LATROBE LIDS NEWSLETTER| ISSUE 3

October 2016

LA TROBE UNIVERSITY

Living with Disability RESEARCH CENTRE

In the news….

Message from the Director

Professor Chris Bigby

Research is not complete until it is published and disseminated in ways that are accessible to those who might use it to make change. Members of LiDs presented more than 20 papers on their research about lived experiences of people with intellectual disabilities and service systems to international audiences at the IASSID congress held in Melbourne in early August. Details of these papers and some action pictures of the PhD students are in later pages of this newsletter. Notably too, Jacinta Douglas has just returned from Macau and the 39th Annual Brain Impairment Conference where she and some of her PhD students presented papers and workshops of their research about experiences of living with brain injury. Closer to home, I had the pleasure of speaking about our Support for Decision Making research at the NSW CID conference and a forum of families, advocates and service providers in Qld.

LiDS is about to commence a number of new projects translating our research into more accessible forms. Commissioned by the NDS Centre for Applied Disability Research we are writing three short literature reviews on Active Support, Practice Leadership and Factors that Impact on Quality of Life Outcomes in Supported Accommodation. Each of these reviews will be accompanied by shorter guides to the key issues written for service providers and consumers.
Another new project, funded by the Department of Family and Community Services, LiDS will develop and evaluate a risk enablement training package for support organisations and their staff working with people with cognitive disability**.**
We are also pleased to welcome Identity WA as a new partner in the Embedding Active Support and Practice Leadership study. They are first disability support service from WA to join the study, which now means the study has 14 industry partners from 5 states.

LiDS members have also published an impressive number of papers in peer reviewed journals with at least as many again accepted and still in press (see page 8 for details). In November we will be hosting two international visitors, Jan Killen from Scotland who is on a Churchill Fellowship to investigate supported decision making and Prof Magnus Tideman, an expert on social participation of adults with intellectual disability from Sweden who will be working with us on new research proposals. Both Jan and Magnus together with other leading researchers and advocates will be speaking at the Roundtable on Support for Decision Making to be held on 18 November at the La Trobe City Campus (see p.9 for details)

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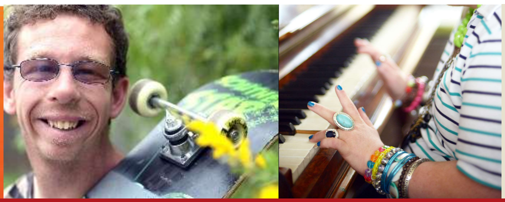

Living with Disability RESEARCH CENTRE

Research in focus

IASSIDD World Congress 2016

IASSIDD 15th World Congress 2016

Written by Sophia Tipping,
PhD Candiate, Living with Disability Research Centre.

Every four years the International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) holds a World Congress.

This provides a global community of intellectual disability stakeholders the opportunity to come together and share knowledge. In 2016 Melbourne was the host city and a sizable contingent of Living with Disability Research (LiDs) centre members were in attendance.

Thirteen members presented on topics as diverse as their disciplines and roles in LiDs. Higher degree researcher students, early career researchers and more seasoned members of the LiDs team were all represented from disciplines as diverse as history, social work and speech pathology.

A strong theme in a number of LiDs presentations was the right to self-determination for people with intellectual disability at both an individual and collective level. Other presenter's topics related to creating social and service environments that facilitate the human rights and potential of people with intellectual disability - for instance in group homes, public transport systems or the broad community.

Attending LiDs members enjoyed in hearing from people with varied relationships to disability. There were a number of speakers with lived experience of intellectual and developmental disability who shared their knowledge and ongoing efforts to create change in the sector and the community more broadly.

Representatives from government departments, service providing agencies and advocacy organisations shared innovative policy and service provision strategies from around the globe.

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

LiDs members agreed that collegiality of attending as a part of the LiDs team enriched the experience. LiDs is keenly awaiting the next IASSIDD World Congress to be held in Glasgow in 2019.

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

Support for Decision Making symposium
(from left) Michelle Browning, Jacinta Douglas, Christine Bigby and Julie Beadle-Brown.

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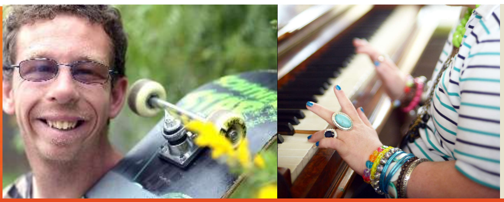


Research in focus

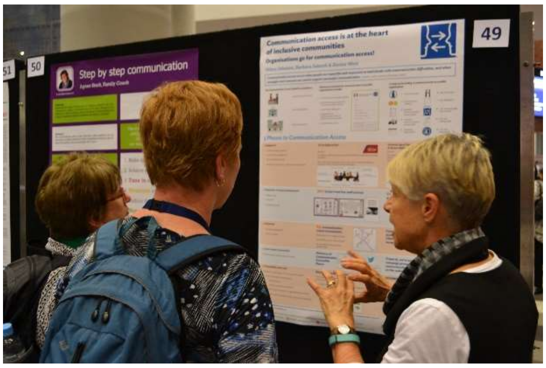
IASSIDD World Congress 2016

Research into early communication and language development. Oliver Wendt (from back left), Steve Warren, Meredith Allan, Teresa Iacono, Juliet Goldbart, and Susan Balandin.

Networking with industry leaders from NSW CID

IASSIDD members (from left) Karen Nankervis, Roger Stancliffe, Robert Davis & David Felce

LiDs PhD Students (Left to right) Row 1: David Henderson, Row 2: Claire Quilliam, Lincoln Humphreys, Row 3: William Crisp, Sophia Tipping and Michelle Browning.



Poster Presentations with Hilary Johnson

Thank you to all LiDs members for contributing to the IASSIDD 15th World Congress 2016.

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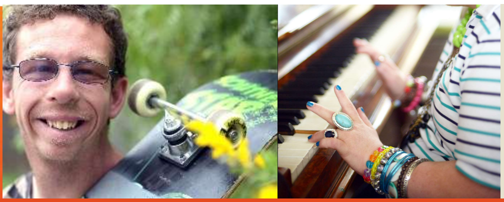


Living with Disability RESEARCH CENTRE

Research in focus

IASSIDD World Congress 2016

IASSIDD presentations by the LiDs team

Culture in group homes

- Dimensions of culture in underperforming and better Group Homes for people with severe ID - **Christine Bigby**
- Development of a scale to measure organisational culture in group homes - **Lincoln Humphreys**
- Being in two minds: Staffs' perspectives of paperwork in group homes for people with ID - **Claire Quilliam**
- Understanding the culture of supported accommodation for individuals with severe/profound ID: Preliminary findings from 'good' services - **Lisa Richardson**

Active Support

- The role of practice leadership in active support: Impact of practice leaders' presence in services - **Emma Bould**
- Implementation of active support over time in Australia - **Christine Bigby**
- Does the model matter? Comparing outcomes for people with ID in 'supported living' and group homes - **Christine Bigby**
- Exploring the relationships between active support, practice leadership and staff knowledge and values - **Julie Beadle-Brown**

Decision-making

- Development of an evidence-based support for a decision-making practice framework to guide decision-making supporters of people with ID - **Jacinta Douglas**
- Models of delivering decision-making support to people with ID in Australia - **Christine Bigby**
- The process of supported decision-making: a Canadian model - **Michelle Browning**
- The role of active support in decision-making - **Julie Beadle-Brown**

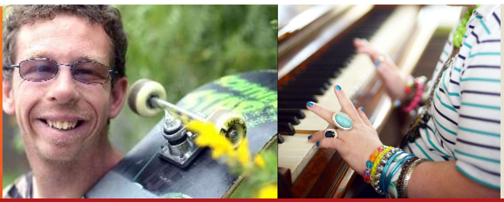
Self-determination, Rights & Inclusion

- The complexity of self-determination for people with ID - **William Crisp**
- Mainstream, inclusionary and convivial places: Locating encounter between people with and without ID - **Ilan Wiesel**
- The political participation of people with ID: A mapping review - **Sophia Tipping**
- Supporting train travel for people with communication disabilities - **Hilary Johnson**
- 'It's a lonely world out there': Kew Cottages Parents' Association and opposition to deinstitutionalisation - **David Henderson**

Health

- Hospital encounters of adults with cognitive disability: Report on 10 cases - **Teresa Iacono**
- A scoping review of pathways to dementia diagnosis for people with and without intellectual disabilities - **Teresa Iacono**
- Healthy dying for people with intellectual disabilities in residential services - **Andrea Grindrod**
- Death and the disability residential home: Mining narratives to enhance practice - **Andrea Grindrod**
- The implementation and effectiveness of progressive resistance training programmes in people with Down Syndrome - **Nora Shields**
- FitSkills programme for young people with disabilities: Translating evidence into practice - **Nora Shields**
- Does foot posture and footwear fit influence the level of physical activity of children with Down syndrome? - **Nora Shields**

Abstracts for all IASSIDD 2016 LiDs presentations can be downloaded from https://goo.gl/IlZGch



Research in focus

Decision making support

Decision making aids & discussion guides for partial foot amputation

People need assistance from healthcare professionals to make informed decisions about screening, treatment and health related interventions. Decision aids are designed to support the decision making process and provide information about different treatment options as well as the potential risks and benefits.

Research indicates that decision aids help people to be better informed about the treatment options, reduce uncertainty and result in greater satisfaction with the decision making process.

Dr. Dillon and his collaborators, Matt Quigley, La Trobe Universit and Dr Fatone, Northwestern University, Illinois have undertaken a comprehensive systematic review into the outcomes of partial foot amputation and used the evidence to develop a *patient decision aid* (pictured) and a *clinician-patient discussion guide.*

These resources can be used as part of a consultation to ensure that important topics are discussed. The decision aid is designed to be taken home, which allow people to read over the information and share it with their family. In this way, people can familiarize themselves with the different options and likely outcomes, at a time when they can really take in the information.

Patient decision aids must meet international standards designed to ensure that information is accurate and easy to understand. The standards also require decision aids to be rigorously tested by the people who will ultimately use them. The decision aids are currently being tested.

The research was supported by the American Orthotic and Prosthetic Association (AOPA) and was recently presented to the AOPA National Assembly in Boston.

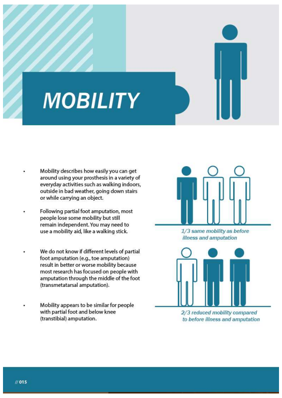
If you are interested to learn more about this work, please attend **the next LiDs seminar this coming Wednesday 12th October 3-5pm, Health Sciences 1, Room 203.**

About Dr Michael Dillon

Dr Michael Dillon is a Senior Lecturer in prosthetics and orthotics at La Trobe University.

Dr Dillon's research has focused on the outcomes of lower limb amputation, particularly partial food amputation. This research has led to the development of resources to help inform difficult decisions about amputation surgery.

Dr Dillon is a member of La Trobe University's Living with Disability Research Centre.



MOBILITY

- Mobility describes how easily you can get around using your prosthesis in a variety of everyday activities such as walking indoors, outside in bad weather, going down stairs or while carrying an object.
- Following partial foot amputation, most people lose some mobility but still remain independent. You may need to use a mobility aid, like a walking stick.
- We do not know if different levels of partial foot amputation (e.g., toe amputation) result in better or worse mobility because most research has focused on people with amputation through the middle of the foot (transmetatarsal amputation).
- Mobility appears to be similar for people with partial foot and below knee (transtibial) amputation.

1/3 same mobility as before illness and amputation

2/3 reduced mobility compared to before illness and amputation

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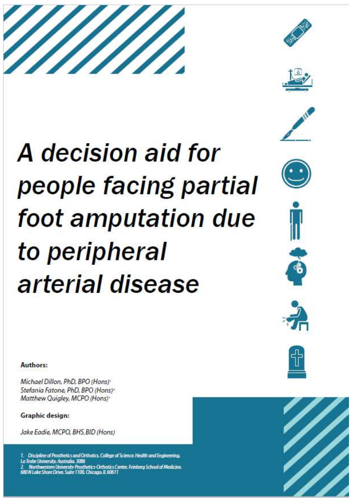

A decision aid for people facing partial foot amputation due to peripheral arterial disease

Authors:

Michael Dillon, PhD, BPO (Hons)[1]
Stefania Fatone, PhD, BPO (Hons)[2]
Matthew Quigley, MCPO (Hons)[1]

Graphic design:

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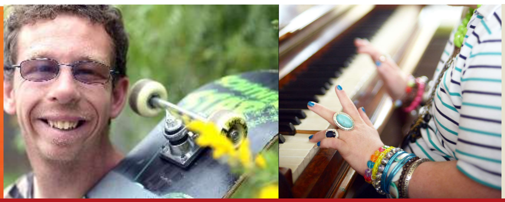

Living with Disability
RESEARCH CENTRE

Research in focus

Person-centre active support

A trial: The effectiveness of training for practice leaders in disability services

It has been found that person-centred active support is an effective approach to support people with disabilities to engage in meaningful activities and social relationships. Despite this evidence, embedding person-centred active support within organisations has proven to be difficult. Previous research acknowledges that *practice leaders*, who are the front-line managers, have a key role in the implementation of person-centred active support and the quality of support provided by disability support workers.

This study aims to trial a training program to increase the quality of practice leadership provided by front-line managers. Commencing in October, the project aims to pilot a participatory training program for up to 30 practice leaders from three disability organisations in Victoria.

Delivered through six three-hour workshops, the training program will focus on:

- the elements of practice leadership;
- quality of life outcomes,
- allocating and organising staff,
- observation,
- modelling and coaching,
- and one-to-one supervision and team meetings.

We will evaluate the impact of the training by comparing practice leaders baseline and post training scores on the five key elements of practice leadership using the Observed Measure of Practice Leadership (Beadle-Brown, Bigby & Bould, 2015).

This is a timely project, given the reforms occurring in disability services with the National Disability Insurance Scheme, the variable and often poor quality of supported accommodation services, and the need for disability services to provide evidence of good practice and front line management.

Following completion of the study, it is hoped that the results will provide support for further grant applications to develop an online practice leadership resource within an Australian context.

This project has been funded by La Trobe University, School of Allied Health, 2016 Strategic Research Grant Scheme.

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

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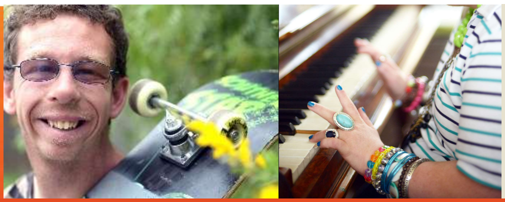


Living with Disability RESEARCH CENTRE

PhD research in focus

Do self directed approaches lead to greater self determination for people with intellectual disability?

The aim of my research is to identify some of the factors that enable people with intellectual disability with high support needs to successfully achieve self-determination. For the purposes of my research I have broadly conceptualized self-determination as being about how individuals are being supported to make choices and decisions, and in turn how these choices and decisions "…are encouraged, respected, and supported" (Agran et al., 2010, p. 78).

Governments, policy makers, the disability sector and other families in similar situations need to have a better understanding of the complexity of the processes involved in supporting people with high support needs to live the lives they choose.

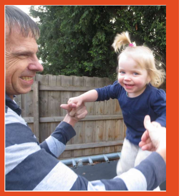
Most contemporary public policy about disability, including the National Disability Insurance Scheme, emphasis the notion of choice in theory, but how does this apply to people with intellectual disability in reality.

It is generally assumed that people with moderate to severe levels of intellectual disability either cannot achieve self-determination or do so like other community members which probably is not the case. If we can learn from those people successfully being supported to be self- determined, these learning can be applied to this group of people more broadly.

The primary method used to identify these factors was to interview those people, primarily families and paid staff who are supporting people and to observe people following their daily routines.
This was due to a belief that those providing the support would be a significant part of the explanation about people's self-determination. Currently families are being engaged to participate in the research however it has been more difficult to recruit than expected.

The results of this PhD will be interesting to behold and will most likely not be the outcomes we all expected.

About William

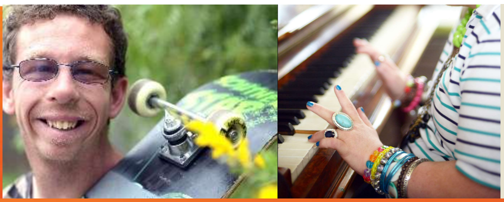


For almost 20 years I have worked in the disability sector, first for DHS in a number of roles for about 11 years. I have then worked for a number different NGO's doing person centred planning, case management and advocacy. More recently I worked at NMIT as a disability support officer and in local government undertaking project work again in the disability area.

My interest in the sociology of disability or the social nature of disability stems from my own physical disability, cerebral palsy. I just ended up working with people with intellectual disability by default because that was where the work was! Then caught the research bug. In 2010 I started a Graduate Diploma of Research Methodology here at LaTrobe under the supervision of Chris Bigby. She also taught me at the University of Melbourne and kept on encouraging me to come and do more research.

But seriously the nuanced connections between the lived experience of physical and cognitive disability is my real interest. The social model of disability was developed by people with physical disability yet it is just as applicable to people with cognitive disability.

My aim in undertaking a PhD is to critique some of the underlying assumptions about disability that are incorrect and do not reflect people's lived experience of the "phenomena". This aim is probably rather grandiose, so in practical terms my aim is simply to highlight the complex practices that need to go on to aid people with intellectual disability to have their will and preferences reflected in their everyday lives.



Our team and our work

Recent articles

Recent papers published by LiDs members include:

The role of practice leadership in active support: impact of practice leaders' presence in supported accommodation services (2016). Emma Bould, Julie Beadle-Brown, Christine Bigby and Teresa Iacono. http://dx.doi.org/10.1080/20473869.2016.1229524

"I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury (2016). Lucy Knox, Jacinta M Douglas & Christine Bigby. http://dx.doi.org/10.1080/09638288.2016.1219925

A case study of an intentional friendship between a volunteer and adult with severe intellectual disability: "My life is a lot richer!" (2016) Christine Bigby & Diane Craig. http://dx.doi.org/10.3109/13668250.2016.1219701

Confidence of group home staff in supporting the health needs of older residents with intellectual disability (2016).Ruth Webber, Barbara Bowers & Christine Bigby **http://dx.doi.org/10.3109/13668250.2015.1130218**

Supporting Students with Invisible Disabilities: A Scoping Review of Postsecondary Education for Students with Mental Illness or an Acquired Brain Injury (2016). Annie Venville, Margaret Mealings, Priscilla Ennals, Jennifer Oates, Ellie Fossey, Jacinta Douglas & Christine Bigby. http://dx.doi.org/10.1080/1034912X.2016.1153050

Family caring of older adults with intellectual disability and coping according to loci of responsibility (2016).Teresa Iacono, Elizabeth Evans, Adrian Davis, Anjali Bhardwaj, Beth Turner, Jennifer Torr, Julian N. Trollor. http://dx.doi.org/10.1016/j.ridd.2016.07.004

If you would like a copy of any of these papers please just send us an email.

Unpacking complex health needs. Commentary on Assessing health needs of children with intellectual disabilities: a formative evaluation of a pilot service (2016). Teresa Iacono http://dx.doi.org/10.1080/23297018.2016.1194226

Exploring the validity of the Transsexual Voice Questionnaire (male-to-female): Do TVQ^{MtF} scores differentiate between MtF women who have had gender reassignment surgery and those who have not? (2016). Georgia Dacakis, Jennifer M. Oates & Jacinta M. Douglas. http://dx.doi.org/10.1080/15532739.2016.1222922

"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 (2016). Margaret Pozzebon, Jacinta Douglas & David Ames. http://dx.doi.org/10.1080/02687038.2016.1230840

Culture in better group homes for people with severe and profound intellectual disability. (2016) Christine Bigby & Julie Beadle-Brown. http://dx.doi.org/10.1352/1934-9556-54.5.316

We were more radical back then: Victoria's first self-advocacy organisation for people with intellectual disability (2016). David Henderson & Christine Bigby. http://www.jstor.org/stable/10.5401/healthhist.18.1.0042

AUDIO SLIDES:
Family caring of older adults with intellectual disability and coping according to loci of responsibility - Teresa Iacono
http://audioslides.elsevier.com/getvideo.aspx?doi=10.1016/j.ridd.2016.07.004

Cited in:
Including Disability in the Social Work Core Curriculum: A Compelling Argument (2016). Judith Moyle
http://dx.doi.org/10.1080/0312407X.2016.1216575

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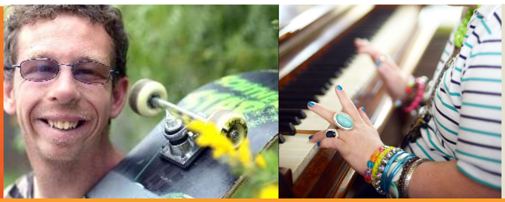

Living with Disability RESEARCH CENTRE

What's new & What's on

Seminar:

Putting Rights into Practice: Political Citizenship for People with Intellectual Disabilities

Date: Wednesday 9 November 2016
Time: 2.00pm - 5.30pm
Where: La Trobe University City Campus
Lvl 20, 360 Collins Street
Melbourne VIC 3000

To register go to for this seminar go to:
https://goo.gl/9d6BcH

Roundtable:

Supporting People with Cognitive Disabilities with Decision Making

Date: Friday 18 November 2016
Time: 9.30 – 3.00 pm
Where: La Trobe University City Campus
Lvl 20, 360 Collins Street
Melbourne VIC 3000

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 12 October

Shared decision making to inform decisions about partial foot amputation – **Dr Michael Dillon**

Development & psychometric evaluation of the Transsexual Voice Questionnaire - **Georgia Dacakis**

Wednesday 14 December

Dental Services for Children with Intellectual Disability - **Rahila Ummer Christian**

The perspectives of front-line staff in Disability Employment Services, specifically in relation to supporting clients with mental illness - **Caitlin McDowell**

The 2017 LiDs Seminar Series will be available soon!

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