



Living with Disability RESEARCH CENTRE



In the news....

Building the evidence for
NDIS – Prof Chris Bigby

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Message from the Director

Professor Chris Bigby

The roll out of the NDIS promises to improve the quality of life of people with disabilities, by greater access to better quality support to enable people with disabilities to be included in society. The senior researchers in the Living with Disability Research centre have long track records of contributing to the evidence base on which the NDIS is being built. All our current research will inform the development of NDIS in one way or another.

Particularly important to current debates about housing is our longitudinal study of Person Centred Active Support. This demonstrates that ordinary housing in the community is a necessary but not sufficient condition for a good quality of life. Housing on its own, no matter how innovative, is only one ingredient, people with intellectual disabilities also require high quality support.

Our research has shown the significance of person centred active support to good outcomes, and is beginning to identify the organisational factors necessary for this type of staff practice – strong front line leaders who can coach and model good support, robust HR practices that make it clear to staff what is expected of them and do not tolerate disrespectful attitudes.

Two of our new research projects will tackle other key issues.

- In collaboration with NDS and funded by the National Disability Research and Data Working Group we are developing a person centred model of community participation and identifying key elements of effective programs.
- With 12 Industry partners across 3 states our new Linkage grant will explore the processes of support for decision making and trial evidence based resources designed to equip 'supporters' of people with cognitive disabilities to better enable the people they support to participate in decisions about their own lives.

Check out our new home!

Visit the new Living with Disability Research Centre (LiDs) website which gives you valuable information about our Centre, our research, our projects, resources and much more!

www.latrobe.edu.au/lids  lids@Latrobe.edu.au

Living with Disability Research Centre



Building an evidence base to support inclusion
Making a positive difference in the lives of people living with disabilities.

[OUR APPROACH >](#)



Research
The Living with Disability Research Centre has three research themes.



Resources
For people with a disability, their families, carers and the services that they use.



HDH Students
We have a thriving research group and welcome HDH students to apply for research with us.



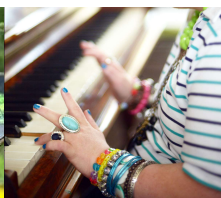
Our Staff
Find contact details for our Centre staff.

[RESEARCH PROJECTS >](#)

[RESOURCES AND EVENTS >](#)

[HDH STUDENTS >](#)

[FIND STAFF >](#)



Living with
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Research in focus

Enabling mainstream services to be inclusive

Adults with cognitive disability & the health system

People with cognitive disability are amongst the most frequent users of hospital systems, yet they have poor health outcomes. The team at the Living with Disability Research Centre have been successful in receiving support from a National Disability Research and Development Grant to investigate the encounters and experiences of people with cognitive disabilities, their families and hospital staff in the health system.

Australian and international reports indicate that while in hospital, people with cognitive disabilities have their basic needs go unmet, and interactions with the hospital system are often difficult both for people with cognitive disability and their families. As a result the project teams in Bendigo and Metropolitan Melbourne will be expanding their scope to investigate how the encounters impact people's experiences as well as their long term health outcomes.

Through this project, we are seeking to understand the many issues to be addressed to ensure that people with cognitive disability receive optimal health care while in hospital. With the pilot complete, the study includes encounters in Emergency Departments, acute care wards, in-patient wards and day procedure centres in specific metropolitan and regional catchment areas.

It is expected that we will have completed the collection of data by the end of 2016. Our results will provide direction for systematic changes that will strengthen the ability of hospitals to make reasonable accommodations to meet the needs of people with cognitive disability, thereby affording them the same quality of care available to others.

If you would like to be involved in the project or **find out more** go to our website www.Latrobe.edu.au/lids

Meet the project team:

This study is being led by Christine Bigby, Teresa Iacono and Jacinta Douglas

Project Team: Cindy Cheng, Sophia Tipping, Ruth Quibell (Melbourne) & Jo Spong (Bendigo)



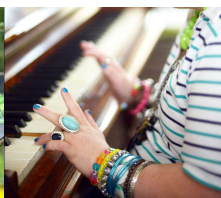
For more information, to get involved, to keep up to date or contact the researchers



HospitalCD@latrobe.edu.au



(03) 9479 5740



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Research in focus

Improving disability services



Australian Government
Australian Research Council

Active support longitudinal study update

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

The Active Support study has been undertaken by La Trobe University since 2013 to investigate how to improve frontline staff practices, active support delivery and managerial influences that impact the use of Active Support and the subsequent quality of life outcomes for people with cognitive disability.

The study involves the collection of 5 annual waves of data from 2013-2017. It is funded by an Australian Research Council (ARC) Linkage grant and contributions from Industry Partners.

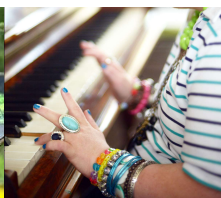
Summary of findings in year 3 (2015)

- There has been a (non-significant) steady increase in active support at an overall level over time (50% Year 1, 58% Year 2 & 63% Year 3).
- There has also been improvement in levels of engagement overall, with people spending on average 57% of the time engaged (34 minutes per hour).
- Despite levels of assistance remaining low, there has been an increase overall (6%, 4 minutes per hour compared to 4%, 2 minutes per hour in Year 2).
- Although levels of practice leadership remain low, we have identified an association between practice leadership and higher levels of active support.
- A new initiative this year is a 5 session practice leadership course for participating organisations. The course is trialling new training materials that will be developed into an online course.

For more information go to our website or check out the online Active Support resource:
<http://www.activesupportresource.net.au/>

Thank you to our Industry Partners





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Watch this space....
Participation and inclusion

Catalyst for inclusion of people with intellectual disability in the community

Building social relationships in the community is difficult for anyone, let alone for a person with an intellectual disability. There is also a lack of evidence and few effective models to increase social relationships or enable people to connect with peers, places or activities in the community. With the impending launch of the National Disability Insurance Scheme (NDIS) and the heightened awareness of people with disability participating and being included in the community, investigating catalysts for community inclusion could not be more timely.

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

Our answer: Cute, adorable, friendly dogs.

This study aims to support 40 adults with intellectual disability to regularly walk a dog in their local community and evaluate the impact on their social connections, quality of life and emotional wellbeing.

Currently we are recruiting a range of participants for the pilot, which include an equal number of people living in shared supported accommodation as well as supported living options.

With generous support of the Righteous Pups Australia and local disability support organisations in Bendigo, we will be inviting people with intellectual disabilities and their families to be involved in local information sessions to find out more about the project and how they can be involved.

If you know of anyone in the Bendigo area that might be interested in this project, please contact us at lids@Latrobe.edu.au

Meet the team:

Living with Disability Research Centre: Dr Emma Bould, Professor Christine Bigby and Lisa Hamilton,
Anthrozoology Research Group: Associate Professor Pauleen Bennett, & Dr Tiffani Howell



About the primary researcher

Emma has a diverse background of research experience which is underpinned by quantitative methodologies and analysis. Since August 2010 she has been working as a Research Fellow in the Living with Disability Research Centre at La Trobe University, and currently has 7 research papers under review.

The focus of her work is on front line practice that supports quality of life outcomes and enables community participation for people with intellectual disability. Her current research projects are examining the effectiveness of supported accommodation services, and the nature and meaning of social inclusion for people with intellectual disability.

This project takes a new direction to address the lack of research evidence that exists about effective models for supporting people to negotiate often difficult social relationships. We are investigating how best to provide effective and consistent support to enable people to connect with peers, and the places or activities in the community.



LA TROBE
UNIVERSITY

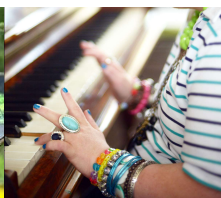
The project is funded by La Trobe Building Healthy Communities.



www.latrobe.edu.au/lids/research



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**Living with
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Research in focus

Enabling mainstream services to be inclusive



Reading difficulties, dyslexia & university study

Dyslexia is a developmental learning disability characterised by a primary deficit in decoding written words. Secondary consequences involve poor spelling, poor reading comprehension and reduced opportunity for ongoing oral language growth and knowledge building. Given the permanent nature and consequences of dyslexia, dyslexic university students represent a distinct group who are likely to require specifically targeted support and reasonable adjustments to ensure equitable access to the curriculum.

Our research focuses on establishing what barriers and facilitators are operating in Australian universities that optimise or restrict educational opportunities and participation for students with dyslexia. A central aim is to explore how the knowledge and expectations held by tertiary educators' about their students with dyslexia may influence their beliefs and their capacity to provide support and accommodations to these students.

Our research team have conducted research investigating the lived experience of Victorian university students with dyslexia and have surveyed their views about receiving support and reasonable adjustments to enhance their study experiences.

We are about to commence an exploration of Australian university academic teaching staff's knowledge about dyslexia and their experiences and views of teaching and/or supporting university students who have this condition.

The results of this research will be used to inform better practices and resources needed to support students with dyslexia who are studying in tertiary or higher education settings.

About Tanya

Dr Tanya Serry, B.App. Sc (Sp Path), M.Arts (Applied Linguistics), PhD. is a Senior Lecturer in the Discipline of Speech Pathology and a member of LiDs at La Trobe University. She is also an Honorary Research Fellow at the Murdoch Children's Research Institute.

Dr Serry's research interests focus on the prevention, early identification and intervention for people with dyslexia and other reading, spelling and writing difficulties.

She has researched policy and practices to support this population and currently advises Speech Pathology Australia on evidence-based practices for management practices and interventions for people with these problems.

Dr Serry conducts both quantitative and qualitative research and she has published book chapters on qualitative research methodology.

Want to know more about the projects at LiDs?

Visit our website for more detail and how to get involved!

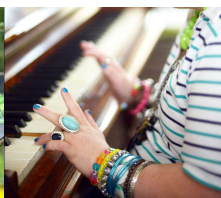
www.latrobe.edu.au/lids/research



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



lids@Latrobe.edu.au



Living with Disability

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PhD research in focus



Capable and different: A grounded theory of studying at university for students with mental ill-health

Between 20 and 25% of university students experience mental ill-health and up to 45% experience elevated psychological distress, making mental ill-health and distress important issues for both students and universities. While universities attempt to meet the needs of these students a detailed understanding of the experience of students with mental ill-health is not available to inform students or to direct policy development or intervention efforts.

This study used a participatory framework to explore the experiences of university students experiencing mental ill-health. Data were gathered through 21 in-depth interviews with 15 current students, and twelve reference group meetings that involved discussions between six people with lived experience of mental ill-health and the investigators.

Rigorous comparative analysis of data and theoretical sampling generated a substantive theory of the process of studying for students with mental ill-health.

The study found that students with mental ill-health feel both capable and different, and that they strive to be 'regular' university students. The central issue for all participants was feeling different and needing to manage that feeling of difference in order to persist with study.

When the demands of being a student outweighed their resources, participants dropped out of studying. Participants that had dropped out, all found ways to return to study after tolerating despair they experienced as a consequence of dropping out.

The development of the theory found that participants managed feeling different in three different ways a) by hanging in with difference, b) wrestling with difference and c) reconciling difference.

We hope that this theory may promote awareness of students' shared experiences, decrease students' sense of isolation and shame, and may guide alternative actions for students and universities.

LiDs is very sad to say farewell to Priscilla and thanks her for her contribution to the little LiDs group and projects about education and disability.

Read one of the papers in Priscilla's study:

Ennals, P., Fossey, E., & Howie, L. (2015). Postsecondary study and mental ill-health: A meta-synthesis of qualitative research exploring students' lived experiences. *Journal of Mental Health*, 24(2), 111-119. doi:10.3109/09638237.2015.1019052

About Priscilla

I am an occupational therapist who worked for 14 years in mental health services before joining the teaching team in occupational therapy at La Trobe.

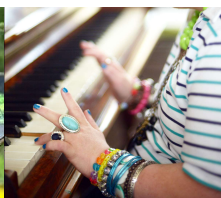


I decided to do a PhD to develop my skills and confidence in research. In deciding on a research topic I combined my two areas of expertise – mental health and higher education.

I felt that the experiences of students with mental ill-health were poorly understood and that better understanding student perspectives might better inform policies and practices, and potentially improve outcomes for this group of students.

Doing my PhD on a full time scholarship, while maintaining a day of teaching, and juggling family life with three children, was a great balance for me. Now that I have completed my PhD I have decided to take on a role as a manager of research and evaluation within a mental health NGO. I look forward to continuing to build my skills, partnering with multiple universities, and being involved in research that aims to improve outcomes for people living with mental illness.





Living with Disability

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Our team and our work

Conferences

2015

The Living with Disability Research Centre was well represented at the 50th Annual ASID Conference in Melbourne.



All presentations are accessible on the conference website www.asid.asn.au/conferences

Teresa Iacono - Hospital encounters of adults with cognitive disability: Report of a pilot study.

Claire Quilliam - An evil necessity: Frontline staffs' perspective(s) on group home paperwork

Christine Bigby - Culture in higher performing group homes for people with severe intellectual disabilities.

Mary Whiteside - Supporting people with intellectual disabilities in decision making – processes and dilemmas.

Rahila Ummer Christian - Access and appropriateness of dental services for people with intellectual disabilities

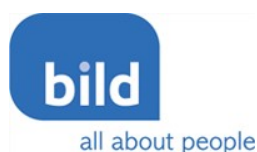
Michelle Browning - The practice of supported decision making in Canada.

Magnus Tideman Policy and practice for people with intellectual disability in Sweden.

Sian Anderson Scaffolding the development of positive identity: support workers in self-advocacy groups

Magnus Tideman Plain English invited speaker - The current situation for people with intellectual disability in Sweden – a role model or a warning example?

BILD's International Ageing Well Research and Practice Conference



Christine Bigby presented *Providing good support to people with intellectual disabilities as they grow older: what do we know and why is it so hard to achieve?*

www.youtube.com/watch?v=8-eA18qlbm0



Awards

2016 ZEST Award

Every Moment Has Potential: Online learning resource for disability support workers

won an award in the category of "Outstanding Use of Technology by a not for profit organisation" at the recent Zest Awards held in Sydney.



Congratulations to all those involved!

www.activesupportresource.net.au/

Honorary Member of Australian Association for Social Workers

Professor Christine Bigby for received an **Honorary Life Membership** from the Australian Association for Social Workers, in recognition of exemplary contribution to the association and the social work profession. Congratulations Chris!

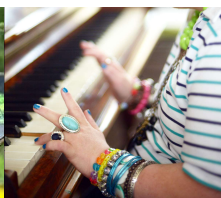


In the media

Interview on Social Inclusion with Prof Chris Bigby and Hilary Harper 774 3LO

Date: 14/11/2015

www.latrobe.edu.au/lids/resources/training-resources



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What's new & What's on

Resources

Recent papers published by LiDs members include:

Venville, A., Mealings, M., Ennals, P., Oates, J., Fossey, E., Douglas, J., Bigby, C. (early on line 2016) **Supporting students with invisible disabilities: A scoping review of postsecondary education for students with mental illness or an acquired brain injury.** *International Journal of Disability, Development and Education*, DOI: 10.1080/1034912X.2016.1153050

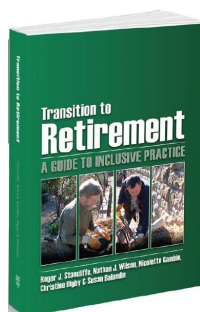
Wiesel, I., & Bigby, C. (2016). **Mainstream, inclusionary and convivial places: locating encounter between people with and without intellectual disability.** *Geographic Review*, 106, 2, 201-214

Knox, L., J. Douglas & C. Bigby (2016). **"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents.** <http://www.tandfonline.com/doi/full/10.1080/09602011.2015.1019519> \I "abstract" *Neuropsychological rehabilitation*, 26,2, 236-260 <http://dx.doi.org/10.1080/09602011.2015.1019519>

See LiDs staff members' pages for fuller list.

Transition to retirement

The Transition to Retirement (TTR) program aims to help older people with long-term disability gradually build an active and socially inclusive retirement lifestyle through volunteering and participating in mainstream community groups.



The TTR manual includes planning forms and video material to make these benefits available more widely.

An ebook format with embedded video clips and links to printable forms is now available **on the iBook Store and Google Play.**

<http://purl.library.usyd.edu.au/sup/9781743323274>



Events

LiDs 2016 Seminar Series

The Living with Disability Research Centre 2016 Seminar Series

Date: 2nd Wednesday of every month

Time: 3.00pm - 5.00pm

Where: Health Sciences 1 Room 203 (HS1 203), La Trobe Bundoora. All are welcome.

Wednesday July 13

Loretta Piccenna

The health and disability interface associated with young people with high complex needs at risk of or residing in residential aged care

Sophia Tipping

The political participation of people with intellectual disability: A critical mapping review of the literature.

IASSIDD 15th world congress

15-18 August in Melbourne

La Trobe University is a sponsor for the conference and LiDs staff and PhD students will be presenting a wide cross section of their research



IASSIDD 15TH WORLD CONGRESS
Global Partnerships: Enhancing Research, Policy and Practice
Melbourne 15-19 August 2016

SAVE THE DATE

18 November Roundtable on support for decision making with international guests from Sweden and Scotland.



For more information on the seminars go to www.latrobe.edu.au/lids/resources/events