



Dear << Test First Name >>,

With our exciting lineup of **New Perspectives - 2017** events just under one month away we present a more detailed look at what you can expect to get out of the masterclasses and our annual roundtable.

We look forward to welcoming international scholars [Professor Jennifer Clegg \(UK\)](#), [Dr Stacy Clifford Simpican \(USA\)](#) and [Dr Jens Ineland \(Sweden\)](#). These events promise to expose all that attend to exciting new perspectives on the important issues of support and participation for people with cognitive disabilities.

Also below are several other short interesting items, including links to newly published research on train travel, peer education in spinal cord injuries and a paper on supported decision-making that came out last week, among others:

- Communication difficulty and rail travel.
- Peer health education in spinal cord injury.
- Learning from 5 years of pilots in supported decision making.
- Using life story work with people with cognitive disability.
- A visual summary of four of our projects.

Professor Christine Bigby

Director, Living with Disability Research Centre.

NEW PERSPECTIVES - 2017

A season of events presenting lively conversations featuring international guest scholars around support and participation for people with cognitive disabilities.

[Annual Roundtable - Community Participation and People with Cognitive Disabilities: How is it understood and what does it take to support it?](#)

Wednesday 01 November 10:00am - 4pm \$150 per seat,

Free to La Trobe staff / Students

Location: MEL City Campus, 360 Collins Street,

Level 20, [Teaching rooms 1 & 2](#)

Concise presentations from researchers followed by intense plenary discussion between researchers and practitioners.

- **Dr Stacy Clifford Simpican** – Conceptualising community participation - what are we counting and measuring
- **Professor Jennifer Clegg** – Living in liquid modernity.
- **Dr Ilan Wiesel** – Perspectives on inclusion from urban geography - convivial encounter
- **Professor Christine Bigby** – Effective interventions for community participation of people with intellectual disabilities

- **Dr Sian Anderson** – What have we learned from case studies of best practice community participation programs in Victoria
- **Gordon Duff** – How can research inform NDIS policy and approaches to community participation
- **Sophia Tipping** – Forming and resourcing circles of support – based on study of a 'circles of support' program at Inclusion Melbourne
- **Professor Jacinta Douglas** – Creating community connections for people with acquired brain injury
- **Daniel Leighton** – Where do the Local Area Coordination programs fit in supporting community participation
- **Dr Jens Ineland** – Organisational perspectives on community participation

CONTACT US TO RESERVE A PLACE >

[Theorising the practice of support work – a master class](#)

Tuesday 24 October 10:00am - 4pm, A\$50 per seat,

Free to La Trobe staff / Students

Location: MEL Bundoora, Room: [RLR-101](#)

[Dr Stacey Clifford Simpican](#) leads this masterclass to stimulate new ways of thinking about direct support work with people with intellectual disability. Drawing on empirical research about the tasks and quality of direct support work Clifford Simpican uses new theoretical lenses to understand how practice might be improved. She uses Tronto's care theory and Democratic theory to draw out perspectives of support work as creative, disruptive and playful that can challenge the exclusion, inequality and stigma experienced by people with intellectual disability.

BOOK YOUR PLACE >

[New Perspectives 2017 - Social Inclusion master class](#)

Friday 27 October 10:00am - 4pm A\$50 per seat,

Free to La Trobe staff / Students

Location: MEL Bundoora, Room: [LIMS 1-205](#)

[Dr Stacey Clifford Simpican](#) gives this masterclass which takes as its starting point the continuing social exclusion of people with intellectual disabilities. It uses Democratic theory to interrogate the way social inclusion has been constructed and tries to understand why successive disability policies have failed to secure little more than increased community presence for people with intellectual disabilities. By reframing and broadening approaches to social inclusion, Clifford Simpican provides new approaches to thinking about interventions to support inclusion.

BOOK YOUR PLACE >

[New Conversations in Challenging Behavior – a master class](#)

Tuesday 31 October 10:00am - 4pm \$50 per seat,

Free to La Trobe staff / Students

Location: MEL Bundoora, Room: [RLR-101](#)

[Dr Stacey Clifford Simpican](#) will lead discussion on how we might begin reconceptualizing challenging behavior. Disability studies scholars have much to offer interventionists, such as questioning the cultural meanings, media portrayals, and complex histories surrounding challenging behavior. Clifford Simpican will explore four approaches that address ethical problems posed by challenging

behavior including embracing neurodiversity, recognizing equality, seeing resistance, and loving redemption.

BOOK YOUR PLACE >

Viewing intellectual disability through different conceptual lenses - a masterclass with Professor Jennifer Clegg

Friday 03 November 10:00am - 4pm \$50 per seat,

Free to La Trobe staff / Students

Location: MEL Bundoora, Room: [RLR-101](#)

This master class is in two parts: Dedifferentiation, intended and the unintended consequences, and Portmanteau words that are commonly used in intellectual disability.

Dedifferentiation. This session reviews research into the intended and the unintended consequences of the international policy of dedifferentiation in order to consider whether/when it may be more useful to maintain focus specifically on people with intellectual disabilities.

Portmanteau The second part of this master class examines two Portmanteau words commonly used in intellectual disability. It invites consideration of the problems they generate, but also the problems they appear to address and how else they might be tackled.

BOOK YOUR PLACE >

To read longer descriptions, find locations and book tickets please visit the [LiDs website events page](#)

Just published...

LiDs researchers have just published a paper that investigates the experiences of people with communication disabilities using a rail network in Victoria, Australia to identify the barriers they encountered.

[The study is open access.](#)



Dr Lisa Chaffey has jointly published a [scoping review](#) as part of ongoing research on a peer education program for people with spinal cord injury in Fiji. We received grants to conduct the research from La Trobe Asia, and La Trobe University Institute for Human Security and Social Change.

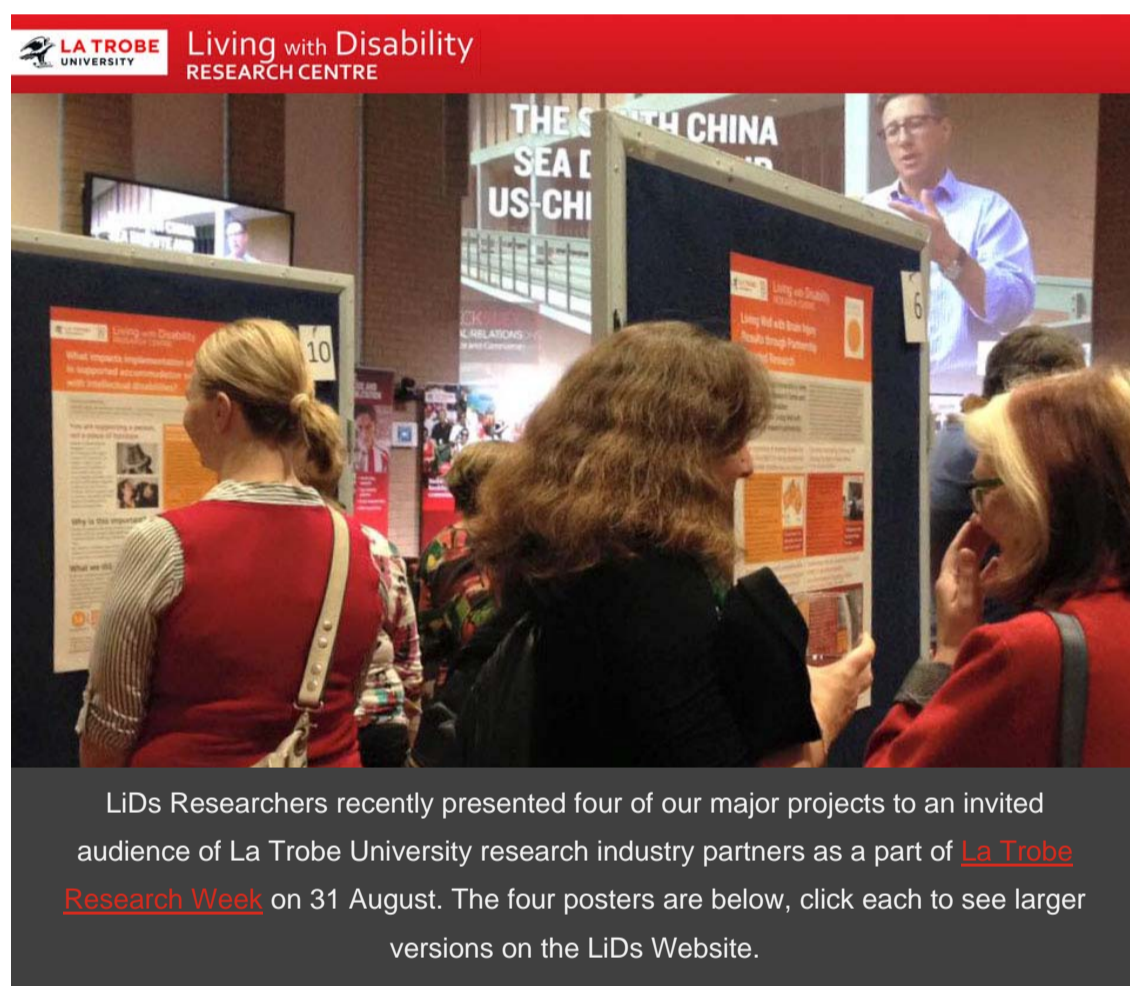


LiDs researchers are part of a team that has just published [a paper summarising what we have learnt about ways to deliver support for decision making](#) from looking at five years of pilot programs across Australia.

The paper is open access



You may have seen [the tweet](#) about two ways life stories have been used in our research. David Henderson's [extract from 'A day in my shoes' in IDA news](#) and [@k_dcruz's](#) LiDs Seminar on the experience of narrative storytelling for adults with acquired brain injury".



LiDs Researchers recently presented four of our major projects to an invited audience of La Trobe University research industry partners as a part of [La Trobe Research Week](#) on 31 August. The four posters are below, click each to see larger versions on the LiDs Website.

LA TROBE UNIVERSITY Living with Disability RESEARCH CENTRE

What impacts implementation of Active Support in supported accommodation services for people with intellectual disabilities?

Authors and Affiliations
Christine Bigby, Teresa Iacono, Emma Boull, Living with Disability Research Centre, La Trobe University & Julie Beadle-Brown, Living with Disability Research Centre & Tiard Centre, University of Kent.

You are supporting a person, not a piece of furniture

Person Centred Active Support is a way of providing just the right amount of assistance, to enable a person with intellectual disability to successfully take part in meaningful activities and social relationships. Support workers can use Person Centred Active Support with everyone, regardless of their degree of intellectual or physical impairment.

Interim findings

Important factors in implementing Active Support: Practice leadership

Levels of Active Support varied over time – despite an upward trend for most organisations, few service users received good active support. The strength of practice leadership and presence of the practice leader in the service are associated with better quality of support (Beadle-Brown, Bigby & Boull, 2017; Beadle-Brown, Bigby & Iacono, 2016).

A weak positive correlation was found between quality of support and the percentage of staff reporting training in active support (Bigby, Beadle & Beadle-Brown, 2017). Further analysis will explore other organisational factors such as culture, training content and human resource management.

3 mins

Across the whole sample, residents received training 3 mins over 7 years.

8 mins

and received other types of contact just under 8 minutes on average over 7 years.

Why is this important?

Research indicates the value of active support in improving quality of life for people with intellectual disabilities. However, implementation is not easy, and little research has explored why.

We aimed to identify some of the factors that impact on implementation of active support in supported accommodation services.

What we did

Data was collected annually for 7 years. We used momentary time sampling to observe the proportion of time service users were engaged in meaningful activity or social interactions. The quality of staff support was measured using the Active Support measure and interviews and observations were used to score the strength of Practice Leadership in each service. Other organisational data such as HR policies and a measure of culture were collected.

14

Organisations

7

Years of Data

41,200

Observations

Conclusions

This is the first longitudinal study of active support in Australia, and one key finding from the study is that active support is hard to maintain over time, but worthwhile in doing.

Our data provides evidence for the importance of systems to support staff practice - these include regular observation, coaching, modelling, teamwork and supervision. Funding for supported accommodation must be sufficient to include staff training in active support and the presence of practice leaders in service.

References: Bigby, C., Beadle, E., & Beadle-Brown, J. (2017). Implementation of active support over time in Australia. *Journal of Intellectual & Developmental Disability Research*. Bigby, C., Beadle, E., & Beadle-Brown, J. (2016). Cultural roots and outcomes of person-centred care in Australia. *Journal of Intellectual & Developmental Disability Research*. Beadle, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2015). The role of practice leadership in active support: impact of practice leader presence on outcomes. *International Journal of Developmental Disabilities*. Beadle-Brown, J., Bigby, C., & Beadle, E. (2015). Promoting Practice Leadership in Intellectual and Developmental Disability Services. *Journal of Intellectual Disability Research*. 30(2), 108 - 120.

LA TROBE UNIVERSITY Living with Disability RESEARCH CENTRE

Effective Decision-Making Support for People with Cognitive Disability
An ARC Linkage grant

Chief Investigators: Christine Bigby, Living with Disability Research Centre, La Trobe University, Jacinta Douglas, Living with Disability Research Centre, La Trobe University, Summer Foundation, Terry Carney AD, Sydney University, Ian Wiesel, Melbourne University, Shih-Ning Then, Queensland University of Technology. Project Team: Elizabeth Smith, Gisa Hamilton, Lucy Stone.

Why is decision making important?

Making decisions about one's own life is important to the health and well-being of all people. The NDIS aims to give people with disabilities more choice and control about the services they receive. Over 1 million Australians have some form of cognitive impairment due to intellectual disability (ID) or acquired brain injury (ABI). They require significantly more support for decision-making than other adults in the community.

What we are doing

We are recruiting 140 dyads of decision supporters and decision makers (either a person with intellectual disability or acquired brain injury). It is a randomised controlled trial with a strand for each of these two groups. The training group will participate in 2 workshops and receive follow-up mentoring for 3 months. At the end of the trial supporters in the control group will also be offered training.

What's the Problem?

Family members, disability support workers and others provide support for decision making, but there are problems and support does not always acknowledge or respect the person's right to make their own decisions. Informal support is not mentioned and supporters get little help to do a good job. Choice support is potentially constrained for much of what is in the best interests of individuals but risk for the person rather than their own preferences. The person's right to make decisions is removed through guardianship.

People with cognitive disabilities need more effective support for decision making if they are going to benefit from the decision making. We are going to provide this support to people with more severe cognitive disabilities to support supporters by providing skills and strategies for dealing with the conflict between rights and protection.

Decision making example

Josh lives in a group home. The organisation managing the home has painted all the bedrooms the same muted colour. Josh wanted to paint his bedroom black but was told this just wasn't on - the colour was not appropriate and it was too expensive anyway. Josh's brother helped him to point out to the organisation that it was his right to choose the colour of his bedroom and to consider how important painting his room is compared to other things he wants to do. Josh decided he was happy to save money by missing out on some upgrading events he was able to attend this.

Research Aims

Our aim is to systematically improve the quality of decision making support for people with cognitive disability. From our research on the provision of decision making support we have developed a practice framework and an intensive capacity building education program for people providing decision-making support to those with cognitive disability. The program includes vignettes of decision-making dilemmas from our research, and used professional actors working alongside actors with cognitive disabilities. This study will evaluate the impact of the educational program on supporters and the type of decision support people with cognitive disability receive.

Partners

References: Bigby, C., Beadle, E., & Beadle-Brown, J. (2017). The role of practice leadership in active support: impact of practice leader presence on outcomes. *International Journal of Developmental Disabilities*. 32(2), 87-101. Bigby, C., & Beadle-Brown, J. (2015). Cultural roots and outcomes of person-centred care in Australia. *Journal of Intellectual & Developmental Disability Research*. 30(2), 108-120. Bigby, C., & Beadle-Brown, J. (2015). Promoting Practice Leadership in Intellectual and Developmental Disability Services. *Journal of Intellectual Disability Research*. 30(2), 108-120.

