



Living with Disability

RESEARCH CENTRE



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Message from the Director

Professor Chris Bigby

In this newsletter is a brief overview of the Roundtable on Supported Decision Making Decision, held late last year and links to all the papers and presentations. We include updates on some continuing projects and snapshots of new projects on inclusive education, voting, community connections and inclusion in community sports for people with cognitive disabilities.

The schedule for LiDs seminars, held from 3-5pm on the second Wednesday of every month is included together with advance notice of several exciting events in the first week of November with international visitors Dr Jennifer Clegg from the UK and Dr Stacy Clifford Simpican from the USA.

I would like to welcome to LiDs Professor Magnus Tideman who joined La Trobe University as the Social Work Discipline Lead in February 2017. Magnus is a leading researcher in the field of intellectual disability in Sweden and brings several projects on self advocacy, support for decision making and post school options (see separate article on page 8).

Dr Tal Araten-Bergman from Israel joined the Social Work Discipline and LiDs early in 2017 bringing with her a strong track record of disability related research.

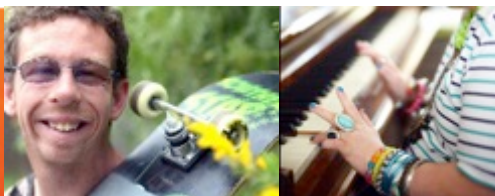
It is with sadness that we have said goodbye to Alice Nicholas who after getting married and a stint in QLD plans to go travelling. Alice leaves a hole in our centre support newsletter team that we are seeking to fill. We also said goodbye to Sam Murray from our Active Support Project who has taken a senior position with Jewish Care, and to Dr Cindy Cheng who completed her two year post doc position. Cindy contributed to the study of hospital access and her systematic review of employment support strategies for people with intellectual disability has just been accepted for publication.

Our research continues to be published in high quality international journals and links to some of the recent papers are on the last page. Over the last few months PhD students and researchers have taken up opportunities to share our research widely through presentations to industry partners, at sector forums, AGMs and invited lectures. Of particular note was the [Allen Martin Annual Memorial Lecture](#) given by Jacinta Douglas.

Indeed Jacinta's outstanding contribution to research in her field was twice recognised recently. She was the Winner of the Singapore Annual Innovation Award and an annual research prize in the journal *Brain Impairment* was named the Douglas Tate Prize in recognition of her role as one of the founding editors.

Finally congratulations to Dr Lucy Knox who graduated with a PhD late last year.





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Research in focus

Support for Decision Making



Improving Support
for Decision Making

The chief investigators for this project are LiDs members Christine Bigby and Jacinta Douglas, Ilan Wiesel (Melbourne Uni), Terry Carney (Sydney Uni) and Shih-Ning Then (QUT)

Other team members are Lizzie Smith, Lisa Hamilton and Lucy Knox.

ARC Linkage Grant 2015-2019 Support for Decision Making

The aim of this project is to improve the quality of support people with cognitive disabilities receive to make decisions. It has developed and is evaluating the effectiveness of an education program for decision making supporters. The study is being conducted with 12 Industry and 3 University partners in QLD, NSW and VIC. The project builds on the series of studies on decision support conducted by LiDs researchers and PhD students over the past few years.

The logo was created by Gavin from La Trobe Life Skills who won the design competition.

We are currently recruiting dyads of decision makers and supporters. We are looking for adults with intellectual disability or acquired brain injury, who have a family member, friend or paid supporter who provides them with regular decision making support.

Supporters will participate in two 3 hour training sessions and receive follow up mentoring for 3 months. The supporter and the person with cognitive disability will participate in a series of interviews about their experiences of giving or receiving support.

If you know of any people with a cognitive disability or supporters who would like to participate please contact Lizzie on e.smith3@latrobe.edu.au or (03) 9479 1954

Find out more about this project on our website <http://www.latrobe.edu.au/lids/research/support-for-decision-making/decision-making-support/how-to-get-involved>

Stop Press – New Project on Barriers and Facilitators of Sport Participation for People with an Intellectual Disability

People from Cultural and Linguistic (CALD) backgrounds with an intellectual disability have mainly been involved in segregated sport programs (and sometimes in culturally specific programs only) with limited options to develop or extend their opportunities. This study will add to the limited knowledge about the process necessary to foster the inclusion of people with intellectual disability from CALD backgrounds in community sport. Research questions are: what barriers and facilitators to participation in sport do people with intellectual disability from CALD backgrounds experience and what benefits do they derive from participation? The study is led by Dr Pam Kappelides, a Lecturer in Sport Management who has many years of expertise as a practitioner and researcher in the community and sport development sector including working with people with a disability and minority groups. To find out more contact Pam on p.kappelides@latrobe.edu.au or 9479 3899





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Research in focus

Support for Decision Making

Support for Decision Making Roundtable

Late in 2016 LiDs hosted a Roundtable on Support for Decision Making to discuss issues arising from current research. The event brought together researchers and interested practitioners from across Australia as well as Sweden and Scotland. Participants shared their experience of decision making support in different systems, with different groups of people with cognitive disability, including people with acquired brain injury, intellectual disability and dementia.

We were delighted to host Jan Killeen a Churchill Fellow from Scotland who talked about her work on the policy and practice of decision making support for people with dementia; Prof Magnus Tideman who presented an overview of the Swedish 'Godman' system drawing attention to the limited research about this unique scheme; and, Belinda Epstein Frisch who presented a paper on decision support developed by the Intellectual Disability reference group of the NDIS Independent Advisory group.

All papers/presentations are available on our website - [click here](#).



From Left: Deirdre Featherstonhaugh, John Chesterman, Magnus Tideman, Jan Killeen, Chris Bigby, Yvette Proud, Terry Carney, Jacinta Douglas, Lucy Knox



Round Table Presenters

John Chesterman

Perspectives from the Office of the Public Advocate in Victoria

Jan Killeen, Alzheimer's Society of Scotland

Scottish experiences supporting decision making of people with dementia

Belinda Epstein Frisch

Perspectives from the Independent Advisory Committee and the Intellectual Disability Reference Group

Dr Deirdre Featherstonehaugh, La Trobe University

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

Dr Lucy Knox, LiDs

Issues for practitioners in supporting people with acquired brain injury to make decisions.

Prof Magnus Tideman, La Trobe University

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

Prof Christine Bigby, LiDs

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

Professor Jacinta Douglas, LiDs

A Practice framework to build capacity of supporters of people with cognitive disabilities.

Emeritus Professor Terry Carney, University of Sydney

Meeting the challenge of moving from capacity to capacity-building

Yvette Proud

Experiences of supporting people with intellectual disability and their family members to make decisions





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Research in focus

Active Support Study

Embedding Active Support and Practice Leadership in Accommodation Support Services - ARC Linkage Study

Year 4 Results

This longitudinal study started in 2009 with a small pilot group of Victorian organisations and now involves 14 organisations from 5 states - WA, SA, VIC, NSW and QLD. Some are new to implementing Active Support and others have been doing it for many years. The study aims to identify the organisational factors associated with high levels of Active Support. It is based on evidence that when staff use Active Support the people they support are more engaged, have more choice and less challenging behaviour. However the reason for the study is that Active Support has been hard to embed into the every practice of staff.

Data on service user outcomes and the quality of support is collected using observational methods. The report prepared for each organisation every year provides independent evidence about the quality of their services and comparison with a large sample of other organisations. To date we have identified the importance of Practice Leadership to achieving higher levels of Active Support and service user engagement. We have also found that Active Support is likely to be higher when the Practice Leader is on shift compared to when they are not there.

Building on earlier ethnographic research on culture in group homes PhD student Lincoln Humphreys has developed the Group Home Culture Scale. This will enable us to test the relationships between service culture and service user outcomes and quality of practice in the final round of data collection in 2017.

During 2016 we collected data from 71 group homes across 11 organisations involving 257 people with intellectual disability. In February the team of Chris Bigby, Em Bould, Teresa Iacono and Lincoln Humphreys presented the results for 2016 to a room packed with senior leaders from our 14 Industry Partners.

Summary of the findings for 2016 which was Year 4 for most organisations:

- The level of Active Support and service user engagement remains variable across the organisations.
- There are pockets of very good quality and very poor practice.
- Most services in most organisations are providing mixed levels of active support.
- The average staff: service user ratio on shift has increased from Year 3 of the study.
- People with mild intellectual disability continue to receive better Active Support than people with more severe disabilities.
- Observation showed that since 2015 there has been an increase in age appropriate activities, warm and respectful interactions and the use of appropriate forms of communication for service users.
- Staff practices that contributed to poor levels of active support, included: poor preparation for activities, opportunities being overlooked, insufficient support to participate in more complex activities such as use of gas or electrical appliances, and failure to break down tasks appropriately.

The three most recent papers from this study are available by clicking these links.

[Observing Practice Leadership](#) - [Staff rated v observation of practice leadership](#) - [Presence of practice leader](#)

For more information on Active Support and Practice Leadership visit our website:

<http://www.latrobe.edu.au/lids/research/active-support-And-practice-leadership>





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Research in focus
Decision making support



Models of Supporting Community Participation

Working with National Disability Services (NDS), this study is investigating different ways of understanding and supporting community participation. We have identified three distinct support models. These are Supporting the development of friendships – Supporting convivial encounters in community groups or community spaces – Supporting development of identity and belonging.

Using case studies we are investigating best practice examples of each model to understand the 'program logic' and key elements necessary for good outcomes. The first of these best practice case studies was Arts Project Australia.

Sian Anderson presented "Community participation as a valued sense of belonging and identity – a case study of Arts Project Australia" at the February LiDs Seminar.

Arts Project Australia

The mission of this project is to support artists with a disability to produce works of art, to promote their work and advocate for their inclusion in the arts community. Over 120 artists, most with mild intellectual disabilities work in the studio, located in a former shoe factory in Westgarth, between Monday and Friday attending an average of three days per week. Arts Project staff are artists themselves and are called 'Staff Artists'. The Staff Artists guide the participants in the production of painting, drawing, ceramics, printmaking, 3D sculpture or digital media. They do not offer instruction, but using a 'hand in glove' approach support individuals to develop their technique and personal style. All of the artists exhibit their work in an annual gala show and others who have developed their art practice over many years may have a solo show in the downstairs gallery. Collaborations with artists outside Arts Project are facilitated by staff, as are relationships with other galleries and art dealers with an interest in selling or promoting the work of particular artists.

Our findings suggest that participants develop strong positive identities as working artists, a strong sense of belonging to an arts community, increase the social interactions with other people with intellectual disability in the program and with the local community of shop keepers and others who use the Westgarth shopping strip.

Next Steps

Further case studies are underway and will be completed by November this year.

"I think it's treating the people as adults in this community and not being tokenistic about what we do. Not everybody gets a poster for participating. We think that that's part of being an artist, and you don't always have success, and you don't always get recognised, and sometimes you get pushed down and down and down again and again and again, and so long as we're there to make sure that we support them through that process, it's an important part of being an artist, I think. So, avoiding that tokenism that you can get in a lot of disability services..." (staff)



Living with Disability Research Centre,
College of Science Health & Engineering
LaTrobe University, Bundoora Campus, Victoria, 3086



lids@Latrobe.edu.au



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Research in focus

supporting inclusive education



Developing Options to enable Specialist Schools to become “Centres of Expertise” to support Mainstream Schools to implement inclusive education

This project aimed to develop options to configure the relationship between specialist and mainstream schools and build mainstream school capacity reflective of contemporary evidence and existing models.

Five activities were completed between November 2016-April 2017:

- review of the literature;
- a survey of members of the Victorian Principals' Association of Specialist Schools to identify the nature of current supports to mainstream schools which had a 98% response rate;
- interviews with 32 stakeholders from specialist and mainstream schools (including parents);
- forum of 33 stakeholders to co-design options for how the expertise in specialist schools could be harnessed to support inclusive education;
- a survey to determine stakeholder ratings of the acceptability, feasibility and resource needs of the co-designed options.

Eight preferred options were identified through the project activities. These reflect previous models and practices that have been implemented in Australia and internationally, and have varying support from research evidence. The options were perceived by stakeholders to be resource-intensive, in particular in terms of budget allocation required and staffing to ensure the implementation of any option did not result in additional work for individual staff members that could overburden them or detract from their core or daily work. It should be noted that these were perceptions only in that the project did not include any attempt to cost options.

The preferred options have been included in a final report, submitted to PASS and the Department of Education and Training. This report will be used to submit recommended options to the Minister for Education.

Led by LiDs Professor Teresa Iacono this project brought together researchers from LiDs, the La Trobe Rural Health School (Amanda Kenny and Carol McKinstry), and the School of Education (Mary Keeffe).

It was funded by the Victorian Principals' Association of Specialist Schools (PASS)



Living with Disability Research Centre,
College of Science Health & Engineering
LaTrobe University, Bundoora Campus , Victoria, 3086



lids@Latrobe.edu.au



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Snapshots of new projects



Maximising Social Connection and Building Relationships in the Community: Evaluation of a Multi-component Community Connection program (M-ComConnect) for People with severe TBI - led by Jacinta Douglas

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 wellbeing and enhance community integration of individuals with severe brain injury, thus making a significant contribution to improving their long-term outcome.

The project is funded by the Institute of Safety Compensation and Research Recovery (ISCRR) and participants are currently being recruited for inclusion in the program. If you are interested in being part of this study, please email louise.dixon@latrobe.edu.au and one of the research team will contact you.

Strategies to Support People with Intellectual Disability to Participate in Voting

This study is funded by the Victorian Electoral Commission and grew out of the seminar on political participation and citizenship held by LIDs in collaboration with ASID and Inclusion Melbourne last year. It is being led by Sophia Tipping and Chris Bigby.

It will investigate what best supports the participation of people with intellectual disability to participate in elections in Australia aiming to identify the factors that facilitate or obstruct voting of people with intellectual disability. In collaboration with the Victorian Electoral Commission and Inclusion Melbourne the study will use the findings from a survey of disability support organisations and focus groups with people with intellectual disability to trial and evaluate strategies to support voting at the next State election in November 2018.

Please contact us if you would like to participate in the survey or one of the focus groups. S.Tipping@latrobe.edu.au

Developing the capacity of NSW Ability Linkers and Local Area Coordinators to support decision making

This study is a partnership with the St Vincent de Paul Society of NSW who are responsible for an Ability Linkers and LAC program. It will develop knowledge about existing strategies used by workers in these positions to support decision making by people with disabilities, deliver and evaluate a training program to extend their skills.

Risk Enablement for people with cognitive disabilities – Funded by Dept of Family and Community Services NSW

The aim of this project is to develop and evaluate a risk enablement training package for support organisations and their staff working with people with cognitive disability. It will

- Compile a summary of evidence-based best practice models.
- Develop a modular, risk enablement training package for face-to-face delivery to support a range of supporters of people with cognitive disabilities
- Pilot and refine the training package with support staff from one disability organisation.
- Develop materials for online delivery of the training package.





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Our team and our work



**Introducing Professor Magnus Tideman
Social Work Discipline Lead School of
Allied Health and Member of LiDs.**

The purpose of my research is to identify, analyse and critically examine the relationship between society's welfare system and people's every-day lives and living conditions. A particular focus is to highlight and analyse the marginalised perspectives. Close cooperation and collaboration with authorities, organisations, service-users and professionals is an important feature of my work.

I have been particularly interested in young adults with intellectual disability and their struggles to exert increased influence over their circumstances and to participate more fully in society. Other research areas are the social construction of normality and deviance in school, self-advocacy, supported decision-making and transition from school to adulthood.

I graduated from the School of Social Work at Lund University, Sweden, in 1982 and worked as Social worker, Director and Project Manager within the public sector from 1983 to 1992. I was chair of Disability Studies with focus on social work at Halmstad University in Sweden from 2008 until February 2017.

Current projects

- Adults with intellectual disability and self-advocacy in Sweden – paternalism or empowerment? Active citizens?
- Supported decision-making and young adults with intellectual disability
- Transition from school to labour market for young adults with intellectual disability

Contact details M.Tideman@latrobe.edu.au



Congratulations to Dr Lucy Knox (pictured here with her primary supervisor, Jacinta Douglas) who graduated with her PhD at the end of 2016. Lucy's thesis was a groundbreaking study about decision-making support for adults with traumatic brain injury. It included 5 publications in leading journals.

Knox, L., Douglas, J. & Bigby, C. (2016, early online). "I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury. [Disability and Rehabilitation](#).

Knox, L., Douglas, J. & Bigby, C. (2016). Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury. [Research and Practice in Intellectual and Developmental Disabilities](#), 3(1), 12-21.

Knox, L., Douglas, J. & Bigby, C. (2016). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents." [Neuropsychological Rehabilitation](#), 26(2), 236-260.

Knox, L., Douglas, J. & Bigby, C. (2015). "The biggest thing is trying to live for two people": The experience of making decisions within spousal relationships after severe traumatic brain injury. [Brain Injury](#), 29(6), 745-757.

Knox, L., Douglas, J. & Bigby, C. (2013). Whose decision is it anyway? How clinicians support decision making participation after acquired brain injury. [Disability and Rehabilitation](#), 35(22), 1926-1932.



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What's new & what's on

Selected new publications

Fossey, E., Chaffey, L., Venville, A., Ennals, P., Douglas, J., & Bigby, C. (2017). Navigating the complexity of disability support in tertiary education: Perspectives of students and disability service staff.

[International Journal of Inclusive Education](#)

Douglas, J., Knox, L., De Maio, C., Bridge, H., Drummond, M., & Whiteoak, J. (2016). Effectiveness of Communication-specific Coping Intervention for Adults with Traumatic Brain Injury (TBI): Preliminary Results.

[Neuropsychological Rehabilitation](#).

Pozzebbon, M., Douglas, J., & Ames, D. (2017). "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, 31\(4\), 375-387](#).

Johnson, H., Bigby, C., Iacono, T., Douglas, J., Kathagan, S., & Bould, E. (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 & Developmental Disability](#).

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

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](#).

Mineur, T., Tideman, M. & Mallander, O. (2017). Self-advocacy in Sweden—an analysis of impact on daily life and identity of self-advocates with intellectual disability. [Coqent Social Sciences, 3\(1\), 1304513](#).

Bigby, C., & Craig, D. (2017) "My life is a lot richer!" A case study of an intentional friendship between a volunteer and adult with severe intellectual disability.

[Journal of Intellectual and Developmental Disabilities](#) 42, 180-189. goo.gl/DPD7Zo



Events

LiDs 2017 Seminar Series

Date: 2nd Wednesday of every month

Time: 3.00pm - 5.00pm

Where: Health Sciences 1 Room 203 (HS1 203), La Trobe Bundoora

More Info: Go to www.latrobe.edu.au/lids/resources/events

All are welcome!

Wednesday 10 May Seminar

3:00pm - Prof. Magnus Tideman

A research perspective on the current situation for people with intellectual disability in Sweden – some examples of housing, employment, self-advocacy and changes in the welfare system

4.00pm - Dr. Maureen Long & Dr. Annie Venville
Accessing mental health services for people with intellectual disability

Wednesday 14 June Seminar

3.00 pm – Dr Tal Araten-Bergman

4.00 pm – Dr David Henderson

'We didn't even really know what we were volunteering for': Welfare, volunteerism and the origins of the Kew Cottages Parents' Association

Wednesday 12 July Seminar

3.00 pm - Andrea Grindrod

Improving end-of-life outcomes for people with intellectual disability: Public health approaches to care

4.00 pm - Dr Darren O' Donovan

Design flaws in the NDIS

Save the Date: Wed Nov 1

2017 La Trobe Roundtable on Community Participation for People with Cognitive Disabilities

Plus a week of master classes and seminars with international guests

