A., & Bigby, C. Service users with intellectual disability and access to mental health services; La Trobe University Building Healthy Communities Research Focus Area
- Serry, T. Reading difficulties, dyslexia and university study; La Trobe University Faculty of Education, Disciplinary Research Program
- Pozzebon, M., Douglas, J., & Ames, D. Understanding the lived experiences of spousal caregivers of individuals diagnosed with a language dominant

dementia, Mary Elizabeth Watson Fellowship in Allied Health

- Rose, M. Living well with aphasia through community aphasia groups; Australian Research Council, Future Fellowship
- Holmes, K., Henderson, D., & Bigby, C. 'It's a lonely world out there': Deinstitutionalisation In Victoria; La Trobe University Transforming Human Societies, Research Focus Area grant
- Beadle-Brown, J., Bigby, C & Bradshaw, J. Uncovering the staff culture of good quality supported accommodation for people with intellectual disabilities; School for Social Care Research, UK
- Bigby, C. & Douglas, J. Supported decision making pilot, Kangara Centre NSW; New South Wales - Department of Family and Community Services National Disability Research
- Bigby, C., Wiesel, I. & Beadle-Brown, J. Understanding 'Encounter' as a dimension of social inclusion for people with intellectual disability; Australian Research Council, Linkage Projects

#### Led by other organisations, with LiDs as a significant partner

- McDonald, S., Anderson, V., Ponsford, J., Tate, R., Togher, L., Morgan, A., Fleming, J., Ownsworth, T., Douglas, J., & Murdoch, B. CRE in traumatic brain injury psychosocial rehabilitation: Breaking down barriers for social reintegration; National Health and Medical Research

#### Council

- Worrall, L., Togher, L., Simmons-Mackie, N., Kneebone, I., Hoffman, T., Khan, A., Power, E., & Rose, M. Preventing depression and reducing the impact of aphasia in stroke patients and their caregivers a year post onset via a brief early intervention: a cluster randomised control; National Health and Medical Research Council
- Carey, L. NHMRC CRE in stroke rehabilitation and brain recovery (administered by University of Melbourne); National Health & Medical Research Council - Centres of Research Excellence
- Douglas, J. Provider performance measurement and management external environment scan (administered by Monash University); Institute for Safety, Compensation and Recovery Research

## Publications

(Based on interim data at time of press)

### Book Chapters

- Anderson, S., Bigby, C. (2016). Empowering People with Intellectual Disabilities to Challenge Stigma. 165-178. In Scior, K., & Werner, S. *Intellectual Disability and Stigma Stepping Out from the Margins*. Palgrave Macmillan.
- Beadle-Brown, J., Hutchinson, A. (2016). Person-centred active support The cake not the icing. 211-239. In Carr,

# The ARC Linkage grant examined research practices that support the social inclusion of people with intellectual disabilities and their encounters with strangers.

A., Linehan, C., O'Reilly, G., Walsh, P. N., & McEvoy, J. (Eds.). *The handbook of intellectual disability and clinical psychology practice: Second Edition*. Routledge.

- Trembath, D., Iacono, T. (2016). Standardized assessment of prelinguistic communication. 75-100. In Keen, D., Meadan, H., Brady, N. C., & Halle, J. W. (Eds.). *Prelinguistic and minimally verbal communicators on the autism spectrum*. Springer.

## Conference Proceedings

- Davis, H., Francis, V. (2016). ICT in construction: Can it reduce work-family conflict by decreasing workloads? In *Proceedings of the 28th Australian Computer-Human Interaction Conference, OzCHI 2016*, (pp. 447-451). Association for Computing Machinery, Launceston, Tasmania.
- Ferdous, HS., et al. (2016). TableTalk: Integrating personal devices and content for commensal experiences at the family dinner table, (pp. 132-143). In *UbiComp 2016 - Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, Heidelberg, Germany. Association for Computing Machinery.

## Refereed Journal Articles

- Arvidsson, J., Staland-Nyman, C., Widén, S., Tideman, M. (2016). Sysselsättning för unga vuxna med intellektuell funktionsnedsättning; boendegeografiska skillnader [Employment for young adults with intellectual disabilities – geographic differences in housing conditions]. *Tidskrift för velferdsforskning*, 19(3), 241-260.
- Arvidsson, J., Widen, S., Staland-Nyman, C., Tideman, M. (2016). Post-school destination - a study of women and men with intellectual disability and the gender-segregated Swedish labor market. *Journal of Policy and Practice in Intellectual Disabilities*, 13(3), 217-226.
- Bhopti, A., Brown, T., Lentin, P. (2016). Family quality of life: A key outcome in early childhood intervention services: A scoping review. *Journal of Early Intervention*, 38(4), 191-211.
- Bigby, C., Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual disability at severe levels. *Intellectual and Developmental Disabilities*, 54(5), 316-331.
- Bigby, C., Beadle-Brown, J. (2016). Improving quality of life outcomes in supported accommodation for people with intellectual disability: What Makes a Difference? *Journal of Applied Research in Intellectual Disabilities*.
- Bigby, C., Bould, E., Beadle-Brown, J. (2016). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*.
- Bigby, C., Craig, D. (2016). A case study of an intentional friendship between a volunteer and adult with severe intellectual disability: "My life is a lot richer!". *Journal of Intellectual and Developmental Disability*, 1-10.
- Bould, E., Beadle-Brown, J., Bigby, C., Iacono, T. (2016). Measuring practice leadership in supported accommodation services for people with intellectual disability: Comparing staff-rated and observational measures. *Journal of Intellectual and Developmental Disability*.
- Bould, E., Beadle-Brown, J., Bigby, C., Iacono, T. (2016). The role of practice leadership in active support: impact of practice leaders' presence in supported accommodation services. *International Journal of Developmental Disabilities*.
- Callaway, L., et al. (2016). Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study. *Australian Occupational Therapy Journal*, 1-9.
- Callaway, L., et al. (2016). The Community Integration Questionnaire - Revised: Australian normative data and measurement of electronic social networking. *Australian Occupational Therapy Journal*, 63(3), 143-153.
- Carey, L.M., et al. (2016). Same intervention-different reorganization:



# Working closely with people with a disability and disability services, researchers are investigating current service models.

- The impact of lesion location on training-facilitated somatosensory recovery after stroke. *Neurorehabilitation and Neural Repair*, 30(10), 988-1000.
- Carey, L.M., Lamp, G., Turville, M. (2016). The state-of-the-science on somatosensory function and its impact on daily life in adults and older adults, and following stroke: a scoping review. *OTJR: Occupation, Participation and Health*, 36(2S), 27S-41S.
  - Cavanagh, J., et al. (2016). Supporting workers with disabilities: a scoping review of the role of human resource management in contemporary organisations. *Asia Pacific Journal of Human Resources*, 55(1), 6-43.
  - Cherbuin, N., Carey, L., Mortby, M., Anstey, K.J. (2016). Predictors of future stroke in adults 60-64 years living in the community. *World Journal of Neurology*, 6(1), 14-22.
  - Dacakis, G., Oates, J.M., Douglas J. (2016). Exploring the validity of the Transsexual Voice Questionnaire (male-to-female): Do TVQ (MtF) scores differentiate between MtF women who have had gender reassignment surgery and those who have not? *International Journal of Transgenderism*, 17(42828), 124-130.
  - Dacakis, G., Oates, J.M., Douglas J. (2016). Further Evidence of the Construct Validity of the Transsexual Voice Questionnaire (TVQ MtF) Using Principal Components Analysis. *Journal of Voice*, 31(2), 142-148.
  - D'Cruz, K., et al. (2016). Engaging patients with moderate to severe acquired brain injury in goal setting. *International Journal of Therapy and Rehabilitation*, 23(1), 20-31.
  - Dorstyn, D., et al. (2016). Piloting an email-based resource package for job seekers with multiple sclerosis. *Disability and Rehabilitation*, 1-7.
  - Douglas, J., Bracy, C., Snow, P. (2016). Return to work and social communication ability following severe traumatic brain injury. *Journal of Speech, Language, and Hearing Research*, 59, 511-520.
  - Douglas J., et al. (2016). Effectiveness of communication-specific coping intervention for adults with traumatic brain injury: preliminary results. *Neuropsychological Rehabilitation*, 1-19.
  - Ennals, P.J., et al. (2016). Supporting students with invisible disabilities: a scoping review of postsecondary education for students with mental illness or an acquired brain injury. *International Journal of Disability, Development and Education*, 63(6), 571-592.
  - Erickson, S., Serry, T.A. (2016). Comparing alternate learning pathways within a problem-based learning speech-language pathology curriculum. *International Journal of Speech-Language Pathology*, 18(1), 97-107.
  - Ferdous, H.S., Ploderer, B., Davis, H., Vetere, F., O'Hara, K. (2016). Commensality and the social use of technology during family mealtime. *ACM Transactions on Computer - Human Interaction*, 23(6), 1-26.
  - Fisher, F., Philpott, A., Andrews, S.C., Maule, R., Douglas, J. (2016). Characterizing social communication changes in amyotrophic lateral sclerosis. *International Journal of Language and Communication Disorders*, 1-6.
  - Fortune, T., et al. (2016). Bridging identity 'chasms': occupational therapy academics' reflections on the journey towards scholarship. *Teaching in Higher Education*, 21(3), 313-325.
  - Foster, A., O'Halloran, R., Rose, M., Worrall, L. (2016). "Communication is taking a back seat": speech pathologists' perceptions of aphasia management in acute hospital settings. *Aphasiology*, 30(5), 585-608.
  - Frederico, M., et al. (2016). A consortium approach for child and family practice education. *Social Work Education*, 35(7), 780-793.
  - Furlong, L.M., Morris, M.E., Erickson, S., Serry, T.A. (2016). Quality of mobile phone and tablet mobile apps for speech sound disorders: protocol for an evidence-based appraisal. *JMIR Research Protocols*, 5(4), 1-7.
  - Godecke, E., et al. (2016). A randomized controlled trial of very early rehabilitation in speech after stroke. *International Journal of Stroke*, 11(5), 586-592.
  - Henderson, D., Bigby, C. (2016). We were more radical back then: Victoria's first

- self-advocacy organisation for people with intellectual disability. *Health and History*, 18(1), 42-66.
- Hughes, M., Bigby, C., Tilbury, C. (2016). Australian social work research on ageing and aged care: A scoping review. *Journal of Social Work*.
  - Iacono, T., et al. (2016). Family and practitioner perspectives on telehealth for services to young children with autism. *The Promise of New Technologies in an Age of New Health Challenges*, 231, 63-73.
  - Iacono, T., et al. (2016). Family caring of older adults with intellectual disability and coping according to loci of responsibility. *Research in Developmental Disabilities*, 57, 170-180.
  - Iacono, T., Stagg, K., Pearce, N., Chambers, A.H. (2016). A scoping review of Australian allied health research in ehealth. *BMC Health Services Research*, 16, 1-8.
  - Iacono, T., Trembath, D., Erickson, S. (2016). The role of augmentative and alternative communication for children with autism: current status and future trends. *Neuropsychiatric Disease and Treatment*, 12, 2349-2361.
  - Johnson, H., et al. (2016). Increasing day service staff capacity to facilitate positive relationships with people with severe intellectual disability: Evaluation of a new intervention using multiple baseline design. *Journal of Intellectual and Developmental Disability*.
  - Johnson, H., Solarsh, B., Bloomberg, K., West, D. (2016). Supporting people with complex communication needs through community capacity building: The communication access network. *Tizard Learning Disability Review*, 21(3), 130-139.
  - Knox, L., Douglas J., Bigby, C. (2016). "I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury. *Disability and Rehabilitation*, 1-11.
  - Logan, K., Iacono, T., Trembath, D. (2016). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *AAC: Augmentative and Alternative Communication*, 1-14.
  - McPherson, L., et al. (2016). Secrecy Surrounding the Physical Abuse of Child Athletes in Australia. *Australian Social Work*, 70(1), 42-53.
  - Mealings, M., Douglas, J., Olver, J. (2016). Beyond academic performance: Practice implications for working with students following traumatic brain injury. *International Journal of Speech-Language Pathology*.
  - Migliorini, C., Enticott, J., Callaway, L., Moore, S., Willer, B. (2016). Community Integration Questionnaire: Outcomes of people with traumatic brain injury and high support needs compared with multiple matched controls. *Brain Injury*, 30(10), 1201-1207.
  - Migliorini, C., Sinclair, A., Brown, D., Tonge, B., New, P. (2016). A randomised control trial of an Internet-based cognitive behaviour treatment for mood disorder in adults with chronic spinal cord injury. *Spinal Cord*, 54(9), 695-701.
  - Nagpal, A., et al. (2016). TOOTH (The Open study Of dental pulp stem cell Therapy in Humans): Study protocol for evaluating safety and feasibility of autologous human adult dental pulp stem cell therapy in patients with chronic disability after stroke. *International Journal of Stroke*, 11(5), 575-585.
  - Nguyen, V.A., et al. (2016). A pathway proteomic profile of ischemic stroke survivors reveals innate immune dysfunction in association with mild symptoms of depression - a pilot study. *Frontiers in Neurology*, 7, 1-16.
  - O'Halloran, R., Coyle, J., Lamont, S. (2016). Screening patients for communication difficulty: The diagnostic accuracy of the IFCI staff questionnaire. *International Journal of Speech-Language Pathology*, 1-11.
  - Pozzebon, M., Douglas, J., Ames, D. (2016). "It was a terrible, terrible journey": an instrumental case study of a spouse's experience of living with a partner diagnosed with semantic variant primary progressive aphasia. *Aphasiology*, 1-13.
  - Pozzebon, M., Douglas, J., Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. *International Psychogeriatrics*, 28(4), 537-556.
  - Richardson, L., et al. (2016). I felt that I deserved it - Experiences and implications of disability hate crime. *Tizard Learning Disability Review*, 21(2), 80-88.
  - Rose, M.L., Mok, Z., Sekine, K. (2016). Communicative effectiveness of pantomime gesture in people with aphasia. *International Journal of Language and Communication Disorders*, 52(2), 227-237.
  - Serry, T.A., Liamputtong, P., Rose, M.L., Bretherton, L. (2016). Parents' experiences of their children's supplementary reading intervention: A qualitative exploration. *Australian Journal of Learning Difficulties*, 21(1), 3-20.
  - Simmons-Mackie, N., et al. (2016). The top ten: Best practice recommendations for aphasia. *Aphasiology*, 31(2), 131-151.
  - Simpson, A., Stewart, L., Douglas, J. (2016). The plan(ner) is always changing: self-directed funding for children with hearing loss. *Deafness and Education International*, 18(3), 151-158.
  - Steel, G., Rose, M., Eadie, P. (2016). The production of complement clauses in children with language impairment. *Journal of Speech, Language, and Hearing Research*, 59(2), 330-341.
  - Tate, R.L., et al. (2016). The single-case reporting guideline in behavioural interventions (SCRIBE) 2016 Statement. *Neuropsychological Rehabilitation*, 27(1), 1-15.
  - Taylor, S., et al. (2016). Does somatosensation change with age in children and adolescents? A systematic review. *Child Care Health and Development*, 42(6), 809-824.
  - Trollor, J.N., et al. (2016). Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Medical Education*, 16, 1-9.
  - Trollor, J.N., et al. (2016). Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught. *Nurse Education Today*, 45, 72-79.

# When support workers use Person Centred Active Support, it leads to a better quality of life for the people they support.

- Tse, T., Carey, L., Cadilhac, D., Koh, G.C-H., Baum, C. (2016). Application of the World Stroke Organization health system indicators and performance in Australia, Singapore, and the USA. *International Journal of Stroke, 11*(8), 852-859.
- Turnpenny, A., et al. (2016). Developing an easy read version of the Adult Social Care Outcomes Toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities.*
- Wolf, S.L., et al. (2016). Best practice for arm recovery post stroke: An international application. *Physiotherapy (United Kingdom), 102*(1), 1-4.
- Bigby, C. Social Work and the NDIS: opportunities and challenges.; October 2016; Invited Keynote one day conference to celebrate 20 years of Social Work at La Trobe, Bendigo, Vic.
- Bigby, C. & Douglas, J. Building an Evidence Base about Support for Decision Making in Australia.; August 2016, Invited keynote paper at Forum on Supported Decision Making, Brisbane, QLD.
- Davis H. & Farmer, J. Workshop on Digital Participation: Engaging Diverse and Marginalised Communities, OzCHI conference.; November, 2016, Launceston, Tasmania.
- Douglas, J. "He went back into his shell like a tortoise." Exploring the challenging journey of stroke survival.; September, 2016; 39th ASSBI Brain Impairment Conference, Macau.
- Douglas, J., Bracy, C. & Snow, P. Return to work and social communication ability following severe traumatic brain injury.; July, 2016; World Federation of NeuroRehabilitation, Neuropsychological Rehabilitation Symposium, Glasgow, Scotland.
- Douglas, J. & Bracy, C. Marital Coping and Satisfaction following Severe Traumatic Brain Injury.; July, 2016; International Neuropsychological Society, London, UK.
- Douglas, J. Measuring and coping with cognitive-communication problems following brain injury.; July, 2016; Invited ASSBI Workshop.; London, UK.
- Douglas, J., Knox, L., De Maio, C., Bridge, H., Drummond, M. & Whiteoak, J. Coping with communication breakdown: The effectiveness of a new intervention for adults with traumatic brain injury.; February, 2016; 11th World Congress on Brain Injury, The Hague, Netherlands.
- Douglas, J. "Nobody wants to know you." Understanding the experience of friendship following severe traumatic brain injury.; February 2016; 11th World Congress on Brain Injury, The Hague, Netherlands.
- Ashley D., Fossey, E. & Bigby, C. Time use and occupational engagement of people with an intellectual disability in supported independent living.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Bigby, C. & Beadle-Brown, J. Dimensions of culture in under performing and better group homes for people with severe intellectual disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Bigby, C., Bould, E. & Beadle-Brown, J. Implementation of active support over time in Australia.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental

## Presentations

Researchers from LiDs, are regularly invited to speak on their research to a wide range of audiences; including, families and self-advocates, professionals and academics. Here we list a selection of invited presentations and those at international conferences, including the IASSIDD 2016 presentations.

- Dillon, M. Is partial foot amputation worth the risk of complications? British Association of Prosthetists and Orthotists National Conference.; March, 2016; Invited speaker, Coventry, UK.
- Bigby, C. & Douglas, J. Support for decision making: Development of an evidence-based practice framework for supporters.; September, 2016; Invited plenary NCID annual conference; Sydney.



- Disabilities, Melbourne, Australia.
- Bigby, C., Bould, E. & Beadle-Brown, J. Does the model matter?: Comparing outcomes for people with intellectual disabilities in 'supported living' and group homes.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Bigby, C., Douglas, J., Carney, T., Then, S.-N., Wiesel, I., Cook, J., O'Neill, J., Chesterman, J. & Smith, E. Models of delivering decision-making support to people with intellectual disabilities in Australia.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Bigby, C., Bould, E. & Beadle-Brown, J. The role of practice leadership in active support: Impact of practice leaders' presence in services.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Browning, Bigby, C. & Douglas, J. The process of supported decision-making: a Canadian model.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Crisp, W., Bigby, C. & Whiteside, M. The complexity of self-determination for people with intellectual disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Bigby, C. & Douglas, J. Development of an evidence-based support for a decision-making practice framework to guide decision-making supporters of people with intellectual disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Grindrod, A. & Rumbold, B. Healthy dying for people with intellectual disabilities in residential services.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Grindrod, A. & Varney, H. Death and the disability residential home: Mining narratives to enhance practice.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Henderson, D. & Bigby, C. 'It's a lonely world out there': Kew Cottages Parents' Association and opposition to deinstitutionalisation.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Araten-Bergman, T. Subjective well-being and its correlates among adults with ID; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Araten-Bergman, T. A family experience when a member has an ID: What does ageing bring?; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Araten-Bergman, T. Social workers' attributions toward individuals with dual diagnosis of ID and mental illness; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Humphreys, L., Bigby, C., Iacono, T. & Bould, E. Development of a scale to measure organisational culture in group homes.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Iacono, T., Bigby, C., Douglas, J., Tipping, S., Cheng, C. & Tracy, J. Hospital encounters of adults with cognitive disability: Report on 10 cases.; August, 2016; 15th World Congress of



the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.

- Iacono, T., Pearce, N., Evans L. & Hodgkin S. A scoping review of pathways to dementia diagnosis for people with and without intellectual disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Jackson, S., Bigby, C. & Soldatic, K. Locating Australia's new National Disability Insurance Scheme.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Johnson, H., Solarsh, B., Bould, E., Bigby, C. & Douglas, J. Supporting train travel for people with communication disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne, Australia.
- Quilliam, C., Bigby, C. & Douglas, J. Being in two minds: Staff's perspectives of paperwork in group homes for people with intellectual disabilities.; August, 2016; 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Melbourne,

Australia.

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- Bigby, C. Aug 2016; Parenting an intellectually disabled child: life forever on duty; Sydney Morning Herald newspaper.
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- Bigby, C. The NDIS: A New Landscape. Culture & quality of disability services. (Video); Uploaded by Inclusion Melbourne.  
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- Bigby, C. 2016 Bayley House AGM Guest Speaker – Professor Christine Bigby. (Video) Uploaded by Bayley House  
[www.bit.ly/2016BaleyAGM](http://www.bit.ly/2016BaleyAGM)

## Online Training Resources

**Every Moment Has Potential** - Person Centred Active Support for disability support workers.

[www.bit.ly/LiDsActiveSupport](http://www.bit.ly/LiDsActiveSupport)

**Supporting Inclusion** - Training resource for disability support workers to gain tools and strategies to promote the social inclusion of people with intellectual disability.

[www.bit.ly/LiDsInclusion](http://www.bit.ly/LiDsInclusion)

The Living with Disability Research Centre works with a variety of funders, partners and other universities, all of which are listed here alphabetically.

- Annecto Inc.
- Australian Research Council -
  - Future Fellowship
  - Linkage Projects
- Bayley house
- Civic Disability Services Limited
- Community Accommodation & Respite Agency (CARA)
- Department of Families, Housing, Community Services and Indigenous Affairs
- Department of Health and Human Services (Victoria)
- Department of State Development, Business and Innovation (Victoria)
- E. W. Tipping Foundation
- Endeavour Foundation
- Epworth Health
- Flinders University
- Golden City Support Services
- Greystanes Disability Services
- Halmstad University, Sweden
- House With No Steps
- Hunter Primary Care
- IdentityWA
- Inclusion Melbourne
- Institute for Safety, Compensation and Recovery Research
- Jewish Care
- Karingal Inc.
- Karolinska Institute, Sweden
- Malmö University, Sweden
- Melbourne City Mission
- Melbourne Health
- Monash University
- National Disability Services
- National Disability Research & Data Working Group
- National Health & Medical Research Council -
  - Project grants
  - Centres of Research Excellence
  - Partnership Projects Grant
- National Institute for Health Research
- New South Wales Trustee and Guardian
- New South Wales Public Guardian
- NSW Department of Family and Community Services
- Office of the Public Guardian, (Queensland)
- Office of the Public Advocate (Queensland)
- Office of the Public Advocate, Victoria
- Principals' Association of Specialist School Victoria Inc
- Queensland Mental Health Commission
- Queensland University of Technology
- NIHR School For Social Care Research, UK
- Summer Foundation Inc
- Sunshine Home
- The Mason Foundation - Medical and Scientific Research Grants
- The Public Trustee (Queensland)
- The Tizard Centre, University of Kent
- The University of Queensland
- The University of Sydney
- University of New South Wales
- V LINE
- Yooralla



### Queensland Mental Health Commission

Department of State  
Development, Business and  
Innovation



### Hunter Primary Care



### Department of Social Security National Insurance Disability Scheme



### Department of Human Services (Victoria)



Living with Disability Research Centre  
College of Science Health & Engineering  
La Trobe University  
Bundoora Campus VIC 3086  
T. +61 (03) 9479 3826  
E. lids@latrobe.edu.au | c.bigby@latrobe.edu.au  
W. latrobe.edu.au/lids