

# ANNUAL REPORT 2015



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# HOW WE OPERATE



La Trobe University provides the core funding for the Living With Disability (LiDs) Research Centre. Staff are either teaching and research academics or funded from research grants.

LiDs has a research partnership with the Summer Foundation which 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 works in collaboration with a wide range of advocacy, disability and mainstream service provider organisations. Collaborators work with us to design and implement research and (at times) provide funding. They are also important in enabling LiDs to trial education and training packages developed through our research, as well as assisting with broad dissemination of findings to interested stakeholders.

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

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 American Orthotic and Prosthetic Association, CSIRO, Dementia Care Collaborative Research Centres, Department of Business Innovation, Epworth Health, James McDonald Foundation, Melbourne Health, National Disability Research and Development, National Information Communication Technologies Australia, National Institutes of Health (UK), NSW Family and Community Services, Ossur Asia Pacific, Institute for Safety, Compensation and Recovery Research, Safe Work Australia and Speech Pathology Australia.

## Who We Work With

- annecto
- Bayley House
- CARA Community Accommodation
- Civic Lifestyles
- Endeavour Foundation
- EW Tipping Foundation
- Golden City Support Services
- Greystanes Disability Services
- House With No Steps
- Hunter Primary Care
- Inclusion Melbourne
- Institute for Safety, Compensation and Recovery Research
- JewishCare
- Karringal
- Melbourne City Mission
- NDS Centre for Applied Disability Research
- NSW Civil and Administrative Tribunal (including the Guardianship Division)
- NSW Family and Community Services
- NSW Office of the Public Guardian
- NSW Trustee And Guardian
- QLD Mental Health Commission
- QLD Office of the Public Advocate
- QLD Public Trustee
- Summer Foundation
- Victorian Office of the Public Advocate
- Yooralla



# MESSAGE FROM THE DEPUTY VICE- CHANCELLOR RESEARCH

It was with much pleasure and anticipation that the La Trobe University executive team (including myself) approved the formation of the LiDs Research Centre in late 2014. The track-record of the research group spoke for itself and we anticipated the formation of the research centre, with associated university funding for medium term research support, would help propel the researchers into a new level of national and international competitiveness. We have not been disappointed.

In its first full year of operation, the LiDs Research Centre has attracted more than \$2.5 million in new research funding. This is in addition to significant funding from non-grant sources including government departments, not-for-profits and peak bodies. LiDs' collaborations also include a number of national and international organisations. Without hesitation I can write that the centre has embodied the university's objective of attracting game changing partners that help connect us to the world outside.

At La Trobe University, we address big research problems by organising ourselves



into research focus areas - RFAs. The LiDs Research Centre is 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 a team that crosses 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.

Professor Bigby and her LiDs team make a significant contribution to our university research standing, being ranked amongst the top social work researchers in 2015 and at world standard. The work that LiDs undertakes has a ranking of 4 in the 2015 Australian Research Council Excellence in Research for Australia assessment exercise.

I hope you enjoy reading about the achievements of LiDs in 2015, as much as I have enjoyed witnessing its growth. I look forward to what is in store for 2016 and the contribution LiDs will continue to make to La Trobe University life and Australian society.

# MESSAGE FROM THE DIRECTOR

The Living with Disability research group formally became a research centre in late 2014. And so it is with great pleasure that I welcome readers to this, the first annual report of the LiDs Research Centre.

This year has been particularly successful for the LiDs Research Centre - with more than \$2.5 million of funding for new research projects across our three themes of:

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

The research programs cover a range of initiatives including our flagship research into implementing active support, improving support for decision making and enhancing community participation. For example, 2015 was the third year of a five-year study into factors that embed active support practice in supported accommodation services. We were successful in obtaining a new four-year ARC Linkage grant to investigate decision making support for people with cognitive disability and to trial an evidence-based training program. Members of LiDs were also awarded more than \$500,000 to implement an individualised community participation program for people with acquired brain injury.

The capacity and capability of the team has allowed us to branch out into new areas of research, investigating how mainstream services, such as the health system, adapt to the needs of people with disability. The team has been progressing a major initiative in this area, focused on how people with a disability access emergency departments of hospitals and the interface between hospital staff, families and disability service providers.

The formation of the LiDs Research Centre also coincided with the formal launch of a partnership with the Summer Foundation. The partnership and associated funding will support Professor Jacinta Douglas as the **Summer Foundation Chair, Living Well with Brain Injury**. The partnership is also supporting administrative and research positions across LiDs and the Summer Foundation.

Of course, there are many other achievements of note from 2015, and I trust you will enjoy reading about them all in this report.

The support from La Trobe University to form this centre and recognise the expertise that exists within the University in this field has been invaluable and will be essential to our on-going success. I would also like to thank all of the researchers involved in LiDs for their hard work, including research leaders Professors Douglas and Iacono, and acknowledge the contribution of Professor Ellie Fossey (who left part way through the year to take up a position in another

University). Finally, the outstanding research conducted across the centre would not have been possible with administrative support from Lyn Walker.



# OVERVIEW

## 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.

We adopt a bio-psycho-social approach to understanding disability. The Centre's focus is living with disability across the lifespan. Qualitative and quantitative methodologies are used as are newer inclusive research approaches. Through the application of a systems perspective, our work takes a multi-level approach to interventions targeted at the individual, family, organisation, community and wider society.

The LiDs Research Centre works to ensure that people living with disabilities have a voice in our projects. A key focus is on the experiences of people with disabilities, their families and service users.

Our staff and their collaborators have strong partnerships with advocacy and self-advocacy groups, health, disability and other human service providers as well as key international disability research centres.

## Strategic Plan

The LiDs strategic plan was developed as part of its establishment process in 2014. It closely aligns with the key objectives of La Trobe University's strategic plan **Future Ready**. In particular, LiDs has been very successful in achieving the University vision and aspiration to be a university where inclusiveness and globally recognised excellence meet.

Similarly, LiDs is advancing the College of Science, Health and Engineering (College of SHE) strategic plan by being a leader in our disciplines. LiDs has made significant contribution to the College strategy by establishing and maintaining strong industry partnerships, not to mention our national and international research excellence.

## The LiDs approach

The LiDs Research Centre is dedicated to generating an evidence base to inform and improve practices, programs and policies for people with disability.

We undertake to bring about positive change for people living with disability. Change needs to happen at a policy and practice level. Attitudes also have to change. The LiDs Research Centre is committed to bringing about change on all of these levels so that our society includes everyone.







## Mission

Our mission is to improve the social inclusion and participation of people with cognitive disability through research, education and knowledge transfer. We will generate an 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 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.

## Research

LiDs is a multidisciplinary research centre based in the School of Allied Health at La Trobe University. 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. 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:

- Improving 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 Academic Board through the PVC (College of SHE) and the Deputy Vice-Chancellor (Research).

### Current Advisory Committee Members are:

- The Centre Director - Professor Christine Bigby
- Theme leaders - Professors Teresa Iacono and Jacinta Douglas
- The Deputy Vice-Chancellor (Research) Nominee - Professor Andrew Brennan
- The Pro Vice-Chancellor (College of SHE) Nominee - Professor Jane Farmer
- University Members - Professors Patrick Keyzer and Katie Holmes
- Staff member of Centre - Dr Lisa Chaffey

### External members (from organisations within the sector)

- Daniel Leighton - Inclusion Melbourne
- Dr Christine Fyffe - Consultant and Adjunct Professor
- Dr Di Winkler - Summer Foundation
- Dr Gerry Naughtin - Mind Australia
- Dr Jane Tracy - Centre for Developmental Disability Health Victoria, and Adjunct Associate Professor



# 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 - LiDs adjunct and Halmstad University, Sweden

## Research Fellows

- Dr Sian Anderson
- Dr Nadine Cameron
- Dr Diane Craig
- Dr Jo Spong
- Dr Emma Bould
- Dr Lisa Chaffey
- Dr David Henderson
- Dr Cindy Cheng
- Dr Loretta Piccenna

## Adjuncts

- Dr Chris Fyffe - Adjunct Professor
- Dr Hilary Johnson - Adjunct Associate Professor
- Dr Jane Tracey - Adjunct Associate Professor

## Research Officers

- Mr Samuel Murray
- Ms Lisa Hamilton
- Ms Lucy Knox

## Research Assistants

- Mr Phillip Brown
- Ms Emma Caruana
- Ms Belinda Green
- Ms Emma Hunter
- Mr Lincoln Humphreys
- Ms Melissa Packer
- Ms Natalie Pearce
- Ms Louise Phillips
- Ms Sophia Tipping
- Ms Silvia Warren
- Ms Erin Wilson

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



**Each  
executive  
member heads  
a specific  
research  
theme of LiDs.**

## La Trobe University Staff associated with LiDs

- Professor Tim Bartram – Management
- Ms Lee Anne Bassar - Law
- Mrs Anoo Bhopti – 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
- Ms Pricilla Ennals – Occupational Therapy
- Dr Shane Erickson – Speech Pathology
- Dr Ellie Fossey - Occupational Therapy
- Dr Maureen Long – Social Work
- 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
- SM Abdul Bashar
- Michelle Browning
- Christopher Bruce
- Michelle Caldwell
- Rahila Christian
- Michelle Cimoli
- William Crisp
- Natalie Crothers
- Georgia Dacakis
- Kate D'Cruz
- Nastaran Doroud
- Melanie Drummond
- Gemma Duffield
- Priscilla Ennals
- Maya Menahemi Falkov
- Kate Fitt
- Abby Foster
- Isobel Hubbard
- Lincoln Humphreys
- Susan Jackson
- Adam Kauchki
- Lucy Knox
- Lucie Lanyon
- Yeptain Leung
- Kristy Logan
- Essie Low
- Claire Lynch
- Caitlin McDowell
- Jade McEwen
- Belinda Mclean
- Margaret Mealings
- Elspeth Mitchell
- Amy Muir
- Michaela Pascoe
- Elizabeth Pearson
- John Pierce
- Margaret Pozzebon
- Claire Quillam
- Karen Roberts
- Priscila Rocha
- Jasvinder Sekhon
- Kristy Smith
- Kellie Staff
- Jess Stevens
- Kellie Stagg
- Sophia Tipping
- Tamara Tse
- Russell Ullah
- Barbara Wolfendon

# RESEARCH ACTIVITIES

The research of LiDs is broadly undertaken in three themes:

- Improving 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.

## Improving disability services

Any service - government or private - should be on a constant program of quality improvement. 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 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 current service models, such as supported living and approaches to practice and leadership, such as person centred active support.



Professor Christine Bigby - Research Theme Leader for Improving Disability Services





# Every moment has potential

## Person-centred active support “Every moment has potential”

Person Centred Active Support is 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.

In collaboration with Greystanes Disability Services, LiDs researchers developed an online resource (<http://www.activesupportresource.net.au/>) that provides an introduction to Person Centred Active Support.

When support workers use Person Centred Active Support, it leads to a better quality of life for the people they support. Increasingly, disability support services are adopting Person Centred Active Support as a way of working and are expecting support workers to be skilled in this approach.

This online learning resource is based on research undertaken by many researchers in the UK and Australia including the late Professor Jim Mansell and Professors Julie Beadle-Brown, Christine Bigby as well as Dr Emma Bould.

As well as 5-year program of research into embedding Person Centred Active Support in group homes for people with intellectual disability, LiDs researchers are also trialling the effectiveness of active support practice in supported accommodation services for people with acquired brain injury.

## Effective Decision Making Support for People with Cognitive Disability

This ARC Linkage project aims to produce and test 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. This approach is considered best practice and is also required by various nation and statewide treaties. The project aims to develop innovative education resources, and to then investigate the impact of the resources on the practices of decision-making supporters and the person being supported. This will all be conducted using a randomised control trial (the most powerful type of research possible) within 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 are 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 Multi-component Community Connection program** for people with severe traumatic brain injury (TBI) is a research program whose focus is community connection amongst adults with TBI.

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. This lack of community activity has a negative impact on quality of life for injured individuals and their family members and is a source of considerable ongoing stress. 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 specifically to meet the needs of the individual and the effectiveness of the intervention is evaluated using single case experimental design methods. The improvements that result from this intervention program are expected to facilitate wellbeing and enhance community integration of individuals with severe brain injury, thus making a significant contribution to improving their long-term outcome.



# Any service - government or private - should be on a constant program of quality improvement. This is true for the disability sector as much as any other.

## Encounter as a way of understanding social inclusion

Supporting Inclusion is a free online learning program that was launched in mid-2015 (<http://supportinginclusion.weebly.com>). It is based on the principles of person centred active support, and is focused on how such a framework can be applied out in the community (not just within supported accommodation services).

The program is based on the findings of an ARC Linkage grant (a specific granting program aiming to connect university research with non-university end-users). This Linkage grant examined practices that support the social inclusion of people with intellectual disabilities and their encounters with strangers.

The online learning program creates a space to think about social inclusion and learn about useful tools and strategies for supporting people with intellectual disability to be included. The resource has eight modules that include vignettes, lecture and activity videos, exercises, reflective questions and access to other resources designed to provoke discussion about what constitutes good practice. It can be viewed on smart phones and tablets as well as computers. A workbook and additional resources can also be downloaded from the site.

## Models for facilitating community participation of adults with cognitive impairment

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. Through their investigative work, LiDs researchers will also identify promising staff practices and organisational strategies for supporting community participation.

The study will develop a typology for understanding community participation and identify practices for achieving it from both the literature and develop case studies of best practice in Australian disability or mainstream services.





# The health system stands out as being unresponsive to the particular requirements of people with disabilities and their families...

## Enabling mainstream services to be more inclusive

Despite the implementation of the National Disability Insurance Scheme and the existence of specialist services for people with a disability, the reality is the vast majority of services and supports required need to be (and should be) provided via mainstream services. Furthermore, when we think of services we should not limit ourselves to health but also consider the myriad of other services society has in place including legal, library, entertainment, public transport and education. Led by Professor Teresa Iacono, this theme takes a closer look at mainstream services to identify cost-effective opportunities for them to better account for the needs of people with a disability.



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

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. Many have additional disabilities (physical, sensory, psychosocial), and their difficulties with cognition, communication and self-direction pose some of the most complex issues requiring adjustment or reconsideration of the current processes used within health services. Their healthcare outcomes are poor and resource use is high. A key factor is the failure of staff and service delivery processes to 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. It aims to understand the barriers to responding appropriately to people with disabilities and delivering them quality healthcare services; and identify promising **ad hoc** and systematic processes and practices - **Promising Practices** - that facilitate inclusion and responsiveness

# EVENTS

## Advanced masterclass in Person Centred Active Support

Delivered by Professor Julie Beadle-Brown, this two-day masterclass (20-21 Aug 2015) built on the learner resources provided in the **Every moment has potential** online program. The masterclass helped grow participant's 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.

## International Perspectives on Self Advocacy for People with Intellectual Disability

**Magnus Tideman, Professor of Disability Studies, Halmstad University**

**Ove Mallander, Assoc. Professor in Social Work, Malmo University**

**Therese Mineur, Senior Lecturer in Disability Studies, Halmstad University**

In November, LiDs hosted a delegation of researchers from Sweden – where self-advocacy is an underlying feature of their support for people with a disability. In recent years, young adults with intellectual disability have organised themselves into self-advocacy groups to increase power over their own lives and at the same time to influence the society in the direction for increased participation. This presentation, based on national mapping and case-studies, highlighted the new self-organised activities of people in Sweden. Variability in organisational forms and size show how self-advocacy groups can be everything from totally independent to controlled by parents or staff. Interviews showed that the self-advocacy groups have an important impact on the lives of their members.



## Disability Services Research to Action - Melbourne Seminar

LiDs and National Disability Services' (NDS) Centre for Applied Disability Research, in collaboration with the NDS Victorian Research Advisory Group hosted a one-day seminar in August 2015. More than 130 people from across disability sector organisations participated in the Seminar, which:

- Informed practitioners in an engaging, succinct way about current research findings to underpin evidence based good practice in an array of areas.
- Provided practical examples of how disability services can distil and implement research evidence into practice.
- Exchanged and challenged research findings in the context of realistic practice settings.
- Highlighted the type of research that will be necessary in the new NDIS environment and its greater emphasis on evidence of what works.
- Helped identify evidence gaps for people with disabilities, their families and carers in exercising genuine choice.
- Built greater research mindedness and capacity in the disability sector.



From left to right: Professor Christine Bigby (LiDs), Professor Keith Nugent (La Trobe University), Gordon Duff (NDS) & Richard Madden (University of Sydney)



From left to right: Dr Di Winkler (Summer Foundation), Professor Keith Nugent (La Trobe University), Professor Jacinta Douglas (LiDs & Summer Foundation)



Disability Services Research to action - Melbourne seminar



**In 2015, eight events were held from March to November; covering the broad range of disability research within LiDs.**



## **LiDs Seminar Series**

Supporting the development of early career researchers, as well as the exchange of ideas between academia and industry, LiDs hosts a monthly seminar series. In 2015, eight events were held from March to November; covering the broad range of disability research within LiDs.

# MONTH

# PRESENTERS

# TOPIC

<b>MAR</b>	Associate Professor Ellie Fossey Dr Lisa Chaffey Priscilla Ennals	Supporting tertiary students with disabilities: Exploring the use of individualised and institution-level approaches in practice
<b>APR</b>	William Crisp	How do people with intellectual disability successfully achieve self-determination?
<b>MAY</b>	Nastaran Doroud	A scoping review exploring participation IN recovery and participating AS recovering of people experiencing mental health issues
<b>MAY</b>	Dr Mary Whiteside	Challenges and Dilemmas of supporting people with a cognitive disability make decisions
<b>JUN</b>	Claire Lynch	Addressing the sexual needs of people with disability: health professionals' conceptualisations
<b>JUL</b>	Professor Christine Bigby Dr Emma Bould	'Not as connected with people as they want to be' - Optimising outcomes for people with intellectual disabilities in supported living arrangements
<b>AUG</b>	Lee Ann Bassar	Human Rights and disability
<b>AUG</b>	Ann Williams	Using online resources to promote personal recovery in users of mental health services: A qualitative study
<b>SEP</b>	Bashar Bashar	Factors influencing work participation for people with lower limb amputation in Bangladesh
<b>OCT</b>	Claire Quillam	A frontline perspective of paperwork in group homes for people with intellectual disabilities
<b>OCT</b>	Michelle Browning	How is supported decision making realised in practice? An exploration of two models of supported decision making in British Columbia, Canada: Representation Agreements and Microboards
<b>NOV</b>	Associate Professor Miranda Rose Michelle Attard Lucie Lanyon	Improving social participation and mood in people with persisting post stroke aphasia through community-level programs

# RESEARCH OUTPUTS, OUTCOMES & IMPACT

## Publications

### Books

- Ashman, B., Beadle-Brown, J. (2015). *An Introduction to Active Support: A guide to supporting children and adults with intellectual and developmental disabilities*. Pavilion Publishing.
- Fossey, E., Chaffey, L., Venville, A., Ennals, P., Douglas, J., Bigby, C. (2015). *Supporting tertiary students with disabilities: Exploring the use of individualised and institution-level approaches in practice*. Adelaide: NCVER.

### Book Chapters

- Bigby, C., Frawley, C. (2015). Conceptualising inclusive research with people with intellectual disability: paradigm or method. In G Higginbottom and P. Liampittong. *Using Participatory Qualitative Research Methodologies in Health*. Thousand Oaks: Sage Publications
- Bigby, C., McCallion, P., McCarron, M. (2015). Serving an elderly population. In Agran, M., Brown, F., Hughes, C., Quirk, C., & Ryndak, D. *21st Century Issues for Individuals with Severe Disabilities: Ensuring Quality Services and Supports in Challenging Times*, Paul H. Brookes.
- Douglas, J., Drummond, M., Knox, L., Mealings, M. (2015). Rethinking social-

relational perspectives in rehabilitation: traumatic brain injury as a case study. In McPherson, K, Gibson BE, Leplege A, (eds), *Rethinking Rehabilitation Theory*, CRC Press: Boca Raton.

- Iacono, T., Johnson, H. (2015). The role of AAC in fostering the inclusion of adults with Angelman's syndrome in post-school, home and community settings. In Calculator (Ed.), *Angelman Syndrome: Communication, educational and related considerations* (pp. 285-315). Bentham Publishers.

### Refereed Journal Articles

- Adams, V., Callister, R., Mathisen, B., Lazarus, C., Baines, S. (2015). Reliability of measurements of strength and endurance using the Iowa Oral Performance Instrument in old adults. *Disability and Rehabilitation*, 37 (5): 389.
- Attard, M., Lanyon, L., Rose, M. (2015). Consumer perspectives on community aphasia groups. A narrative literature review in the context of psychological wellbeing. *Aphasiology*, 29(8), 893-1019.
- Beadle-Brown, J., Bigby, C., Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. *Journal of Intellectual Disability Research*, 59(12), 1081-1093.
- Bigby, C. (2015). Preparing manuscripts that report qualitative research – avoiding common pitfalls and illegitimate questions. *Australian Social Work*, 68(3), 384- 391.

- Bigby, C., Knox, M., Beadle-Brown, J., Clement. T. (2015). 'We just call them people': Positive regard for people with severe intellectual disability who live in of group homes. *Journal of Applied Research in Intellectual Disability*, 28, 283-295.
- Bigby, C., Webber, R., Bower, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work*, 68, 453-468.
- Bigby, C., Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disability*, 28, 307-318.
- Bridgman, K., Block, S., O'Brian, S. (2015). Webcam delivery of the Lidcombe Program. Insights from a clinical trial. *Journal of Clinical Practice in Speech-Language Pathology*, 17(3) 126-129.
- Bruce C., Unsworth C., Tay R., Dillon M.P. (2015). The development and validation of the Occupational Therapy Risk Propensity Risk Test (OT-RiPT) for drivers with disability. *Scandinavian Journal of Occupational Therapy*. 2015, 22(2), 147-52.
- Buckley, K. L., O'Halloran, P.D., Oates, J.M. (2015). Occupational vocal health of elite sports coaches: An exploratory pilot study of football coaches. *Journal of Voice*, 29(4), 476-483.





- Craig, D., Bigby, C. (2015). Critical realism in social work research: examining participation of people with intellectual disability. *Australian Social Work*, 68(3) 309- 323.
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# Working closely with people with a disability and disability services, researchers are investigating current service models.

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- Ummer Christian, R., Gussy, M., Iacono, T., Grills, N., Pradan, A. (2015). Access and appropriateness of dental services for people with developmental disabilities – A scoping review.
- Venville, A., Sawyer, A., Long, M., Edwards, N., Hair, S. (2015). Supporting people with an intellectual disability and mental health problems: a scoping review of what they say about service provision. *Journal of Mental Health Research in intellectual Disabilities* 8: 186-212.
- Vogel, A., Block, S., Kefalianos, E., Onslow, M., Eadie, P., Barth, B., Conway, L., Mundt, J., Reilly, S. (2015). Feasibility of automated speech sample collection with stuttering children using interactive voice response (IVR) technology. *International Journal of Speech-Language Pathology*, 17(2), 115-120.
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- Wilson, N., Stancliffe, R., Bigby, C., Balandin, S., Craig, D. (2015). A case study about the supported participation of older men with lifelong disabilities at Australian community-based men's sheds. *Journal of Intellectual and Developmental Disability*, 40(4), 330-341.

## 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.

- Beadle-Brown, J; Promoting the inclusion of people with intellectual and developmental disabilities – lessons from the UK and Australia.; November, 2015; Landsforenigen LEV Conference on Inclusion, Nyborg, Denmark.
- Beadle-Brown, J; Shaping up decision making: The role of active support; October, 2015; 2015 International Conference on Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding, Vancouver, BC.

- Bernstein-Ellis, Jones, Rose, Mahendra; Aphasia choirs go global: Results of an international survey.; March, 2015; Aphasia Access Conference, Boston.
- Bigby, C; Culture in higher performing group homes for people with severe intellectual disabilities; May, 2015; International Association of Scientific Study into Intellectual & Developmental Disabilities Americas Regional Congress, Honolulu.
- Bigby, C; More than just getting there – insights into enabling social inclusion of people with intellectual disability. Invited plenary presentation, July, 2015.; NSW CID Conference, Sydney.
- Carey-Sargeant, C., Brown, M., Dettman, S., Mathisen, B; Cochlear implantation and eye tracking technology: Where do children look when listening? How gaze patterns may assist our understanding of long term outcomes for school age children with cochlear implants after graduating from a range of early intervention programs (EIP)s.; June, 2015; 12th European Symposium on Cochlear Implants, Toulouse, France.
- De Beer, C., Carragher, M., van Nispin, K., de Ruiter, J., Hogrefe, K., Rose, M; Which gesture types make a difference to the interpretation of semantic content communicated by people with aphasia via difference gesture types?; September, 2015.; Gesture and Speech in Interaction (GESPIN), Nantes, France.



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

- Dillon M.P; Emerging evidence challenges beliefs about the benefits and complications of partial foot amputation.; February, 2015.; 41st Annual Scientific Meeting of the American Academy of Orthotists and Prosthetists, New Orleans, USA.
- Dillon M.P; Emerging evidence challenges beliefs about the benefits and complications of partial foot amputation.; October, 2015; American Orthotic and Prosthetic Association National Assembly, San Antonio, USA.
- Dillon M.P., Fatone S; Biomechanics of partial foot amputee gait: implications for pedorthotists tackling high rates of ulceration and reamputation; February, 2015. ; 41st Annual Scientific Meeting of the American Academy of Orthotists and Prosthetists, New Orleans, USA. Symposium.
- Douglas, J; "I don't have many friends – well I don't have any actually." Exploring the source and quality of friendships experienced by adults several years after severe traumatic brain injury; July, 2015; 12th Neuropsych Rehab Symposium, Daydream Island.
- Douglas, J; Understanding the source and quality of friendships experienced by adults several years after severe traumatic brain injury.; October, 2015; AFRM & NZRA Rehabilitation Conference Wellington NZ.
- Godecke, Armstrong, Middleton, Rai, Holland, Cadilhac, Whitworth, Rose, M., Cicone, Hankey, Bernhardt; Assessment of therapy fidelity processes in the very early rehabilitation in speech (VERSE) clinical trial.; April, 2015; European Stroke Organisation Congress, Glasgow
- Iacono, T; Family caring for older adults with intellectual disability; May, 2015; International Association for Scientific Study of Intellectual & Developmental Disabilities Americas Regional Congress, Honolulu.
- Iacono, T., Bigby, C., Bould, E., Beadle-Brown, J. Exploring the role of communication within active support; May, 2015; International Association for Scientific Study of Intellectual & Developmental Disabilities Americas Regional Congress, Honolulu.
- Power, E., Thomas, E., Worrall, L., Rose, M., Togher, L., Nickels, L., Hersh, D., Godecke, E., O'Halloran, R., Lamont, S., O'Connor, C. Clarke, K; The development and validation of Aphasia Rehabilitation Best Practice Statements using the RAND/UCLA appropriateness method.; May, 2015; Clinical Aphasiology Conference, Monterey, CA, USA.
- Raghavendra, P., Sampson, J., Iacono, T., Wood, D; Outcomes of a train-the-trainer model for introducing iPads® for communication; September, 2015; Communication Matters National AAC Conference, University of Leeds, UK.
- Šiška, J and Beadle-Brown, J; Rhetoric and Reality in Active Citizenship and Community Living in Europe; October, 2015; 2015 International Conference on Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding, Vancouver, BC.
- Scalzo, T., Oates, J; Factors associated with vocal impairment and voice problems in pre-school-aged children; August, 2015; Pan European Voice Conference.
- Ummer Christian, R., Gussy, M., Iacono, T., Grills, N., Pradan, A; Outcomes of a train-the-trainer model for introducing iPads® for communication; September, 2015; Communication Matters National AAC Conference, University of Leeds, UK.
- Van Nispin, K., Sekine, K., Rose, M; The added value of gesture for communication of people with aphasia.; September, 2015; Science of Aphasia, Portugal.
- Van Nispin, K., Sekine, K., Rose, M; Does gesture add to the comprehensibility of people with aphasia?; September, 2015; Gesture and Speech in Interaction (GESPIN), Nantes, France.
- Bigby, C; Providing good support to ageing people with intellectual disabilities: what do we know and why is it so hard to achieve. December, 2015; Invited keynote, British Institute of Learning Disabilities, Birmingham, UK.



## Funded Projects

### Led by LiDs and new in 2015

- Bigby, C., Embedding Active Support, Cara
- Bigby, C., Iacono, T., Douglas, J., Troller, J., Tracey, N. and Shields, N; Enabling mainstream systems to be more inclusive and responsive to people with disabilities; National Disability Research and Development Grant
- Douglas, J., Bigby, C., Iacono, T., Knox, L., Winkler, D., and 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., Douglas, J., Carney, T., Wiesel, I., Shih-Ning, T., Chesterman, J., and Cook., J; Effective Decision Making Support for People with Cognitive Disability; Australian Research Council Linkage Grant
- Holmes, K., Henderson, D., and Bigby, C; 'It's a lonely world out there': Deinstitutionalisation In Victoria; La Trobe University Transforming Human Societies, Research Focus Area grant
- Bigby, C; Embedding Active Support; House with No Steps
- Chaffey, L., and 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., and 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
- Bigby, C; Embedding Active Support; Bayley House
- Bigby, C., and Douglas, J; Supported Decision Making Pilot – Kanagara Centre, NSW; Department of Family & Community Services, NSW
- Bigby, C., and 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., and 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

### Led by LiDs and continuing from 2014

- Long, M., Morris, M., and Koklanis, C; The validity and reliability of orthoptists in diagnosing and identifying the progression of glaucoma; Orthoptics Australia
- Bigby, C; Embedding Active Support; EW Tipping Foundation
- Bigby, C., Iacono, T. Douglas, J., Beadle-Brown, J., Winkler, D., and 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.
- Iacono, T., Hudry, K., Hulme-Chambers, A., Erickson, S., and Trembath, D; Translating autism research excellence to a regional service through telehealth; La Trobe University Building Healthy Communities, Research Focus Area grant.
- Simpson, A., Douglas, J., Beadle-Brown, J., Winkler, D., and Callaway, L; Impact of the National Disability Insurance Scheme (NDIS) on hearing-impaired children; La Trobe University Building Healthy Communities, Research Focus Area, grant
- Pozzebon, M., Douglas, J., and Ames, D; Understanding the lived experiences of spousal caregivers of individuals diagnosed with a language dominant



- dementia, Mary Elizabeth Watson Fellowship in Allied Health
- Bigby, C., and 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)
- Bigby, C., Iacono, T., Bould, E., and Beadle-Brown, J; Enabling engagement and inclusion: Organisational factors that embed Active Support in accommodation services for people with intellectual disability; ARC Linkage grant
- Rose, M; Living well with aphasia through community aphasia groups, ARC Future Fellowship
- Bigby, C. Wiesel, I., and Beadle-Brown, J; Understanding 'encounter' as a dimension of social inclusion for people with intellectual disability; ARC Discovery grant

## Led by LiDs and completed in 2015

- Bigby, C; Self-Advocacy speaking up over the years; ARC Linkage Grant
- Bigby, C., Iacono, T., Tracy, J., Arnott, N., and Douglas, J; Hospital encounters of people with cognitive disability- A pilot study; La Trobe University Building Healthy Communities Research Focus Area grant
- Bigby, C; Cultures of respect; Disability Donations Trust

- Fyffe, C; Quality systems and outcome measures project: Service effectiveness framework; Disability South Australia
- Bigby, C., Douglas, J., Iacono, T., and Johnson; Positive Relationship. Disability Policy and Research Working Group
- Douglas, J; Coping with communication breakdown.; Institute of Safety, Compensation and Recovery Research,
- Crag; Forming friendships; Inclusion Melbourne
- Bigby, C., Carling, and Jenkins; Support for people with intellectual disability and dementia - training package; Karingal and Department of Health (Victoria)
- Bigby, C; Inclusion of students with disability, La Trobe University Equity Division
- Douglas, J; Conceptualising self and maintaining social connection; La Trobe University Clinical Research Fellowship
- Bigby, C; Evaluation of the neighbourhood connections program; Marillac House
- Fossey, E., Venville, A., Bigby, C., Ennals, P., and Douglas, J; What's reasonable? Best practice inclusive educational support in tertiary settings; National Centre for Vocational Education Research
- INCOG Group; International practice guidelines for cognitive intervention following severe TBI; Transport Accident Commission, and the Ontario Neurotrauma Foundation

- Bigby, C; Guide to Good Group Homes; Office of the Public Advocate grant
- Bigby, C., Douglas, J., and Whiteside, M; Supported Decision Making; Scope (sub-contract via the Legal Services Board of Victoria)
- Fisher, F. and Douglas, J; Interpersonal communication changes associated with ALS; Calvary Health Care Bethlehem
- Bigby, C., and Bould, E; Every Moment Has Potential: Person Centred Active Support Practice in Australia; WELL (via Greystanes)

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

- Bigby, C; Uncovering the staff culture of good quality supported accommodation for people with intellectual disabilities; National Institute for Health Research
- Bigby, C. and Duff, G; Models for facilitating community participation of adults with cognitive impairment; National Disability Research and Development Grant
- Kenzie, J., Dukelow, S., and Carey, L; Proprioception in stroke; RHISE HBI,
- Oakman, J; Reducing MSD risk in the aged care sector using multi-factorial evidence-based interventions; Safe Work Australia
- Dillon, M.P., and Fatone, S; Evaluating outcomes of dysvascular partial foot and transtibial amputation: a systematic



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

review and development of shared decision making resources; American Orthotic and Prosthetic Association

- Erickson, S., and Block, S; The impact of pre-school aged children's stuttering on their parents well-being; Speech Pathology Australia
- Carey, L., Baum, C., Josman, N., Nilson, M., Stinear, C., Rose, M., Frey, S., and Domerick, A; Advancing the Science of Rehabilitation: Translating Neuroscience and Rehabilitation into Everyday Life; James Mc Donnell Foundation
- Bernhardt, J., Nilsson, M., Carey, L., van Vliet, P., Cadilhac, D., Parsons, M., Bladin, C., Middleton, S., Levi, S., and Donnan, G; NHMRC Centre of Research Excellence in Stroke Rehabilitation and Brain Recovery; National Health and Medical Research Council
- Fossey, E; Working together with shared values towards recovery-oriented practice - Principles Unite Local Services Assisting Recovery - the PULSAR project; Victorian Department of Health
- Douglas, J; Understanding the lived experience of spousal caregivers living with partners diagnosed with a language dominant dementia; Melbourne Health
- Fossey, E; Use of online technology to promote self-management and recovery in people with psychosis; Victorian Department of Health
- 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., and 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
- Oakman, J., and Keegel T; Workplace barriers to reducing incidence of musculoskeletal and mental disorders; Institute for Safety, Compensation and Recovery Research
- Rose, M; Multi-modal aphasia therapy: A computerised extension (Maya Menehemi-Falkov), Victorian Department of Business Innovation
- Douglas, J; Chair, Living Well with Brain Injury; Summer Foundation
- Erickson, S; Virtual Speech Therapy; National Information Communication Technologies Australia
- Worrall, L., Kneebone, I., Simmons-Mackie, N., Khan, A., Brown, K., Hoffman, T., Power, E., Togher, L., Rose, M; Can a brief early intervention prevent depression and help people live with aphasia a year after stroke?; National Health and Medical Research Council

## Media

- Bigby, C; Jan 2015; Supported Decision Making; Interview with Samantha Donovan on AM (Radio National, ABC)
- Bigby, C; Feb 2015; Control and Choice for people with intellectual disability; Life Matters (Radio National, ABC)
- Dillon, M; Mar 2015; Similarity in quality of life for people with partial foot and transtibial amputation, study finds; Orthotics/Prosthetics Business News
- Bigby, C; May, 2015; Social inclusion of people with disabilities; interviewed by Daniel Glover (ABC Radio)
- Dillon, M; Jul 2015; Amputation: Patients cite lack of education about partial foot procedures; Lower extremity review
- Bigby, C; Nov 2015; participation of adults with intellectual disabilities in conferences; Interview with Hilary Harper (ABC 774, Melbourne)
- Rose, M; Neuroplasticity and constraint aphasia therapy; The Age Newspaper



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