



**LA TROBE**  
UNIVERSITY

LIVING WITH DISABILITY  
RESEARCH CENTRE

# 20 17

## Annual Report



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# How we operate

Research staff at the centre are either funded entirely from research grants or hold teaching and research positions. La Trobe University provides the core infrastructure funding for the Living with Disability (LiDs) Research Centre.

LiDs works in collaboration with a large (40+) and evolving range of advocacy, disability and mainstream service provider organisations. Collaborators work with us to design and implement research and frequently provide funding. They are also important in helping LiDs to trial interventions, education or training packages developed through our research, as well as helping share our findings with stakeholders to increase the impact of our research.

LiDs is grateful to the Summer Foundation for their continued co-funding of the Summer Foundation Chair, Living Well with Brain Injury, held by Professor Jacinta Douglas and the research program associated with this chair.

Our external academic collaborators come from across the Australian University sector including, the University of Melbourne, the University of Queensland, University of New South Wales, Southern Cross University, and Griffith University.

LiDs research is funded by national and international competitive grants from the Australian Research Council (ARC), National Health and Medical Research Council (NHMRC) and other industry or government funding bodies.

LiDs is situated in the School of Allied Health but works with academics from Schools across the University, including the Schools of Law, Humanities and Social Sciences, Rural Health and Business. Our PhD students are from various disciplines including, social work, speech pathology, and disability studies.

Who we work with:

**Government (State and Commonwealth)**

**Industry - Disability Services**

**Mainstream services such as health, education and transport**

**Industry peak or advocacy bodies**

For a full list see page 31

# MESSAGE FROM THE DEPUTY VICE CHANCELLOR (RESEARCH)

**The Living with Disability Research Centre is a role model in bridging the gap between academic research and its application in practice. Now firmly established and with a growing reputation within the University and in its many overlapping communities, the centre is highly engaged and generates research that has a transformational impact within the disability sector. Our work is especially vital in the context of the revolutionary change driven by the roll out of the NDIS. National Disability Insurance Scheme (NDIS).**

The centre demonstrates a bi-directional exchange between industry partners and academic researchers, and is an exemplary example of how La Trobe University does things differently to shape the future of our communities.

The centre is connected to its communities via an impressive number of partnerships and exchanges that enable a high level of involvement with the beneficiaries of its research creating impacts far greater than the Centre's size would suggest.

One example is the New Perspectives Series, a series of events LiDs held in November across La Trobe campuses. The series received overwhelmingly positive feedback by a diverse audience. Challenging new ideas were examined

with rigour by academics of our own and other institutions, together with confronting conversations with industry leaders and frontline staff.

LiDs continues to work across our Research Focus Areas delivering ambitious programs of scale and depth as well as trialling innovative ideas and approaches. The contribution to the La Trobe Research Week event in October 2017 gave an overview of the depth of research and bodes well for the impact the centre will have on the La Trobe University research goals outlined in our new strategic plan (2018 – 2022). The centre's research draws on our many campuses and works with our different communities to bring diversity to research projects by working with the Schools of Rural Health in Bendigo and Allied Health in Bundoora.

I am pleased to see that the continued University investments, such as internal grants to support Early Career Researchers, has contributed to the success of Professor Bigby and the Centre. The Centre's output of high quality research publications and success in attracting research grants continue to improve, demonstrating our commitment to excellence and community impact.

I am also pleased to report that LiDs continues to work across an exceptionally varied array of disciplines and research areas. From History to Management and Law, the reach of LiDs reflects the totality of the lives of those we research. Professor Bigby has managed to draw several common threads that form a substantial framework across her research themes



and maintain a consistent appeal to the needs of industry and other partners.

I hope you join me in celebrating their successes. I look forward to an exciting 2018 and the contribution LiDs will continue to make to our proud tradition of service to our many communities.

**Deputy Vice Chancellor (Research)  
Professor Keith Nugent**



# MESSAGE FROM THE DIRECTOR

**2017 will be marked as the year that thousands of people across Australia felt the impacts of the largest change to disability funding in recent history. Throughout our 11 vibrant seminars and NDIS information sharing meetings we heard real stories of the obstacles and opportunities this new system is bringing.**

This new regime is predicated on effective individual choice making and participation in community that makes the coalescing framework of LiDs research even more vital and timely. We are pleased to have expanded in several areas that increase the much-needed body of evidence to inform policy and skills that will impact our communities in a demonstrably good way and will, we hope, in time allow the NDIS to meet its full potential.

Our continued expansion has once again been led by several new and significant grants (see page 23 for a full breakdown) as well as productive research for an increasing number of industry partners, (now 40+) helping them answer difficult, real-world questions with high-quality research.

This vital work with industry and government partners adds new perspectives to our research and brings new ways of thinking to those we work with. Reinforcing this vital linkage continues to be a differentiating strand of our work. Also in this vein we are pleased to continue funding our key research papers and reports to be open access, a full list of which are on the LiDs website ([www.bit.ly/LiDs-papers](http://www.bit.ly/LiDs-papers)), the University's research repository ([www.latrobe.edu.au/library/research-](http://www.latrobe.edu.au/library/research-and-grant-support/research-online)

[and-grant-support/research-online](http://www.cadr.org.au/clearing-house)) and increasingly the valuable Centre for Applied Disability Research (CADR) Clearinghouse

[www.cadr.org.au/clearing-house](http://www.cadr.org.au/clearing-house)  
CADR also published a useful set of Research to Action guides, including one based on our Good Group Homes Seminars, which you can read about on page 20.

Our work on Active Support, supported decision making, community inclusion and ways to improve services to be more inclusive delivered more well-received research, reinforcing our three research pillars. This report presents a broad set of highlights from these research themes and shows how it was shared with a diverse and growing audience across the sector, the country and with other world-class researchers across the globe. We improved the reach and frequency of our communications through our newsletter, to which I encourage you to subscribe:

[www.bit.ly/LiDsNews](http://www.bit.ly/LiDsNews)

The impact of our research was particularly evident in our major series of events in November dubbed 'New Perspectives', the highlight of which was another in-depth roundtable discussion between over 200 attendees from academia, industry leaders

and practitioners and three visiting academics, Dr Stacy Clifford Simplican (USA), Professor Jennifer Clegg (UK) and Dr Jens Ineland (Sweden) who joined us to discuss new theoretical frameworks and how they can inform our practical research, and vice versa.

The staff of the centre play a key role in our successes. I am pleased to see their successes being recognized, with the promotion of Dr Emma Bould to Senior Research Fellow in late 2017. I'm also pleased to announce that Dr Stacy Clifford Simplican (USA) will be joining us as an Adjunct Associate Professor and is someone we look forward to working with in the coming years.

We also wish a fond farewell to Professor Magnus Tideman, who will be returning to Sweden, but will continue to work with LiDs.

Once again, I would like to thank all the staff and partners of the Living with Disability Research Centre for their continued work in improving the lives of one of the most vulnerable groups in our community.

**Director, Living with Disability Research Centre**  
**Professor Christine Bigby**



# MISSION VISION EXPERTISE

## Mission

Our mission continues to be to improve the social inclusion and participation of people with cognitive disability through research, education and knowledge transfer. We will improve the 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 continue 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.

## 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.

## Research and Translation

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.

- Effectiveness of disability services;
- Building the evidence base for participation; and
- Enabling mainstream services to be more inclusive.

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 and aphasia or other language problems.







# GOVERNANCE

LiDs activities are overseen by an Executive Committee comprising the Director (Professor Christine Bigby), Professors Jacinta Douglas and Teresa Iacono.

**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 submit it to the Academic Board through the PVC (College of SHE) and the Deputy Vice-Chancellor (Research).

**Current Advisory Committee Members are:**

## Internal members

- The Centre Director - Professor Christine Bigby
- Theme leaders - Professors Teresa Iacono and Jacinta Douglas
- The Pro Vice-Chancellor (Research) Nominee - Professor Russell Hoye
- The Pro Vice-Chancellor (College of SHE) Nominee - Professor Rob Pike
- University Members - Professors Patrick Keyzer and Katie Holmes
- Staff member of the Centre - Dr Emma Bould (Senior Research Fellow LiDS)

## External members

**(from organisations within the sector)**

- Daniel Leighton - Brotherhood of St Laurence
- Dr Christine Fyffe - Consultant
- Dr Di Winkler - Summer Foundation
- Dr Gerry Naughtin - Mind Australia (Stepped down November 2017)
- Dr Jane Tracy - Centre for Developmental Disability Health Victoria

# Personnel



**Professor Christine Bigby**

Director of the Living with Disability Research Centre



**Professor Jacinta Douglas** - Summer Foundation Chair, Living Well with Brain Injury



**Professor Julie Beadle Brown** - LiDs and The Tizard Centre, University of Kent, UK



**Professor Teresa Iacono** - School of Rural Health

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

## SENIOR RESEARCH FELLOWS

- Dr Emma Bould
- Dr Hilary Davis
- Dr Suzane Vassallo

## RESEARCH FELLOWS

- Dr Sian Anderson
- Dr Nadine Cameron
- Dr Lisa Chaffey
- Dr David Henderson
- Dr Lucy Knox
- Dr Ruth Quibell
- Dr Elizabeth Smith
- Dr Jo Spong
- Ms Rebecca Leeson
- Dr Megan O'Neil



**Professor Magnus Tideman** - Discipline lead, Social Work and Social Policy, and member of LiDs until April 2018

## RESEARCH OFFICERS

- Ms Emma Caruana
- Ms Caitlin Farmer
- Ms Belinda Green
- Ms Lisa Hamilton
- Mr Lincoln Humphreys
- Ms Emma Hunter
- Ms Bronwyn Lacey
- Ms Rosa Solá Molina
- Ms Claire Quilliam
- Ms Sophia Tipping
- Mr Andrew Westle
- Ms Erin Wilson

## ADJUNCTS

- Luke Bo'sher - Adjunct Research Fellow
- Professor Lauren Clark - Adjunct Professor
- Dr Jennifer Clegg - Adjunct Professor
- Dr Stacy Clifford Simpican - Adjunct Associate Professor
- Professor Ellie Fossey - Adjunct Professor
- Dr Chris Fyffe - Adjunct Professor
- Dr Hilary Johnson - Adjunct Associate Professor
- Dr Natasha Layton - Honorary Research Fellow
- Dr Kristina Szönyi - Honorary Research Fellow
- Dr George Taleporos - Adjunct Senior Research Fellow
- Dr Jane Tracy - Adjunct Associate Professor
- Dr Di Winkler - Adjunct Associate Professor







## La Trobe University staff associated with LiDs

Dr Tal Araten-Bergman – Social Work  
 Mrs Anoo Bhojti – Occupational Therapy  
 Professor Leanne Carey – Occupational Therapy  
 Dr Marcella Carragher – Speech Pathology  
 Dr Jillian Cavanagh – Management  
 Ms Kate D'Cruz – Occupational Therapy  
 Dr Michael Dillon – Prosthetics & Orthotics  
 Dr Shane Erickson – Speech Pathology  
 Dr Pam Kappelides – Sport & Tourism  
 Dr Maureen Long – Social Work  
 Dr Darren O'Donovan – Law  
 Dr Robyn O'Halloran – Speech Pathology  
 Dr Jodi Oakman – Public Health  
 Professor Jennifer Oates – Speech Pathology  
 Professor Miranda Rose – Speech Pathology  
 Dr Tanya Serry – Speech Pathology  
 Dr Andrea Simpson – Audiology  
 Dr Rwth Stuckey – Public Health  
 Dr Mary Whiteside – Social Work

## Higher Degree by Research Students

Danielle Ashley	Jenna MacNab
Michelle Attard	Jade McEwen
Michelle Browning	Margaret Mealings
William Crisp	Margaret Pozzebon
Kate D'Cruz	Claire Quillam
Peter Dorsett	Gail Ritchie
Melanie Drummond	Bojana Sarkic
Priscilla Ennals	Ondine Stachnow
Amy Ford (Muir)	Kellie Stagg
Kate Fitt	Sophia Tipping
Lincoln Humphreys	Elizabeth Williams
Susan Jackson	Barbara Wolfendon
Yeptain Leung	Rahila Ummer Christian
Kristy Logan	



# RESEARCH ACTIVITIES

The research of LiDs is broadly undertaken in three themes:

- Effectiveness of disability services;
- Building the evidence base for participation; and
- Enabling mainstream services to be more inclusive.

The work in these themes is necessarily complementary and overlapping, with projects often covering two themes.

The following pages present snapshots of some of our projects. A full listing of our current projects starts on page 23.



**Professor Christine Bigby**

Director of the Living with Disability Research Centre

Professor Bigby continued to edit the journal **Research and Practice in Intellectual and Developmental Disabilities** during 2017, editing a special issue on Citizenship and Inclusion for People with Intellectual Disabilities during 2017.

See: [www.bit.ly/RAPIDD17-4-1](http://www.bit.ly/RAPIDD17-4-1)

## The disability inclusive city, how will the NDIS change Australian cities?

LiDs researchers are partners in a major new ARC Discovery grant-funded study led by Dr Ilan Wiesel, looking at how the NDIS will affect participation in mainstream urban services (education, health, transport, community centres, open space, recreational facilities and other urban services).

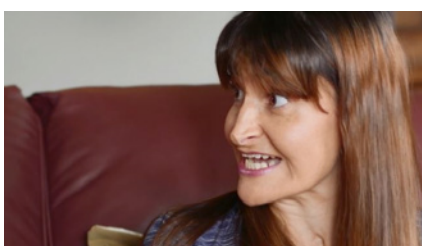
The grant will run over a three year period and will aim to improve policy, capacity building and help the NDIS deliver on some of its challenging goals. Stay tuned for more news as the project develops.

The project website:  
[www.bit.ly/LiDs-City](http://www.bit.ly/LiDs-City)



## Effectiveness of disability services

The work in and around this theme has created a structured evidence base on which disability services can improve the quality of life for the people they serve. Working closely with people with a disability and disability services, researchers are investigating new models of services, such as supported living, new practices such as supported decision making, exploring community participation and how to improve outcomes in group homes through embedding active support and practice leadership.



### Embedding Active Support and Practice Leadership in supported accommodation services

Active Support is one of a number of person-centred approaches, and there is strong research evidence that has shown that frontline staff practice based on Active Support leads to better quality of life outcomes for people with intellectual disabilities.

This project includes 14 Industry Partners from 5 states (NSW, QLD, SA, WA and VIC). It has been funded through contributions from Industry Partners and an ARC Linkage grant.

Achievements to date include several published papers, available at: [www.bit.ly/CBigbyPapers](http://www.bit.ly/CBigbyPapers).

Lincoln Humphreys developed the Group Home Culture Scale which provides a snap shot of culture in services that can be used as a diagnostic tool.

In terms of service and policy development, the study has demonstrated the variability in quality of support between and within organisations, the value of independent evidence about quality of support, and the importance of practice leadership to good outcomes.

### Effective Decision Making Support for People with cognitive disability

Ensuring that all people with cognitive disability have support for decision making that respects their will, preference and rights is even more fundamental to the NDIS now we have started to see its practical rollout.

This ARC Linkage project is testing 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. The resources were developed from previous projects investigating support for decision making led by Professors Bigby and Douglas. They include a practice framework and illustrative film clips. These clips are tailored either to people with intellectual disability or those with acquired brain injury, made by professional actors working with people with cognitive disabilities.

We are investigating the impact of the resources on the practices of decision making supporters and the person being supported. A randomised control trial is being conducted in 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).

The main deliverable will be a suite of adaptable training materials to improve support for decision making for people with an intellectual disability. An additional project has involved training Local Area Coordinators and Ability Linkers from St Vincent de Paul Society in NSW in supported decision making.



# Building the evidence base for participation



Professor Jacinta Douglas - Summer Foundation Chair, Living Well with Brain Injury

Many people with a disability continue to be unnecessarily excluded from participating in wider society or activities that most of us take for granted.

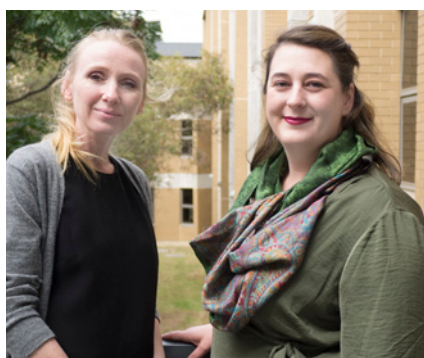
The projects in this theme make use of academic research to identify challenges, promising practices and strategies to facilitate participation and social inclusion of people with cognitive disability.



**M-COM Connect or Maximising Social Connection and Building Relationships in the Community: Evaluation of a Multicomponent Community Connection program for people with severe traumatic brain injury (TBI)** is a research program focusing on community connection amongst adults with TBI.

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. 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.

The project is funded by the Institute of Safety Compensation and Research Recovery (ISCRR) and the first participants have been recruited for inclusion in the program.



Rebecca Leeson (L) Megan O'Neill (R)

## New Research staff for the M-Com Connect project

### Rebecca Leeson

During Rebecca's career as a Speech Pathologist she has developed interests including all aspects of traumatic brain injury as well as Progressive Disorders, developed after her Masters which used Conversation Analysis to analyse the conversations of people with Parkinson's disease with their spouses. Then followed several years working in the UK, at John Radcliffe Hospital as a Senior Speech Pathologist and then in Bristol as Lead Clinician for Progressive disorders at Frenchay Hospital.


After moving to Melbourne in 2013,

she joined Independent Rehabilitation Services working in a Multidisciplinary Community team which has given her an understanding of the complex issues encountered by clients and their families during the rehabilitation journey.

### Dr Megan O'Neil

Megan studied a Doctor of Psychology (Clinical Neuropsychology) at Monash University and is currently a generally registered psychologist. She has worked extensively with people with acquired disorders, particularly those following stroke and traumatic brain injury.

Her experiences have taken her across a wide range of both clinical and research settings. In recent years, Megan has worked on a number of projects focused specifically on rehabilitation. These have included an environmental enrichment intervention program that aimed to improve functional outcomes during sub-acute rehabilitation, a multi-site randomised control drug trial to improve mobility post-stroke and spinal cord injury, and memory rehabilitation post-stroke in both group and individualised formats.



**The NDIS is the greatest chance for wide and meaningful participation in the community that this group has had in many years.**

## **Social Participation for people with low vision**

Low vision creates difficulties participating in activities of daily living such as reading and writing. The expected outcome of this project is a better rehabilitation method that will help clients achieve meaningful goals.

The project will take place in Singapore, supervised by Professor Leeanne Carey but will have a high level of interest for rehabilitation practitioners here in Australia.

This research aims to understand the barriers to participation in activities of daily living. Reasons may include difficulty identifying client centred goals, resistance to change and the lack of resources to follow up with recommendations. This may be related to older adults viewing low vision as part

of ageing and accepting their decreasing independence and the tendency to rely on a family member or domestic worker to take care of them.

Without addressing this problem, continuing the current practice of low vision rehabilitation may not be effective to help older adults participate in activities of daily living and this may increase the risk of depression, functional decline and create problems in high-risk activities like medication management.





**“To see these very isolated, beautiful individuals come alive and smile, as friendships were formed as these new people addressed them by their name, was just wonderful”**

Righteous Pups managing director, Joanne Baker

## Dogs as 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 intellectual disabilities. There is a lack of evidence about how to provide effective and consistent support to facilitate people with intellectual disabilities to have convivial encounters in community or commercial places. So we raised the question... What might be a catalyst for encounters in the community for individuals with intellectual disabilities? Our answer: Cute, adorable, friendly dogs.

With the launch of the NDIS and the heightened awareness of people with disability participating and being included in the community the study could not be timelier.

Dr Emma Bould, senior research fellow from LiDs, received funding from the Building Healthy Communities Research Focus Area, and the study led to a new collaborative partnership between two schools, two research groups (Living

with Disability Research Centre and Anthrozoology Research Group), and two campuses (Melbourne and Bendigo). Dr Emma Bould and Professor Christine Bigby from LiDs, in partnership with Dr Pauleen Bennett and Dr Tiffani Howell from the Anthrozoology Research Group trialled a visiting dog walking program in collaboration with two qualified and experienced dog handlers from a national not for profit organisation based in a regional city in Victoria, Australia, specialising in assistance and therapy dog programs.

Sixteen adults with intellectual disabilities were divided into two groups, with half having 14 outings with a dog and its handler, while the other half had 14 outings with a handler alone, followed by five outings with a handler and a dog. Findings showed there were significantly more encounters between participants and strangers when a dog was present. Furthermore, those with a dog experienced more positive encounters with others, were more quickly recognised and acknowledged and showed greater confidence to engage socially with strangers.

On 14th November 2017 Dr Emma Bould along with five participants, the handlers and dogs gathered at Lake Weeroona,

Victoria. Press were invited to attend for interviews video and photographs. The research subsequently featured on WIN News Bendigo, 9 News Central Victoria, and in the Bendigo Advertiser, Bendigo Weekly, Riverine Herald and National Disability Guide.

The study highlights the potential for a dog walking program to encourage encounters, which in the long term could be catalysts to help people build a sense of identity and belonging in the community. The researchers are now seeking further funding to conduct a larger trial.



Dr Emma Bould (kneeling), Jimmy the dog and a participant in the trial.



# RESEARCH ACTIVITIES

## Supporting People with Intellectual Disability to Vote

This project is a collaboration between LiDs and the Victorian Electoral Commission with support from Inclusion Melbourne and a consortium of other Australian Electoral Commissions.

The project aims to fill a research gap that exists around the voting habits of people with intellectual disabilities and an absence of co-created interventions to increase and support the exercise of political citizenship. Since last year's fruitful seminar on Political Citizenship a research team led by Professor Bigby has conducted a survey of support workers and focus groups with people with intellectual disabilities. Results revealed that there was an awareness of politics among people with an intellectual disability and a number of barriers to voting. There was a strong desire to facilitate voting among support staff and organisations but minimal action taken to support voting.

Results of the survey were presented by LiDs researcher Sophia Tipping as a part of the LiDs 'New Perspectives' events and at the ASID Conference in Hobart, both in November.

Sympathetic to our supported decision-making research, and our research theme around participation in society this project will co-design an intervention which will be tested and trialled in the upcoming Victorian State election in late 2018. A scoping review will also be published during 2018.

**View both reports online:**

[www.bit.ly/LiDs-VotingReport](http://www.bit.ly/LiDs-VotingReport)



## Risk Enablement training and resources

Enabling people with cognitive disabilities to participate in activities that involve risk is a part of good support practice. Following an extensive literature review and consultations with members of the NSW Council on Intellectual Disability, a draft training program was developed. During August and September 2017, staff from LiDS (Lisa Hamilton, Dr Suzane Vassallo) travelled to NSW to trial the program in four face-to-face workshops with disability support workers. The workshops focussed on how to incorporate positive risk taking into their support practice. Topics covered in the

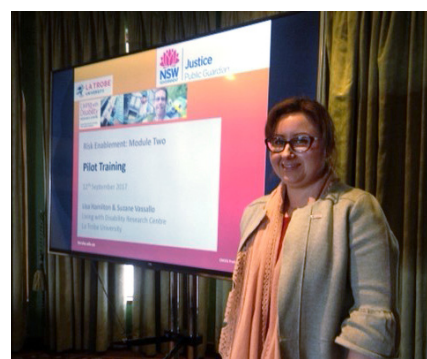
training included: positive outcomes from risk taking, what happens when support workers operate in a risk averse manner, and how to put risk enablement into practice so the people they support live full and meaningful lives. Findings from the face to face training sessions have since been used in the development of a freely-accessible online learning resource about enabling risk in disability support work. This resource will provide a sustainable means whereby support workers, and anyone who supports people with cognitive disabilities, can learn about this type of practice. It will be launched in 2018. This project was supported by funding from the New South Wales Department of Family & Community Services.

### The Essentials of Risk Enablement



**View the online training:**

[www.enablingriskresource.com.au](http://www.enablingriskresource.com.au)



Dr Suzane Vassallo



Professor Teresa Iacono - School of Rural Health

## Enabling mainstream services to be more inclusive

Led by Professor Teresa Iacono, this theme identifies cost-effective opportunities to better account for the needs of people with a disability. Mainstream services (Health, but also legal, library, entertainment, public transport and education etc) will continue to provide the vast majority of services and supports required despite the implementation of the NDIS.

### Supporting the inclusion of people with disability in the health system

Previous reports suggest that 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. Their healthcare outcomes are poor and resource use is high. Key to redressing this problem is that staff and service delivery processes make the adjustments required to accommodate their needs. This study, funded by the National Disability Research Agenda, has been conducted across three hospital systems from metropolitan and rural locations. Findings for 60 adults with cognitive disability show that they are high end

users of Emergency Departments (with 179 encounters documented over a period of 35 months). There was no evidence of systematic problem practices; rather, hospital staff applied good practice and often made accommodations to meet the needs of this patient group. The findings indicated the longer than benchmark time of 4 hours required to provide quality care for people with cognitive disabilities in Emergency Departments. It also showed that when problems did occur they often stemmed from a lack of collaboration between the health and disability sectors. There was also poor understanding about their respective roles together with family members in supporting hospital encounters for people with cognitive disabilities who found it difficult to express or explain their own needs.

**View the report online:**

<http://bit.ly/LiDs-HealthInclusion>





## Developing options to enable specialist schools to become “Centres of Expertise” to support inclusion in mainstream schools

This project resulted from the recent review of the Victorian Government's Program for Students with Disabilities, addressing a recommendation that options be developed for how specialist schools can support inclusive mainstream education. Funding for this project was awarded by the Victorian Principals' Association of Specialist Schools. The project brought together researchers from across LiDs and La Trobe Rural Health School (Teresa Iacono, Amanda Kenny and Carol McKinstry), and the School of Education (Mary Keeffe). A forum was used as a key mechanism to develop options, which were informed by policy and research literature reviews and interviews of 20 stakeholders from across specialist and mainstream school communities. The options were then prioritised for preference and acceptability through a survey of specialist and mainstream schools and were included in a report to the Department of Education and Training.

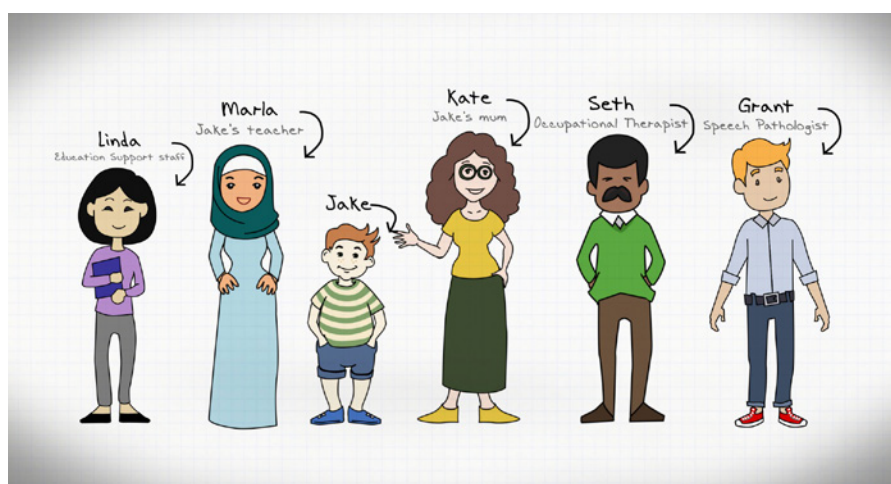
**View the report online:**

<http://bit.ly/LiDs-SchoolReport18>

## Co-designing online modules to strengthen inclusive educational supports for children with disability through collaboration with allied health

This project was funded by an Information, Linkages, and Capacity building (ILC) Readiness grant (2017). It brings together allied health (Teresa Iacono, Carol McKinstry, Nerida Hyett, Oriane Landry, Kerryn Bagley) and education (Mary Keeffe) researchers, in partnership with mainstream and

special education schools, and an allied health practice in Bendigo. A co-design group comprising parents of children with disability, education staff, and allied health practitioners are developing the content for an online package that will support the development of reasonable accommodations within mainstream schools to support the inclusion of students with disability. The package will demonstrate how these supports can maintain a child-focus, while meeting requirements under the NDIS and The Program for Students with Disability funding. Evaluations of the package will be completed by co-design participants and external stakeholders.



Screenshot from an online module capturing team members involved in inclusive education



# EVENTS

This year's Annual Roundtable was the feature event in a two week long, seven event series dubbed 'New Perspectives 2017' that drew over 200 attendees from across disciplines industry and our research partners.

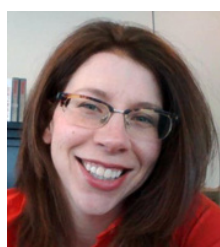
New theoretical perspectives were presented by three invited international academics who brought invigorating new theoretical perspectives to the question of community participation.

All the presentations from the roundtable are available to download from the LiDs Website. We would like to thank the presenters for sharing their insights and time with a very appreciative audience.

Presentations available at: [www.bit.ly/LiDs-NP17](http://www.bit.ly/LiDs-NP17)

**"A good day - really challenged the way we think"**

Andrew James, CEO of Inclusion Melbourne



## Dr Stacy Clifford Simplican

Senior Lecturer in the Women's and Gender Studies Program at Vanderbilt University. Her research interests include social inclusion, disability studies, democratic theory, and care ethics. She is the author of *The Capacity Contract: Intellectual Disability and the Question of Citizenship* (2015, University of Minnesota Press).



## Professor Jennifer Clegg

Honorary Associate Professor at the University of Nottingham and Adjunct Professor at the La Trobe University. Jennifer's recent work has focused on transition from child to adult services, with particular attention to ideas that drive services and how people and systems co-operate in the delivery of services.



## Dr Jens Ineland

Associate professor, Department of Education at Umeå University, Sweden. Jen's research has primarily addressed human service professionals and how norms and values in welfare organizations effect the identities and life projects for people with intellectual disabilities.



## Big ideas about community participation

10.00 - 10.45 Dr Stacy Clifford Simplican – **Conceptualising community participation - what are we counting and measuring**

10.45 – 11.15. Professor Jennifer Clegg – **Living in Liquid Modernity.**

11.15 – 11.45. Dr Ilan Wiesel – **Perspectives on inclusion from urban geography - convivial encounter**

**As well as the roundtable above, six other events were organised for academics, industry and other stakeholders.**

## Tuesday 24 October

Theorising the practice of support work – a master class with Dr Stacy Clifford Simplican  
Clifford Simplican used Tronto's care theory and democratic theory to stimulate new ways of thinking about direct support work.



# ROUNDTABLE 2017

11.45 - 12.15 Emma Bould – **Dogs as a catalyst for convivial encounters**

12.15 - 12.45 Dr Jens Ineland – **Organisational perspectives on community participation**

**Programs to Support Community Participation of people with cognitive disability**

1.30 – 2.15 Professor Christine Bigby – **Effective interventions for community participation of people**

**with intellectual disabilities – what does the literature say - Case study snapshots - What have we learned from case studies of best practice community participation programs in Victoria**

2.15 - 2.45 Professor Jacinta Douglas – **Creating community connections for people with acquired brain injury**

**Bigger picture approaches to supporting community participation**

2.45 – 3.15 Amanda Pagan & Daniel Leighton – **Where do the Local Area Coordination programs fit in supporting community participation**

3.15 – 3.45 Gordon Duff – **How can research inform NDIS policy and approaches to community participation**

3.45 **Closing remarks** Christine Bigby and Jacinta Douglas

[www.bit.ly/LiDs-NP17](http://www.bit.ly/LiDs-NP17)

## Friday 27 October

New perspectives on social inclusion and people with intellectual disability – a master class with Dr Stacy Clifford Simpican  
By reframing and broadening approaches to social inclusion, Clifford Simpican provided new approaches to thinking about interventions.

## Monday 30 October

Getting to the nub: Quick-fire accounts of research published, in progress and planned – Led by Professor Jennifer Clegg.

## Monday 30 October

Publishing in Journals - Master class with Professors Jennifer Clegg, Christine Bigby and Jacinta Douglas.

## Tuesday 31 October

New conversations in challenging behaviour – a master class with Dr Stacy Clifford Simpican  
This session explored new approaches to ethical problems posed by challenging behaviour:

## Wednesday 1 November

Annual Roundtable - Community participation and people with cognitive disabilities  
See above for details.

## Friday 3 November

Viewing intellectual disability through different conceptual lenses – a master class with Professor Jennifer Clegg  
This master class was in two parts: Dedifferentiation, and two portmanteau words that are commonly used in intellectual disability.



# EVENTS



Attendees at the Melbourne event of the Good Group Home seminar series.

**“I, like many of my colleagues in SA are very thankful that someone has taken the bull by the horns and undertaken such comprehensive research on the least “sexy” area of disability research.”**

**Denice Wharldall, Executive Manager  
Client Services, Disability Living Inc.**

## Is there such a thing as a Good Group Home?

Group homes are a very significant part of the system of services that supports people with intellectual disability. Prior to the NDIS approximately half of all Australian disability expenditure was on accommodation and most of this was on group homes.

Professor Christine Bigby presented a synthesis of current research to sold out events in Sydney, Adelaide and Melbourne during 2017. These events were incredibly popular with service designers, and organisations that manage accommodation for people with intellectual disabilities, as well as families, demonstrating the relevance of our research to industry. Attendees learnt about the impact of the culture in group homes and the role of practice leadership.

The collected research led to some confronting conclusions about the variable nature of quality and the level of effort required to sustain a Good Group Home.

The research also looked at some alternatives to group homes, in cost and quality of life aspects.

The sessions inspired a great deal of discussion and networking. The sessions also inspired the commissioning of a set of ‘Research to Practice’ guides, by the National Disability Service, the Australian peak body for non-government disability services. See more opposite.

The Seminars were reviewed extensively in the Intellectual Disability Australia magazine from the Australasian Society for Intellectual Disability, in which one attendee from the Adelaide event commented:

“The take home messages for us were:

- It is complicated
- One thing alone will not work e.g. Active Support
- It takes a whole of organisational approach, for example HR practices are key
- There are now a range of

Organisational Cultural factors that research tells us make a difference

- Your best performing group home can become the worst performing due to a single change such as a key Team Leader leaving
- Local leadership plays a key role in success
- The effort is constant and no-one can afford to take their eye off the ball so to speak

It is great to be able to utilise the research in conversations with staff, funders and Boards of Management.”

**Denice Wharldall, Executive Manager  
Client Services, Disability Living Inc.**



## Australasian Society for Intellectual Disability - 2017 Conference, Hobart, Tasmania, November 8 - 10

The ASID conference presented a valuable chance to share LiDs research with other academics and more importantly with industry practitioners and leaders. Ten LiDs staff presented their research, details on page 27, including well received keynote presentations by Dr Jennifer Clegg and Professor Christine Bigby, Director of LiDs. The Guide to Good Group Homes was launched by The Centre for Applied Disability Research at the conference and LiDs was a proud sponsor of a keynote address, raising awareness of the Centre and the work of its researchers.



Summary of LiDs research, given to all attendees at the Hobart conference.



Research to Action guide, launched at the Hobart Conference, based on the seminars, and including an easy access English version.  
[www.bit.ly/LiDs-GoodGroupHome](http://www.bit.ly/LiDs-GoodGroupHome)



## La Trobe University Research Week, Research Showcase, September 31

LiDs participated in the La Trobe University Research week, Research Showcase, presenting four research posters to a variety of cross-industry stakeholders, university researchers and invited guests. Some guests travelled interstate to see the presentations and talk to the researchers present.



# LiDs Seminar Series

During 2017 ten more LiDs Seminars were held from February to December; covering the broad range of disability research within the LiDs community. The seminars support the development of early career researchers, as well as the exchange of ideas between academia and industry.

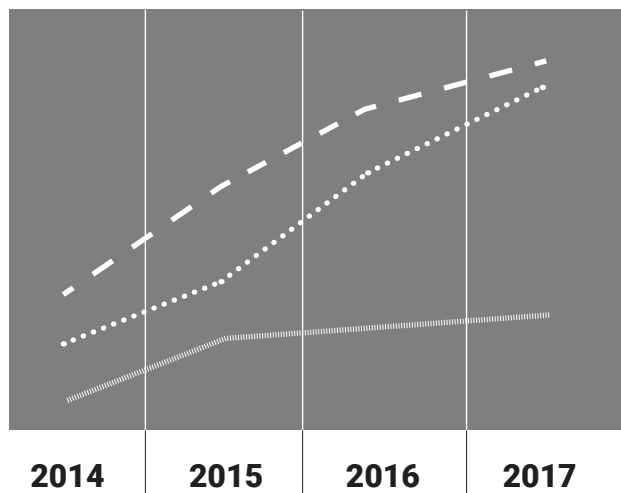
	PRESENTERS	TOPIC
FEB	William Crisp	Guided self-determination: How people with intellectual disability have been supported to have choice and control
	Chris Bigby	Using different conceptualisations of community participation to support people with intellectual disability to make choices
	Sian Anderson	Community participation as valued a sense of belonging and identity – a case study of Arts Project Australia
MAR	Ilan Wiesel	NDIS and the housing affordability crisis
	Andy Calder	Investigating the spirituality of adults with an intellectual disability. Seeking a voice within policy and practices of human services in Victoria, Australia
APR	Gail Ritchie	Keeping vulnerable people safe in care
	Tanya Serry	Managing dyslexia and other reading related problems: University students' perspective
MAY	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
	Maureen Long & Annie Venville	Accessing mental health services for people with intellectual disability
JUN	Lincoln Humphries	Development of a scale to measure organisational culture in group homes
	David Henderson	'We didn't even really know what we were volunteering for': Welfare, volunteerism and the origins of the Kew Cottages Parents' Association
JUL	Andrea Grindrod	Improving end-of-life outcomes for people with intellectual disability: Public health approaches to care
	Darren O'Donovan	Design flaws? The National Disability Insurance Act and the forthcoming Productivity Commission Review
AUG	Robyn O'Halloran	Patient Experience: Who do we hear from and why does it matter?
	Luke Bo'Sher	Policy issues and solutions in the National Disability Insurance Scheme
SEP	Kate D'Cruz	Narrative storytelling following acquired brain injury: a grounded theory study
	Leeanne Carey	Mapping activity participation in the first year after stroke in Australian and International cohorts.
OCT	Lucy Knox	From evidence to practice: Supporting the decision-making participation of adults with acquired brain injury
	Jenna Macnab	'Fifty Shades of Grey: Interpretation of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)'
DEC	Sophia Tipping	Strategies to support people with intellectual disability to participate in voting
	Emma Bould	Dogs as catalysts for inclusion of people with intellectual disability

# RESEARCH OUTPUTS, OUTCOMES & IMPACT

## Funded Projects

### Led by LiDs and new in 2017

- Bigby, C., Douglas, J., Hamilton, L. Training in support for decision making training for Ability Linkers and building capacity to undertake future training within St Vincent de Paul Society NSW; St Vincent de Paul Society NSW
- Bigby, C., Douglas, J. Delivering and monitoring the impact of training local area coordinators in support for decision making and building the capacity of St Vincent de Paul Society; St Vincent de Paul Society NSW
- Bigby, C., Douglas, J. Supporting decision making resources for community workers and peer to peer programs; St Vincent de Paul Society NSW
- Bigby, C., Tipping, S. Strategies to support people with intellectual disability to vote; Victorian Electoral Commission
- Bigby, C., Araten-Bergman, T., Ritchie, G. C., Douglas, J. Literature review prevention of abuse for people with disability within disability services; Victorian Department of Health and Human Services
- Bigby, C., Douglas, J. Network and assistance services icare project: evaluation proposal; St Vincent de Paul Society NSW
- Bigby, C., Henderson, D., Araten-Bergman, T. Models for forming and supporting circles of support for people with intellectual disabilities; Inclusion Melbourne
- Iacono, T., Mckinstry, C., Keeffe, M., Hyett N., Landry, O. Using co-design to strengthen the



### LiDs research by the numbers

- Research Income - \$2,749,373 in 2017
- ..... Active Projects - 38 in 2017
- New Projects - 12 in 2017
- Publications - 60 in 2017

capacity of mainstream schools to make accommodations to meet the functioning, developmental, educational and psychosocial needs of children with disability; Community Inclusion Capacity Development Program / Information, Linkages and Capacity Building / National Readiness

- Serry, T., Snow, P., Douglas, J., Learning difficulties including dyslexia professional training; Victorian Department of Education and Training
- Knox, L., Douglas, J., Goldsmith, S., Rushworth, N., Understanding the information and support needs of individuals with mild traumatic brain injury (mTBI) and post-concussion syndrome (PCS); Brain Injury Australia
- Carey, L., Nilsson, M., Donnan, G., Thijs, V., Lannin, N., Hillier, S., Cadilhac, D., Churilov, L., Walker, M. A network of sites and 'up-skilled' therapists to deliver best-practice stroke rehabilitation of the upper limb; NHMRC Partnership Projects Grants
- Carey, L., Fitzmaurice, K., Tse T., Boey, S. D. Facilitating participation in daily

activities and attainment of goals for older adults with low vision; Tan Tock Seng Hospital

### Led by LiDs and continuing from 2016

- Bigby, C., Research to Action Guides; National Disability Service
- Bigby, C., Bayley House -active support project non-linkage partner; Bayley House
- Bigby, C., Calloway, L., Douglas, D., Winkler, D., Bould, E., Beadle-Brown, J., Iacono, T., Developing and maintaining person centred active support (PCAS): a demonstration project in supported accommodation for people with neurotrauma; Institute for Safety, Compensation and Recovery Research
- Bigby, C., Douglas, J. Effective decision making support for people with cognitive disability; Australian Research Council, Linkage Projects
- Bigby, C., Bould, E. Embedding active support and practice leadership; Civic Disability Services Limited
- Bigby, C., Beadle-Brown, J., Iacono, T., Enabling engagement and inclusion:





Organisational factors that embed active support in accommodation services for people with intellectual disability; Australian Research Council, Linkage Projects

- Bigby, C., Iacono, T., Shields, N., Trollor, J., Douglas, J., Tracy, J. Enabling mainstream systems to be more inclusive and responsive to people with disabilities; NSW Family & Community Services Research Data Working Group
- Bigby, C., Embedding active support - House with No Steps
- Bigby, C., Beadle-Brown, J., Iacono, T., Implementing and embedding active support in The Tipping Foundation
- Bigby, C., Inclusion of CARA in embedding active support and practice leadership in supported accommodation services; Community Accommodation & Respite Agency
- Bigby, C., Duff, G. Models of facilitating community participation for adults with cognitive impairments; National Disability Service
- Bigby, C., Non-linkage partner IdentityWA embedding active support and practice leadership in supported accommodation services; IdentityWA
- Bigby, C., Douglas, J. Risk enablement project; National Disability Service
- Douglas, J., Summer Foundation Research Chair
- Douglas, J., Iacono, T., Bigby, C. 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
- Rose, M., Ong, B., Nickels, L., Godecke, E., Rodriguez, A., Togher, L., MacDonald, B., Copland, D., Meinzer, M., Cadilhac, D. COMPARE- constraint

induced or multi-modal aphasia rehabilitation: an RCT of therapy for stroke related chronic aphasia; National Health & Medical Research Council - Project Grant

## Led by LiDs and completed in 2017

- Iacono, T., Keeffe, M., Snow, P., Kenny, A., McKinstry, C. Developing options to enable specialist schools to become "Centres of Expertise" to support local mainstream schools to implement inclusive education; Principals' Association of Specialist School Victoria Inc
- Bigby, C., Tipping, S. NDIS evaluation subcontract Flinders - older persons study; Department of Social Security National Insurance Disability Scheme
- Bigby, C., Knox, L., Douglas, J., Request for quotation / review of contemporary third party insurance models; Transport Accident Commission
- Bigby, C., Tipping, S., Long M., Atkins, P. Experiences of involvement in circle of support; Inclusion Melbourne
- Rose, M., Menehemi-Falkov, M. Multi-modal aphasia therapy: a computerised extensions (Maya Menehemi-Falkov); Department of State Development, Business and Innovation
- Bigby, C., Bould, E., Warren, S., Blackall, L. Every moment has potential: person centred active support practice in Australia; Greystanes Disability Services

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

- Bigby, C., Tilbury, C., Hughes, M., Fisher, M. The production, use and effect of social work research (administered by Griffith University); Australian Research Council - Discovery Projects
- Bellon, M., Fisher, A., Lawn, S., Sohlberg, M., & Douglas, J. Positive behaviour support following TBI: A family directed approach. Lifetime Support South Australia
- McDonald, S., Anderson, V, Ponsford, J., Tate, R., Togher, L., Morgan, A., Fleming, J., Ownsworth, T., Douglas, J., Murdoch, B. NHMRC CRE in Traumatic Brain Injury Psychosocial rehabilitation: Breaking down barriers for social reintegration National Health and Medical Research Council - Centres of Research Excellence
- Rose, M., Worrall, L., Kneebone, I., Simmon-Mackie, N., Hoffman, T., Khan A., Bronw, K., Power, E., Togher, L. Can a brief early intervention prevent depression and help people live with aphasia a year after stroke? . (administered by UQ); National Health & Medical Research Council - Project Grant



## Publications

(Based on interim data at time of press)

### Refereed Journal Articles

- Anderson, S., & Bigby, C. (2017). Self-advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really'. *Journal of Applied Research in Intellectual Disabilities*, 30(1)
- Araten-Bergman, T., & Werner, S. (2017). Social workers' attributions towards individuals with dual diagnosis of intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 61(2)
- Bigby, C. (2017). Perspectives on social work in Australia from the Norma Parker addresses and key papers in Australian social work. *Australian Social Work*, 70
- Bigby, C., & Craig, D. (2017). A case study of an intentional friendship between a volunteer and adult with severe intellectual disability: "My life is a lot richer!". *Journal of Intellectual and Developmental Disability*
- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Comparing costs and outcomes of supported living with group homes in Australia. *Journal of Intellectual and Developmental Disability*
- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 42(4)
- Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Implementation of active support over time in Australia. *Journal of Intellectual and Developmental Disability*, 1-13.
- Bigby, C., Douglas, J., Carney, T., Then, S. -, Wiesel, I., & Smith, E. (2017). Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015: *Australian Journal of Social Issues*, 52(3)
- Bigby, C., Johnson, H., O'Halloran, R., Douglas, J., West, D., & Bould, E. (2017). Communication access on trains: A qualitative exploration of the perspectives of passengers with communication disabilities. *Disability and Rehabilitation*, 1-8
- Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability*, 1-14.
- Cavanagh, J., Bartram, T., Meacham, H., Bigby, C., Oakman, J., & Fossey, E. (2017). Supporting workers with disabilities: A scoping review of the role of human resource management in contemporary organisations. *Asia Pacific Journal of Human Resources*, 55(1), 6-43.
- Chaffey, L., & Bigby, C. (2017). 'I feel free': The experience of a peer education program with fijians with spinal cord injury. *Journal of Developmental and Physical Disabilities*, 1-14.
- Chaffey, L., & Bigby, C. (2017). Health education by peers with spinal cord injury: A scoping review. *Journal of Developmental and Physical Disabilities*, 1-14.
- Crook, A., Kenny, J., Johnson, H., & Davidson, B. (2017). Perspectives of a mobile application for people with communication disabilities in the community. *Disability and Rehabilitation: Assistive Technology*, 12(2), 184-196.
- Dacakis, G., Oates, J., & Douglas, J. (2017). Further evidence of the construct validity of the transsexual voice questionnaire (TVQMtF) using principal components analysis. *Journal of Voice*, 31(2), 142-148.
- Dacakis, G., Oates, J., & Douglas, J. (2017). Associations between the transsexual voice questionnaire (TVQMtF) and self-report of voice femininity and acoustic voice measures. *International Journal of Language and Communication Disorders*, 52(6), 831-838.
- Davis, H., Ferdous, H. S., & Vetere, F. (2017). 'Table manners': Children's use of mobile technologies in family-friendly restaurants. Paper presented at the Conference on Human Factors in Computing Systems - Proceedings, Part F127655 969-978.
- Davis, H., Hespanhol, L., Farmer, J., Fredericks, J., Caldwell, G. A., & Hoggenmueller, M. (2017). Designing participation for the digital fringe. Paper presented at the ACM International Conference Proceeding Series, Part F128532 321-324.
- de Beer, C., Carragher, M., van Nispen, K., Hogrefe, K., de Ruiter, J. P., & Rose, M. L. (2017). How much information do people with aphasia convey via gesture? *American Journal of Speech-Language Pathology*, 26(2), 483-497. 10.1044/2016\_AJSLP-15-0027
- Devan, H., Dillon, M. P., Carman, A. B., Hendrick, P., Hale, L., Boockock, M., & Ribeiro, D. C. (2017). Spinal and pelvic kinematics during gait in people with lower-limb amputation, with and without low back pain: An exploratory study. *Journal of Prosthetics and Orthotics*, 29(3), 121-129.
- Dillon, M. P., Fortington, L. V., Akram, M., Erbas, B., & Kohler, F. (2017).





Geographic variation of the incidence rate of lower limb amputation in Australia from 2007-12. *PLoS ONE*, 12(1).

- Dillon, M., Fatone, S., & Quigley, M. (2017). While mortality rates differ after dysvascular partial foot and transtibial amputation, should they influence the choice of amputation level? *Archives of Physical Medicine and Rehabilitation*, 98(9), 1900-1902.
- Douglas, J. (2017). So that's the way it is for me - always being left out: acquired pragmatic language impairment and social functioning following traumatic brain injury. *Brain Impairment*, 18(3), 321-331.
- Douglas, J., & Togher, L. (2017). Managing acquired social communication disorders. *Neuropsychological rehabilitation: The international handbook* (pp. 251-265)
- Drummond, M., Douglas, J., & Olver, J. (2017). "I really hope it comes back": Olfactory Impairment following Traumatic Brain Injury: A Longitudinal Study. *NeuroRehabilitation*, 41, 241-248.
- 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*, 21(8), 822-832.
- Fisher, F., Maule, R., Douglas, J. Andrews, S., & Philpott, A. (2017). Characterising social communication changes in Amyotrophic Lateral Sclerosis. *International Journal of Language & Communication Disorders*, 52 (2), 137-142.
- Henderson, D., & Bigby, C. (2017). Whose life story is it? self-reflexive life story research with people with intellectual disabilities. *Oral History*

Review, 44(1), 39-55.

- Howe, T., & O'Halloran, R. (2017). Issue editor foreword: "a turning point for inclusion" of adults with aphasia: Removing barriers and implementing facilitators. *Topics in Language Disorders*, 37(1), 3-5.
- Iacono, T., Dissanayake, C., Hudry, K., Trembath, D., Erickson, S., & Spong, J. (2017). Translating research into practice in low-resource settings: An Australian case study of early autism service provision in a regional town. *Journal of Intellectual and Developmental Disability*, 1-9.
- Jamwal, R., Callaway, L., Ackerl, J., Farnworth, L., & Winkler, D. (2017). Electronic assistive technology used by people with acquired brain injury in shared supported accommodation: Implications for occupational therapy. *British Journal of Occupational Therapy*, 80(2), 89-98.
- Jamwal, R., Callaway, L., Farnworth, L., & Winkler, D. (2017). Electronic assistive technology use in Australian shared supported accommodation: Rates and user characteristics. *Disability and Rehabilitation: Assistive Technology*, 1-7.
- Johnson, H., Bigby, C., Iacono, T., Douglas, J., Katthagen, S., & Bould, E. (2017). 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 and Developmental Disability*, 42(4), 391-402.
- Knox, L., Douglas, J., & Bigby, C. (2017). "I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury. *Disability and Rehabilitation*, 39(22), 2250-2260.
- Knox, L., Douglas, J., & Bigby, C. (2017). "I've never been

a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury. *Disability and Rehabilitation*, 39(22), 2250-2260.

- Logan, K., Iacono, T., & Trembath, D. (2017). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *AAC: Augmentative and Alternative Communication*, 33(1), 51-64.
- Meacham, H., Cavanagh, J., Bartram, T., & Laing, J. (2017). Ethical management in the hotel sector: Creating an authentic work experience for workers with intellectual disabilities. *Journal of Business Ethics*, 1-13.
- Meacham, H., Cavanagh, J., Shaw, A., & Bartram, T. (2017). HRM practices that support the employment and social inclusion of workers with an intellectual disability. *Personnel Review*, 46(8), 1475-1492.
- Meacham, H., Cavanagh, J., Shaw, A., & Bartram, T. (2017). Innovation programs at the workplace for workers with an intellectual disability: Two case studies in large Australian organisations. *Personnel Review*, 46(7), 1381-1396.
- Mealings, M., Douglas, J. & Olver, J. (2017). Beyond academic performance: Practice implications for working with students following traumatic brain injury. *International Journal of Speech Language Pathology*, 19(5), 441-453.
- O'Halloran, R., Carragher, M., & Foster, A. (2017). The consequences of the consequences: The impact of the environment on people with aphasia over time. *Topics in Language Disorders*, 37(1), 85-100.
- Potter, A., Sansonetti, D., D'Cruz, K., & Lannin, N. (2017). What is known about transitional living services for adults with an acquired brain injury? A scoping review. *Brain Impairment*,

18(2), 240-257.

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- Quilliam, C., Bigby, C., & Douglas, J. (2017). Staff perspectives on paperwork in group homes for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 1-10.
- Serry, T., Oates, J., Ennals, P., Venville, A., Williams, A., Fossey, E., & Steel, G. (2017). Managing reading and related literacy difficulties: University students' perspectives. *Australian Journal of Learning Difficulties*, 1-26.
- Simpson, A. & Baldwin, E.M. 2017. Googling NDIS: evaluating the quality of online information about the National Disability Insurance Scheme for caregivers of deaf children, *Deafness & Education International*, 19(1).
- Simpson, A., Enticott, J., & Douglas, J. (2017). Socio-economic status as a factor in Indigenous and non-Indigenous children with hearing loss: analysis of national survey data. *Australian Journal of Primary Health*, 23(2) 202-207
- Solarsh, B., & Johnson, H. (2017). Developing communication access standards to maximize community inclusion for people with communication support needs. *Topics in Language Disorders*, 37(1), 52-66.
- Snow, P. & Douglas, J. (2017). Psychosocial aspects of pragmatic disorders, in L. Cummings (ed.), *Research in Clinical Pragmatics*, Series: Perspectives in Pragmatics, Philosophy & Psychology, Vol. 11, Cham, Switzerland: Springer-Verlag, pp 617-649.
- Stagg, K., Douglas, J. & Iacono, T. (2017): A scoping review of the working alliance in acquired brain injury rehabilitation, *Disability and Rehabilitation*, 1-9.
- Stuckey, R., & Domingues-Montanari, S. (2017). Telemedicine is helping the parents of children with neurodevelopmental disorders living in remote and deprived areas. *Paediatrics and International Child Health*, 37(3), 155-157.
- Tilbury, C., Hughes, M., Bigby, C., & Osmond, J. (2017). Social work research in the child protection field in Australia. *British Journal of Social Work*, 47(1), 256-274.
- Tilbury, C., Hughes, M., Bigby, C., Fisher, M., & Vogel, L. (2017). A comparative study of Australian social work research. *British Journal of Social Work*, 47(8), 2217-2237.
- Tse, T., Douglas, J., Lentin, P., Lindén, T., Churilov, L., Ma, H., Carey, L. M. (2017). Reduction in retained activity participation is associated with depressive symptoms 3 months after mild stroke: An observational cohort study. *Journal of Rehabilitation Medicine*, 49(2), 120-127.
- Tse, T., Yusoff, S. Z. B., Churilov, L., Ma, H., Davis, S., Donnan, G. A., & Carey, L. M. (2017). Increased work and social engagement is associated with increased stroke specific quality of life in stroke survivors at 3 months and 12 months post-stroke: A longitudinal study of an Australian stroke cohort. *Topics in Stroke Rehabilitation*, 24(6), 405-414.
- Ullah, M. M., Fossey, E., & Stuckey, R. (2017). The meaning of work after spinal cord injury: A scoping review. *Spinal Cord*, 1-14.
- Waycott, J., & Davis, H. (2017). Sharing the housebound experience through visual storytelling. Paper presented at the C & C 2017 - Proceedings of the 2017 ACM SIGCHI Conference on Creativity and Cognition, 2-14.
- Waycott, J., Davis, H., Warr, D., Edmonds, F., & Taylor, G. (2017). Co-constructing meaning and negotiating participation: Ethical tensions when 'giving voice' through digital storytelling. *Interacting with Computers*, 29(2), 237-247.
- Waycott, J., Munteanu, C., Davis, H., Thieme, A., Branham, S., Moncur, W., Vines, J. (2017). Ethical encounters in HCI: Implications for research in sensitive settings. Paper presented at the Conference on Human Factors in

Computing Systems - Proceedings, Part F127655 518-525.

- Werner, S., & Araten-Bergman, T. (2017). Social workers' stigmatic perceptions of individuals with disabilities: A focus on three disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 10(2), 93-107.

## Selected Conference Presentations

- Araten Bergman, T., Werner, S. (2017, November). Social worker's attributions towards individuals with dual diagnosis of intellectual disability and mental illness. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
- Attard, M., Togher, L., Loupis, Y., Rose, M. (2017, June). A detailed program model for a multidisciplinary Community Aphasia Group: Results from a Phase I clinical trial 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
- Barry, S., Knox, L., Douglas, J. (2017, June). "You do not live in a nursing home; you exist": Experiences of young people with acquired brain injury (ABI) entering, living in and leaving residential aged care in Australia 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
- Bigby, C., Anderson, S., Cameron, C., (2017, November). A case study of an Effective Community Participation program. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
- Bigby, C., Anderson, S., Cameron, C., (2017, November). Identifying conceptualisations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability. A scoping review. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart,



- Australia.
- Bigby, C., Bould, E. (2017, February). Evidence about achieving quality of life for people with intellectual disability in supported accommodation. Paper presented at the Disability Services Research to Action Forum, Melbourne, Australia.
  - Bigby, C., Quibell, R., Douglas, J., Iacono, T., (2017, November). "Our agenda is not the same as the patient's": Emergency doctor and nurse accounts of treating people with cognitive disabilities. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Bould, E., Bigby, C., Bennett, P., Howell, T. (2017, November). Dogs as catalysts for community participation of people with intellectual disability. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Browning, M., Bigby, C., Douglas, J. (2017, November). The process of supported decision making: Learning from the experiences of people with intellectual disabilities and their supporters in Canada. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Clegg, J. (2017, November). Living with intellectual disability in the twenty-first century. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Davis, H. et al (2017, June). Workshop on Designing Participation for the Digital Fringe, Communities and Technologies Conference – Technology for the Common Good, Troyes, France.
  - D'Cruz, K., Douglas, J., Serry, T. (2017, June). Narrative storytelling following acquired brain injury: Sharing my story to help others 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Douglas, J. (keynote address) (2017, May). Developing Communication Pathways for Adults with Severe Communication Disability following Traumatic Brain Injury. AGOSCI 13th Biennial Conference, Melbourne.
  - Douglas, J. (keynote address) (2017, Mar). Acquired Cognitive-communication Disorders: Meeting the Challenge of Assessment, Sub-acute Speech Pathology Forum, Victoria, Melbourne.
  - Douglas, J. (keynote address) (2017, June). Acquired pragmatic language Impairment and Social Functioning. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Ford, A., Douglas, J., O'Halloran, R. (2017, June). The experience of close personal relationships from the perspective of people with aphasia: Thematic analysis of the literature 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Humphreys, L., Bigby, C., Iacono, T., Bould, E. (2017, November). Dimensions of group home culture as predictors of quality of life outcomes. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Humphreys, L., Bigby, C., Iacono, T., Bould, E. (2017, November). The Relationship Between Group Home Culture and Quality of Life Outcomes for People with Intellectual Disabilities. International Association for the Scientific Study of Intellectual and Developmental Disabilities Asia Pacific Regional Congress, Bangkok.
  - Humphreys, L., Bigby, C., Iacono, T., Bould, E; Group Home Culture Within and Across Organisations; November, 2017; International Association for the Scientific Study of Intellectual and Developmental Disabilities Asia Pacific Regional Congress, Bangkok.
  - Iacono, T. (2017, November). Tracing Policy Reform for Inclusive Education of Students with Intellectual Disability – A Grey Literature Review. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Iacono, T., McKinstry, C., Keefe, M., Kenny, A., Wilson, E., Landry, O. (2017, October). Supporting inclusion of students with disabilities – Is there a role for special schools? Paper presented at The Inclusive Education Summit 2017, Adelaide.
  - Johnson, H., Bigby, C., Douglas, J., Bould, E. (2017, May). How good is that? The process of developing positive communication interactions for train travellers. Paper presented at 13th AGOSCI Biennial Conference, Melbourne, Australia.
  - Knox, L., Douglas, J. (2017, June). Exploring the evidence for extended rehabilitation for adults with very severe ABI: Results from a scoping review. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Knox, L., Douglas, J., Bigby, C. (2017, June). From evidence to practice: Supporting the decision-making participation of adults with traumatic brain injury (TBI). 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Lanyon L., Worrall, L., Rose, M. (2017, June). 'I know where I belong now': Understanding the potential of community aphasia groups. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Lanyon, L., Attard, M., Togher, L., Worrall L., Rose, M. (2017, June). A meta-synthesis of community aphasia group quantitative

- and qualitative evidence. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
- Layton, N., Douglas, J., Winkler, D. (2017, June). Technology, housing and outcomes: a scoping review. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Layton, N., Douglas, J., & Winkler, D. (2017). Integrated technologies within housing, Global Research, Education and Innovation in Assistive Technology (GREAT) Summit, Geneva, Switzerland.
  - Mealings, M., Douglas, J., Olver, J. (2017, June). 'Is this, is this the right path?'- Exploring factors that contribute to students' educational choices following brain injury. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Pierce, J., O'Halloran, R., Togher L., Rose, M. (2017, June). Revisiting the case for single case research. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Pozzebon, M., Douglas, J., Ames, D. (2017, June). Spousal recollections of early manifestations of primary progressive aphasia. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
  - Ritchie, G., Bigby, C., Douglas, J. (2017, November). Factors contributing to the sexual abuse of people with intellectual disability: A review of the literature. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
  - Rose, M., Dalton, D., Attard, M., Carragher M., Lanyon, L. (2017, June). Merri Community Aphasia Group: A Phase I Clinical Trial for chronic post-stroke aphasia. 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.

- Tideman, M. (2017, November). Impact on identity and every-day life – people with intellectual disability and self-advocacy in Sweden. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
- Tipping, S., Bigby, C., Bould, E., (2017, November). Strategies to support people with intellectual disability to participate in voting: Results of a survey. Paper presented at the 2017 annual conference of the Australasian Association for Intellectual Disability, Hobart, Australia.
- Vassallo, S., Douglas, J. (2017, May). Deficits in the eye movement system following traumatic brain injury (TBI). 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.
- Waycott, J., Davis, H. et al (2017, May). Ethical Encounters in HCI: Research in Sensitive Settings, CHI2017, Denver, Colorado.
- Williams, L., Douglas, J. (2017, June). It takes 2 to tango - The therapeutic alliance in community brain injury rehabilitation 40th Australasian Society for the Study of Brain Impairment Conference, Melbourne.



**PHLS: Penny Williams and Jim. Photo: ANDREW PERRYMAN**

For Jim, a four-year-old Labrador of his much loved friend, Penny Williams.

Brought together through the auspices of a pilot study conducted by La Trobe University researchers, two companions have enjoyed gait walks together, all in the name of science.

La Trobe's Living with Disability research Centre has just finished pilot study to track the experiences of those who remained in a community with and without dog.

Research fellow Emma Bould said people with intellectual disabilities were one of the most socially excluded groups in society.

The study found the company of a dog can improve that terrible sense of isolation.

"Ms Williams said when she walked with Jim people often stopped to talk to them.

"If you do that at the same time every week, they get to know you then," she said.

During the study the participants were divided, with half having 14 outings with a dog, and its handler, while the other half had 14 outings with a handler alone, followed by five outings with a handler and a dog.

"Our findings showed there were significantly more encounters between participants and strangers when a dog was present," Dr Bould said.

Researchers worked with Benigo-based charity Righteous Pup and 18 adults with intellectual disabilities. Dr Bould said the Bendigo study was timely given the recent National Disability Insurance Scheme launch.

"Our study highlights the potential for a dog walking program to encourage encounters, which could help people build a sense of identity and belonging in the community she said.

Penny and Jim, who now have to part ways, are hoping that further funding will allow them to see each other again. - Dianne Dempsey

Bendigo Weekly Nov 17, 2017

## Online Training Resources

**Every Moment Has Potential** - Person Centred Active Support for disability support workers.

[www.bit.ly/LiDsActiveSupport](http://www.bit.ly/LiDsActiveSupport)

**Supporting Inclusion** - Training resource for disability support workers to gain tools and strategies to promote the social inclusion of people with intellectual disability.

[www.bit.ly/LiDsInclusion](http://www.bit.ly/LiDsInclusion)

**Enabling Risk: Putting Positives First** is an online learning resource developed specifically for disability support workers.

[www.enablingriskresource.com.au](http://www.enablingriskresource.com.au)

## Media

- Tipping, S. appeared on 3CR, Radio station, on December 6, 2017, Melbourne to discuss LiDs research, and the Voting Project specifically.
- Bould, E. Dogs as catalysts for community participation of people with intellectual disability. On November 14, 2017 a media day was organised in Bendigo, Vic, to allow several press and TV crews access to participants and Canine research assistants. This resulted in numerous local press articles, and a segment on 9 News Central Victoria and WIN News.



**9 News Central Victoria feature, Nov 15, 2017**

# LiDs Reports - 2017 in detail.

## Overview of literature about enabling risks for people with intellectual disabilities on the context of disability support services.

This overview is based on a review of the peer reviewed and grey literature on risk and the practice of frontline staff in supporting service users with cognitive disability.

The aim was to explore the questions: 1) What are frontline staff experiences of enabling risk? 2) What are the barriers and facilitators that confront frontline staff and others involved in disability support services in enabling risk for people with cognitive disabilities in particular people with intellectual disability or acquired brain injury? 3) What are the characteristics of models for risk enablement with people with cognitive disabilities?

[www.bit.ly/LiDs-RiskLit](http://www.bit.ly/LiDs-RiskLit)

## Literature review of best practice supports in disability services for the prevention of abuse of people with disability

Research suggests that compared to the general population, people with disabilities experience significantly higher rates of abuse and that people with intellectual disabilities and those who reside in residential services are at particularly high risk. This report aims to map this broad literature on the abuse of people with intellectual disabilities and identify: 1) personal, environmental and relational aspects, as well as factors in service environments and organisational cultures associated with the vulnerability of people with intellectual disabilities to violence and abuse; 2) preventative abuse strategies for people with intellectual disabilities, and, 3) review the evidence about the quality and effectiveness of these strategies.

[www.bit.ly/LiDs-AbuseRpt](http://www.bit.ly/LiDs-AbuseRpt)

## Strategies to support people with intellectual disability to participate in voting: Interim summary of results from an organisational survey

The right to vote is a core element of political citizenship in Australian democracy. Nevertheless, people with intellectual disability are a highly disadvantaged group in society and the international literature suggests people with intellectual disability vote less often than other groups in society.

Making reasonable adjustments to facilitate participation for people with intellectual disability is complex and involves more than just physical access. The aim of the project is twofold; to identify the factors that facilitate or obstruct voting for people with intellectual disability, and; to develop, trial and evaluate an initiative at the next Victorian state election.

[www.bit.ly/LiDs-VotingReport](http://www.bit.ly/LiDs-VotingReport)

## Strategies to support people with intellectual disability to participate in voting: Interim report 2 summary of results from focus groups.

The second interim report of a collaborative project between LiDs, the Victorian Electoral Commission (VEC) and Inclusion Melbourne that is exploring strategies to support people with intellectual disabilities to vote.

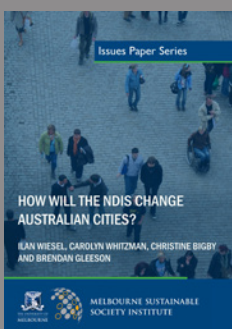
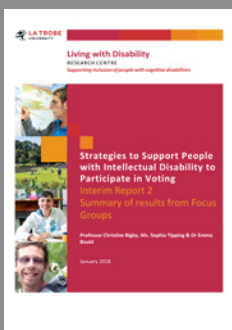
The second report summarises the interim findings of the second phase of the research that through the use of focus groups, aimed to explore the experiences of voting of people with intellectual disabilities in Victoria. The findings of the survey and focus groups will be used to inform the development of an initiative to facilitate the participation of people with intellectual disabilities in elections.

## 'How will the NDIS change Australian cities?'

With the NDIS being progressively rolled out across Australia, this is a particularly appropriate time for the Australian urban research agenda to engage with disability in more meaningful ways. As one of the most urbanised countries in the world, these impacts will be profoundly influenced by the urban contexts in which the NDIS will operate.

This Issues Paper sets out a research agenda for examining the impacts of the NDIS on Australian cities over the first decade of its full implementation (from 2019 onwards). The Issues Paper addresses two primary questions: first, how will outcomes for NDIS participants vary in different urban contexts and domains? And, second, in what ways will the NDIS drive wider change in Australian cities affecting people both with and without disability?

[www.bit.ly/LiDs-City](http://www.bit.ly/LiDs-City)





The Living with Disability Research Centre works with a variety of funders, partners and other universities, all of which are listed here alphabetically



- annecto Inc.
- Australian Research Council -
  - Future Fellowship
  - Discovery projects
  - Linkage Projects
- Bayley house
- Brain injury Australia
- Civic Disability Services Limited
- Community Accommodation & Respite Agency (CARA)
- Community Inclusion Capacity Development Program / Information, Linkages and Capacity Building / National Readiness
- Department of Health and Human Services (Victoria)
- Department of Social Security National Disability Insurance Scheme
- Endeavour Foundation
- Flinders University
- GenU (formerly Karingal)
- Golden City Support Services
- Greystanes Disability Services
- Griffith University
- Halmstad University, Sweden
- House With No Steps
- Hunter Primary Care
- IdentityWA
- Inclusion Melbourne
- Institute for Safety, Compensation and Recovery Research
- Jewish Care
- Karolinska Institute, Sweden
- Malmö University, Sweden
- Marillac
- Melbourne City Mission
- Monash University
- National Disability Services
- National Health & Medical Research Council -
  - Project grants
  - Centres of Research Excellence
  - Partnership Projects Grant
- New South Wales Trustee and Guardian
- New South Wales Public Guardian
- NSW Department of Family and Community Services
- Office of the Public Guardian, (Queensland)
- Office of the Public Advocate (Queensland)
- Office of the Public Advocate, Victoria
- Office of the Public Guardian
- Principals' Association of Specialist School Victoria Inc
- Queensland University of Technology
- St Vincent de Paul Society NSW
- Summer Foundation
- Singapore General Hospital
- Tang Tock Seng Hospital, Singapore
- The Tizard Centre, University of Kent, England
- The Tipping Foundation
- The University of Queensland
- Transport Accident Commission
- Unisson Disability (formerly Sunshine)
- University of Melbourne
- University of Sydney
- V/Line
- Victorian Department of Education and Training
- Victorian Electoral Commission
- Yooralla



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