



# asid 2023 conference

Valuing different perspectives

22 – 24 November 2023  
Crown Promenade Hotel, Melbourne

asid  
research to practice

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## CONVENOR WELCOME

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I recall one evening over a year ago in Fitzroy with members of ASID's Victorian Division Committee when we were tasked with delivering this conference. Our Committee had done it before, in 2015, before the experience of the NDIS and before the impacts of COVID. We thought "we did it then, so we could do it now". I'm pleased to say that we did.

ASID is about intellectual disability. ASID's position statement on dedifferentiation (you can read it on the ASID website in the resources tab) says:

Treat people with intellectual disability as members of the broad disability group wherever possible, and protect and develop differentiated opportunities, services and research whenever necessary.

This is what this conference is about. The presentations and discussions at the conference will equally challenge and motivate us. People with intellectual disability are part of a complicated disability service system which still has a long way to go before it delivers outcomes for all people with disability. The conference theme is 'valuing different perspectives'; the perspectives of people with intellectual disability, their families, supporters, service providers, and researchers. These perspectives help us to develop essential differentiated opportunities, services, and research.

I encourage you to engage as much as possible while you are at the conference. Strike up a conversation with the person sitting next to you, ask questions of the presenters, post your comments on social media (#ASID2023), and reflect on your practice and research.

The conference is finally here. We could not have done it without you: the attendees, presenters, sponsors, volunteers, staff, Board, and Committee. Without you there would be no conference.

Dr Brent Hayward  
2023 Conference Convenor

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## Conference Program, Wednesday 22 November 2023

8:00 AM	7:30 PM	Registration Conference Hall Foyer, Crown Promenade Melbourne		
9:00 AM	11:00 AM	<p>Opening session: Supporting people with complex needs Chair: Brent Hayward Conference Halls 1- 3</p> <p>Evidence about good practice for supporting people with complex behaviour Dr Petra Bjorne   Universities of Lund and Umea, Malmö, Sweden</p> <p>Promoting the reduction and elimination of the use of restrictive practices by providers to the greatest extent possible Mandy Donley   Victorian senior practitioner</p>		
11:00 AM	11:30 AM	Morning tea break		
		<p>Session 1: Supporting people with complex needs Chair: Brent Hayward Conference Hall 1</p>	<p>Session 2: Rights Chair: Simon Wright Conference Hall 2</p>	<p>Session 3: Access Chair: Angela Dew Conference Hall 3</p>
11:30 AM	12:00 PM	1.1 The aggression-severity outburst scale: testing a new behaviour severity measure Glenys Holt	2.1 Shining light on personhood for people with intellectual disability Eden Tuisaula Cruice & Brigit Mirfin-veitch	3.1 People First NZ learn with us webapp: A digital tool Julia Young & Alex Johnsen
12:00 PM	12:30 PM	1.2 What makes a good behaviour	2.2 Saying sorry for disability institutions	3.2 An update on accessible written

		support plan? Maria Vassos	Gina Andrews-Zucker, Phillipa Carnemolla & Jack Kelly	information Cathy Basterfield
12:30 PM	1:00 PM	1.3 Trauma and stigma: The shadow side of belonging Benjamin Garcia-Lee	2.3 4 rights for decision making Ricky Kremer & Alexander Elliott	3.3 Carers from refugee backgrounds: Co-creating Arabic resources Louisa Smith
1:00 PM	2:00 PM	Lunch break		
		Session 4: Housing and leaving home Chair: Ilan Wiesel Conference Hall 1	Session 5: Inclusive research Chair: Sally Robinson Conference Hall 2	Session 6: Health issues Chairs: Laura Hogan & Paul O'Dea Conference Hall 3
2:00 PM	2:30 PM	4.1 Housing and people with multiple and complex disabilities in NZ Umi Asaka & Brigit Mirfin-veitch	5.1 A mental health support program for us by us Erin Louise Whittle	6.1 The healthy discussions project Michelle Wilcox
2:30 PM	3:00 PM	4.2 Post-parental care planning in rural Australia Stuart Wark	5.2 Role of research building agency with people with intellectual disability Morag Kelly	6.2 Enhancing preventive healthcare through service provider education Clare Woods & Jennifer Brennen
3:00 PM	3:30 PM	4.3 Moving out of the family home Irene Belperio	5.3 Lived experience: Profound intellectual disabilities and inclusion in research Michelle King	6.3 Wellbeing Indicators for intellectually disabled New Zealanders Shara Turner
3:30 PM	4:00 PM	4.4 Living a good life in my own home Angela Walter	5.4 The inclusion library Phillippa Carnemolla & Jack Kelly	6.4 Transitioning from prison to community: Reflections from an NDIS OT Sally Lamshed
4:00 PM	4:30 PM	Afternoon tea break		
		Session 7: Abuse prevention Chair: Alan Hough	Session 8: Parenting with intellectual disability	Session 9: Co-production Chair: Michelle Moss & Robert Ellis

		Conference Hall 1	Chairs: Brent Hayward & Donna Best Conference Hall 2	Conference Hall 3
4:30 PM	5:00 PM	7.1 Centering Lived Experience of Intellectual Disability in Violence Prevention Kristy Hill & Alison Maclean	8.1 Reframing parenting with intellectual disability: From problem to solution frame Susan Collings	9.1 CID's working together framework: Making co-production easy Catalina Voroneanu & Jack Kelly
5:00 PM	5:30 PM	7.2 Understanding everyday harm: a scoping review of abuse literature Sally Robinson	8.2 Disability or not, I am still a parent, sometimes I just need a little support Renee Mills & Crystal Richardson	9.2 Co-designing hospital education for healthcare workers about intellectual disability Cathy Beck, Katie Brooker & Catrin Culla
5:30 PM	7:30 PM	Welcome reception and launch of resources for quality hospital care for people with intellectual disabilities Conference Hall Foyer, Crown Promenade Hotel		

## Conference Program, Thursday 23 November 2023

8:00 AM	5:30 PM	Registration Conference Hall Foyer, Crown Promenade Melbourne		
9:00 AM	11:00 AM	<p>Opening session: Encounters between people with and without intellectual disabilities Chair: Christine Bigby Conference Halls 1 - 3</p> <p>Responding to otherness. Encounters with people with severe intellectual disabilities - the potential of experimental-relational spaces of encounter. Dr Gustaaf Bos   University of Humanistic Studies, the Netherlands</p> <p>Making place for encounter across cognitive difference Assoc Prof Ilan Wiesel   The University of Melbourne</p>		
11:00 AM	11:30 AM	Morning tea break		
		<p>Session 10: The Royal Commission and people with intellectual disabilities: a panel discussion Chair: Alan Hough Conference Hall 1</p>	<p>Session 11: Health information Chair: Bronwyn Newman Conference Hall 2</p>	<p>Session 12: Assessing needs Chair: David Thompson Conference Hall 3</p>
11:30 AM	12:00 PM	<ul style="list-style-type: none"> <li>- Sally Robinson, Flinders University</li> <li>- Dru Marsh, Chair, Golden City Support Services</li> <li>- Nicola Crates, Possability</li> </ul>	<p>11.1 Roadmap for Improving the health of people with intellectual disability Nicholas Lennox &amp; Anthony Lark</p>	<p>12.1 Women with intellectual disability and mental health disorders Erin Louise Whittle</p>

12:00 PM	12:30 PM	<ul style="list-style-type: none"> <li>- Kathy Ellem, University of Queensland</li> <li>- Paul O'Dea, Board member ASID</li> <li>- Christine Bigby, La Trobe University</li> </ul>	11.2 Co-designing a healthy cooking program for adults with intellectual disability Roberta Asher	12.2 Scoping review, comparison of proxy and self-reports of internal states Kristen Webb
12:30 PM	1:00 PM		11.3 Just include me: Co-produced easy read health literacy resources Laura Naing, Jack Kelly & Nicole Ascaino	12.3 Lived experience of the fetal alcohol spectrum disorder diagnostic assessment Kerryn Bagley
1:00 PM	2:00 PM	Lunch break		
		<p>Session 13: Group homes Chair: Lincoln Humphreys Conference Hall 1</p>	<p>Session 14: Health research Chair: Laura Hogan &amp; Bruce O'Brien Conference Hall 2</p>	<p>Session 15: Being included Chair: Cat Lancaster Conference Hall 3</p>
2:00 PM	2:30 PM	13.1 Ageing residents in group homes: Exploring staff experiences Tal Araten-Bergman	14.1 Collecting healthcare experience information from people with intellectual disability Bronwyn Newman	15.1 Towards inclusive practice: Reflections on why inclusive practice matters Luke Nelson & Jamie Bannister
2:30 PM	3:00 PM	13.2 Support model for seven people living in shared accommodation Melanie Ingham	14.2 Improving the delivery of annual health assessments Nicholas Lennox & Anthony Lark	15.2 The practical application of the Inclusive Governance Project findings Bernadette Curryer & Will Harding
3:00 PM	3:30 PM	13.3 Checking if services are good and safe for people with intellectual disability Jade McEwen	14.3 Falls in people with intellectual disability who live in group homes Caroline Hart & Stella Koritsas	15.3 TEDx for everyone: People with intellectual disability speaking up Kathy Ellem & Donna Best
3:30 PM	4:00 PM	13.4 Changes in quality of support in group homes Christine Bigby	14.4 Resources for strengthening hospital inclusion of people with intellectual disabilities	15.4 The Silos Project: Working together helps students with intellectual disabilities to get jobs

			Teresa Iacono	Janice O'Connor
4:00 PM	4:30 PM	Afternoon tea break		
		Session 16: Families and group homes Chair: Bernadette Curryer & Will Harding Conference Hall 1	Session 17: Parenting experience Chair: Coral Farr Conference Hall 2	Session 18: Outcomes Chair: Stuart Wark Conference Hall 3
4:30 PM	5:00 PM	16.1 Family's experiences supporting adults in group homes during COVID-19 Tal Araten-Bergman	17.1 Exploring student-parent experiences of a postgraduate disability studies program Sian Anderson	18.1 Contribution: A different perspective on measuring outcomes Samuel Arnold & Sarah Butler
5:00 PM	5:30 PM	16.2 Family perspectives on support in group homes Christine Bigby	17.2 Enduring strength from a labour of love: Family-life with disability Murray Rieck	18.2 Implementation of toolkit for planning and supporting new living arrangements Micaela Goldsmith

## Conference Program, Friday 24 November 2023

8:00 AM	3:30 PM	Registration Conference Hall Foyer, Crown Promenade Melbourne		
9:00 AM	11:00 AM	<p>Opening session: Supported decision making Chair: Ilan Wiesel Conference Halls 1-3</p> <p>Recognising diversity: A framework for implementing supported decision making across sectors and disability groups Prof Christine Bigby, La Trobe University</p> <p>Profound intellectual disability and decision-making: Lived experience from the margins Dr Michelle King, Sociologist and lawyer Daelle Bunker, Artist and advocate</p> <p>Supported decision making law reform Prof Shih-Ning Then, Queensland University of Technology</p>		
11:00 AM	11:30 AM	Morning tea break		
		<p>Session 19: Decision support research Chair: Christine Bigby &amp; Elizabeth Young Conference Hall 1</p>	<p>Session 20: Support practice Chair: Angela Dew &amp; Bruce O'Brien Conference Hall 2</p>	<p>Session 21: Advocacy, rights and peer work Chair: Kathy Ellem &amp; Paul O'Dea Conference Hall 3</p>
11:30 AM	12:00 PM	19.1 Supported decision making: There is no 'except who'	20.1 Making moves in disability support work	21.1 Raising awareness of self advocacy David Corner

		Leanne Pearman & Shewani Shilkar	Catherine Maitland	
12:00 PM	12:30 PM	19.2 Targeting feelings in choice and control workshops for staff Charity Sims-Jenkins, Kathryn Bartlett & Rachael Walters	20.2 He is just like a two-year-old: Controversial? Sheridan Forster	21.2 Being equally valued in economic life Ben Alexander & Raylene Griffiths
12:30 PM	1:00 PM			21.3 Doing peer work with people with intellectual disability Louisa Smith & Jarrod Sandell-Hay
1:00 PM	2:00 PM	Lunch break		
		Session 22: Families Chair: Louisa Smith Conference Hall 1	Session 23: Employment Chair: Andrea Consentino Conference Hall 2	Session 24: Making decisions Chair: Bernadette Curryer Conference Hall 3
2:00 PM	2:30 PM	22.1 The role of the family in finding meaningful employment Jan Kruger & Jack Kruger	23.1 The NDIS and disability employment: A customised approach Peter Smith	24.1 A new way to make choices about the end of life Nicola McKenzie
2:30 PM	3:00 PM	22.2 Family roles in adults' lives: Views of service managers Monica Cuskelly	23.2 NDIS workplace counselling and capacity building Peter Smith & Lauren Pavlidis	24.2 Deciding with support: Bringing supported decision-making to positive behaviour support Sally Robinson
3:00 PM	4:00 PM	ASID awards & conference close		

## **SESSION 1: Supporting people with complex needs**

Wednesday, 22 November 2023

11:30am - 1pm

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### **1.1 The aggression-severity outburst scale: testing a new behaviour severity measure**

Glenys Holt<sup>1,2</sup>, Matthew Spicer<sup>1,3</sup>, Nicola Crates<sup>1,3</sup>

1. Applied Research Centre for Disability and Wellbeing, Launceston, TAS
2. Possability, Launceston, TAS
3. Possability, Burnie, TAS

#### **Main messages**

- We don't know enough about how staff responses to challenging behaviour can make the situation better or worse.
  - Creating a new measure specific to intellectual disability is important.
  - We hope our scale can be used by disability support companies to understand how to improve the outcomes of challenging behaviour for people with intellectual disability.
- 

#### **Abstract**

Background: Currently available measures for the outcomes of challenging behaviours are not made for people with intellectual disability. This study aims to test a new tool that measures the outcome of challenging behaviour episodes. This is important because we need to be able to understand how staff responses can make the outcome better or worse for people with intellectual disability.

Method: People are asked to read some stories and rate the severity on the Aggression-Severity Outcome Scale. This will tell us whether people can use the scale correctly.

Findings: The first part of the data has been collected. From this we can see that people can accurately use most parts of the scale, but some parts need further work. This is an important part of creating a useful scale.

Implications: When finished, this tool will allow disability support organisations to measure the outcomes of different situations and see how staff responses can be improved.

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#### **Presenter biography**

Dr Glenys Holt is a Senior Research Consultant with the Applied Research Centre for Disability and Wellbeing, and Possability. Her research expertise is in the area of applied cognitive psychology, particularly in forensic psychological contexts and those where people with intellectual disability experience systematic risk of disadvantage.

## **SESSION 1: Supporting people with complex needs**

Wednesday, 22 November 2023

11:30am - 1pm

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### **1.2 What makes a good behaviour support plan?**

Maria Vassos<sup>1</sup>, Trent Carberry<sup>1,2</sup>, Radostina Breedt<sup>1</sup>, Karen Nankervis<sup>1</sup>

1. The University of Queensland, St Lucia, QLD
2. Multicap, Eight Mile Plains, QLD

#### **Main messages**

- Past research can help us understand what makes a good positive behaviour support plan, i.e., what information needs to be included to make it a good plan.
  - A good plan tells us how the person with intellectual disability helped develop their plan, outlines a set of strategies that could help the person stop using challenging behaviours, and says when/how these strategies should be used.
  - We want to use this information to make a checklist that will allow people to check if a positive behaviour support plan is good.
- 

#### **Abstract**

Background: Some people with intellectual disability show challenging behaviours (e.g., hitting people). Positive behaviour support plans let families and support workers know how to help people when they show these behaviour. We looked at research papers about behaviour support plans to understand what makes a good plan.

Method: We searched online databases for research papers about good plans. We found 90 papers and read each one.

Findings: We found that good plans tell us: (1) how the person's behaviour was assessed, and if the person with intellectual disability took part in the assessment, (2) why the person shows these behaviours and strategies to help them learn different behaviours, and (3) how families and support workers will be taught the strategies.

Implications: We can use this information about good behaviour support plans to create a checklist. People can use this checklist when reading a plan to make sure that the plan is good and has all the right information.

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#### **Presenter biography**

Maria is an experienced disability researcher who is currently working as a Research Fellow at the University of Queensland. Before this, Maria was the Senior Researcher at Endeavour Foundation.

## **SESSION 1: Supporting people with complex needs**

Wednesday, 22 November 2023

11:30am - 1pm

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### **1.3 Trauma and stigma: The shadow side of belonging**

Benjamin Garcia-Lee<sup>1</sup>

1. School of Education, University of NSW, Kensington, NSW

#### **Main messages**

- Belonging is important to people with intellectual disabilities
  - Traumatic experiences and identity related stigmatisation inhibit belonging
  - Trauma informed approaches to practice focussed on developing a sense of belonging are needed
- 

#### **Abstract**

Background: Belonging has been increasingly recognised as important to the social inclusion of people with intellectual disabilities. This paper reports on inhibitors to a sense of belonging in the lives of people with intellectual disabilities experiencing complex support needs.

Method: In this inclusive research study 16 adults with intellectual disabilities experiencing complex support needs participated in relational mapping and participant-driven photo-elicitation interviews. Reflexive thematic analysis was used to analyse the data.

Results: Traumatic experiences and stigmatised identities were found to be the primary inhibitors to a sense of belonging in the lives of people with intellectual disabilities experiencing complex support needs.

Implications: Trauma informed approaches facilitating a sense of belonging are required to address the ongoing stigmatisation of people with intellectual disabilities.

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#### **Presenter biography**

Ben Garcia-Lee is a PhD candidate in the School of Social Science at UNSW. He is using an inclusive research approach in his PhD about what belonging means to people with intellectual disabilities experiencing multiple forms of marginalisation. Prior to his PhD he worked as an advocate and ally for and with people with intellectual disabilities.

## SESSION 2: Rights

Wednesday, 22 November 2023

11:30am - 1pm

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### 2.1 Shining light on personhood for people with intellectual disability

Eden Tuisaula Cruice<sup>1</sup>, Brigit Mirfin-veitch<sup>1</sup>, Kelly Tikao<sup>1</sup>, Umi Asaka<sup>1</sup>, Hilary Stace<sup>2</sup>, Robbie Francis Watene<sup>1</sup>, Patsie Frawley<sup>3</sup>

1. Donald Beasley Institute, Dunedin, New Zealand
2. Independent Researcher, Wellington, New Zealand
3. University of Waikato, Hamilton, New Zealand

#### Main messages

- Storytellers had their personhood denied in institutions.
  - We need to think about what personhood means.
  - The personhood of people with intellectual disability must be respected.
- 

#### Abstract

**Background:** A research project in Aotearoa New Zealand called "Tell Me About You" explored the experiences of people with intellectual disability and neurodiversity who had spent time in State and faith-based care. The research found that the personhood of people with intellectual disability had not been respected.

**Method:** Story gatherers (researchers) interviewed 16 storytellers (participants) about their experiences in care. Storytellers and story gatherers spent time together to create stories. Stories were analysed using the ecological model of disability violence and abuse.

**Results:** Stories shared by Storytellers about their experiences living in institutions and other types of care showed that their personhood had not been respected.

**Implications:** The lack of respect for personhood identified in the research findings makes it important to think about what personhood means, and what it means to respect the personhood of people with intellectual disability.

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#### Presenter biographies

Eden Tuisaula Cruice is a Researcher at the Donald Beasley Institute, where she is involved in a range of disability research and disabled-led monitoring projects. Brigit Mirfin-Veitch is the Director of the Donald Beasley Institute. She is committed to achieving social change through research and has had a long involvement in inclusive research with people with intellectual disabilities.

## **SESSION 2: Rights**

Wednesday, 22 November 2023

11:30am - 1pm

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### **2.2 Saying sorry for disability institutions**

Gina Andrew-Zucker<sup>1</sup>, Phillippa Carnemolla<sup>2</sup>, Jack Kelly<sup>1,2</sup>, Leigh Creighton, Linda Steele<sup>2</sup>, Ruth Richter<sup>3</sup>

1. Council for Intellectual Disability, Surry Hills, NSW
2. University of Technology Sydney, Sydney, NSW
3. Centre for Disability Research and Policy, Sydney University, Sydney, NSW

#### **Main messages**

- Including people with disability
  - Saying sorry
  - Remembering Australia's history of institutions
- 

#### **Abstract**

Background: We know that people who lived in disability institutions were treated badly.

Method: The speakers have done different things including talking to people with disability about their experiences and remembering institutions, co-research, research about the history of NSW disability institutions, and work with people who were treated badly by institutions as children

Results: We found that people with intellectual disability want the public to learn about the history of disability institutions, but in a way that supports people and with people with intellectual disability as leaders. They also found that people with intellectual disability want to learn more about redress, but don't want empty words. The research found that some people with intellectual disability who have lived in institutions in NSW experienced abuse and that concepts of redress have not featured in their lives.

Implications: Ideas for advocacy to make change.

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#### **Presenter biographies**

Gina Andrews Zucker is a career public servant with more than 20 years expertise in social policy and the NSW criminal justice system. Jack Kelly has worked in the disability research and advocacy sector since 2016. Jack is a project worker at the Council for Intellectual Disability and an Honorary Research Fellow at the University of Technology Sydney. Phillippa Carnemolla is a Senior Research Fellow at the University of Technology Sydney. She is interested in exploring what inclusive design and inclusive research really mean and how to do it well.

## **SESSION 2: Rights**

Wednesday, 22 November 2023

11:30am - 1pm

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### **2.3 4 Rights for decision making**

Ricky Kremer<sup>1</sup>, Alex Elliott<sup>1</sup>

1. Council for Intellectual Disability, Surry Hills, NSW, Australia

#### **Main messages**

- Supported decision making is about people with disability being at the centre of their own decisions.
  - People with intellectual disability can make more of their own decisions when they have the support and adjustments they need and want.
  - Everyone has the right to make decisions, to take risks, to have the right support and have their decision respected.
- 

#### **Abstract**

People with intellectual disability can make more of their own decisions when they have the support and adjustments they need and want.

In this presentation we will talk about things we have learned from the CID's My Rights Matter workshops.

The presenters will share real-life examples about 4 rights in decision making. They will share the different ways people make choices about risks, and how what makes good decision-making is different for everyone.

Audiences will learn about different ways to support people with disability to make more of their own decisions.

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#### **Presenter biographies**

Ricky Kremer is a Project Worker at the Council for Intellectual Disability. He is working to instil confidence in people with intellectual disability to make their own decisions by knowing their rights and having conversations with supporters about making decisions. Ricky is the lead of the Supported decision making Peer mentoring group. Alexander Elliott works at the Council for Intellectual Disability as a Project Worker. Alex has worked on projects on Supported Decision Making, and with the Communications team. Alex uses his expert knowledge from his own experiences as a person with disability, mentors his peers and uses his writing skills to make resources and training.

## **SESSION 3: Access**

Wednesday, 22 November 2023

11:30am - 1pm

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### **3.1 People First NZ Learn with Us webapp: A digital tool**

Julia Young<sup>1</sup>, Alex Johnsen<sup>1</sup>, Sandy Ryan<sup>1</sup>, Patrick Doherty<sup>1</sup>

1. People First NZ, Wellington, New Zealand

#### **Main messages**

- The webapp tool is an example of a project led by people with an intellectual disability working in a co-design process.
  - The webapp tool demonstrates the value of working collaboratively.
  - We have created a digital tool that can be built on and developed more.
- 

#### **Abstract**

Background: People First NZ is an organisation that is run by and for people with an Intellectual Disability. We have created an online webapp, this is a digital tool that people can use on any device. We would like to present our story to share with you our success.

Method: We have used a co-design process, where our members have led the development of this digital tool. Collaborating with the right people was important and we worked with a specialist IT company called Springload. Through the process, we used a 'try, learn' adjust' approach so that we were constantly learning and improving.

Results: We have found that people enjoy using the digital tool, they find it easy to use and they have learnt more about their rights, keeping safe and have become more confident to speak up.

Implications: We have shown that anything is possible and given the time, opportunity and the right assistance, our members can achieve something awesome.

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#### **Presenter biographies**

Alex Johnsen is an active member of the Hamilton People First group, he has held the role of Secretary. He was part of the group that developed the 'Easy Read' version of the Treaty of Waitangi. Julia Young runs her own radio show called the 'Positivity Show' and has made her own short films. Julia is autistic and often communicates using her lemurs as her voice in the third person. Julia is a strong leader within People First Dunedin and the local disability community.

## **SESSION 3: Access**

Wednesday, 22 November 2023

11:30am - 1pm

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### **3.2 An update on accessible written information**

Cathy Basterfield<sup>1</sup>

1. Access Easy English, Mentone East, VIC

#### **Main messages**

- Easy English has the simplest use of sentence structure to support comprehension
  - It is not clear how complex images support comprehension
  - Easy Language is a new label being used in Europe to describe written accessible information.
- 

#### **Abstract**

Background: There is more accessible written content being developed for people with intellectual disabilities with low literacy in Australia and internationally. This paper will provide an overview of current practice and issues on accessible written information being developed from around the world.

Method: A review of research and other publications, and engagement with international practitioners from agencies from Europe, UK and Australia on the development of accessible written information.

Results: Easy English (which is different to Easy Read) continues to have the simplest language and image selection. Group versus 1:1 consumer review have different outcomes. Many European agencies have introduced the term Easy Language.

Implications: Writers need to be aware of the international developments, but also how best practice Easy English meets the needs of people with intellectual disability.

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#### **Presenter biography**

Cathy Basterfield leads a team of expert Easy English writers at Access Easy English. Cathy was involved in the development of the first guidelines for writing Easy English 18 years ago. This is still the basis of quality Easy English. In 2022, Cathy and her team received multiple national and international awards for their work.

## **SESSION 3: Access**

Wednesday, 22 November 2023

11:30am - 1pm

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### **3.3 Carers from refugee backgrounds: Co-creating Arabic resources**

Louisa Smith<sup>1</sup>, Angela Dew<sup>2</sup>, Jo Watson<sup>2</sup>

1. Deakin University, Geelong, VIC

2. Deakin University, Burwood, VIC

#### **Main messages**

- Information about disability services is usually in English
  - Parents and carers of people with intellectual disability from refugee backgrounds need visual resources in Arabic
  - Parents and carers co-designed a video to talk about their challenges and hopes
- 

#### **Abstract**

**Background:** Parents and carers of people with intellectual disability from refugee backgrounds often do not know what services are available to them. Information is not in a language they understand. The aim was to co-create Arabic language resources to increase information.

**Method:** Four stages: (1) assessment of peer-reviewed and grey literature about access to services for people with disability from refugee backgrounds, (2) five workshops with people with disability and family members, (3) online bi-lingual co-design group with carers and a person with a disability from refugee background, and (4) production and dissemination of a co-designed video for and about family and carer experiences.

**Results:** Carers needed visual resources in Arabic-language. They co-designed a video that showed lots of challenges but also pathways to hope.

**Implications:** Resources and training for carers from migrant and refugee backgrounds needs to be co-designed to ensure accessible communication and relevant starting points.

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#### **Presenter biography**

Louisa Smith is a Senior Lecturer in Disability and Inclusion at Deakin University. Louisa has a PhD. She writes about how people with disability and dementia experiences changes. Louisa likes to do inclusive arts-based research.

## SESSION 4: Housing and Leaving Home

Wednesday, 22 November 2023

2pm - 4pm

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### 4.1 Housing and people with multiple and complex disabilities in NZ

Umi Asaka<sup>1</sup>, Brigit Mirfin-veitch<sup>1</sup>

1. The Donald Beasley Institute, Dunedin, New Zealand

#### Main messages

- People with multiple and complex disabilities experience many barriers when choosing where to live and who to live with.
  - Some families feel like the only option for their family member with disability is residential services.
  - The UN Disability Committee deinstitutionalisation guidelines provide clear instructions on what governments must do to ensure people with multiple and complex disabilities have access to adequate housing.
- 

#### Abstract

**Background:** This presentation is about a New Zealand study where family, whānau, and close supporters talked about the housing experiences of people with severe and profound disability. In New Zealand, the term multiple and complex disability is used for this group of people with disability.

**Method:** Seven interviews with family, whānau and close supporters were analysed to understand how people with multiple and complex disabilities accessed housing.

**Results:** People with multiple and complex disabilities experienced a number of barriers when accessing adequate housing. Not many people had choice and control over where they lived or who they lived with.

**Implications:** The government needs to improve access to adequate housing and in-home support for people with multiple and complex disabilities so that they can live in the community in the way that they want to.

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#### Presenter biographies

Umi Asaka is a Junior Research Fellow at the Donald Beasley Institute. Umi has lived experience of disability and a social work background. Brigit Mirfin-Veitch is the Director of the Donald Beasley Institute. Brigit is committed to initiating and achieving social change through inclusive and ethical research.

## **SESSION 4: Housing and Leaving Home**

Wednesday, 22 November 2023

2pm - 4pm

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### **4.2 Post-parental care planning in rural Australia**

Stuart Wark<sup>1</sup>, Lia Bryant<sup>2</sup>, Tyson Morales-Boyce<sup>2</sup>, Kate Deuter<sup>2</sup>

1. The University of New England, Armidale, NSW

2. University of South Australia, Adelaide, SA

#### **Main messages**

- Disability and community support services in rural areas do not always provide the help adults need if they are looking to move out of their family home.
  - These services also do not always work well together to help adults move out of home.
  - Rural services need to be supported to work together to better support adults with intellectual disabilities.
- 

#### **Abstract**

Background: Adults with intellectual disabilities are living longer. Their parents are getting older. Research shows a lack of support for rural adults to move out of their family home when their parents cannot care for them.

Method: We spoke with small groups of disability support workers across rural South Australia. We asked them what was preventing adults moving out of their family home when their parents got older. We also asked them what would help adults to move to a new home.

Results: Our research found four key issues in relation to helping rural adults moving out of home. These issues were staffing, services, parent-carers, and change management.

Implications: We found that support services do not always provide the help rural adults need. Services also did not work well together. There needs to be a focus on supporting services to work together to better support adults with intellectual disabilities.

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#### **Presenter biography**

Stuart Wark is the Clinical Academic Coordinator in the School of Rural Medicine at the University of New England. He has a three decade working history in the community and public health sector, and retains strong relationships with both rural and metropolitan Non-Government Organisations (NGOs).

## **SESSION 4: Housing and Leaving Home**

Wednesday, 22 November 2023

2pm - 4pm

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### **4.3 Moving out of the family home**

Irene Belperio<sup>1</sup>, Fiona Rillotta<sup>1</sup>, Ruth Walker<sup>1</sup>, Christine Bigby<sup>2</sup>, Ilan Wiesel<sup>3</sup>, Claire Hutchinson<sup>1</sup>

1. College of Nursing and Health Sciences, Flinders University, Adelaide, SA

2. Living with Disability Research Centre, School of Allied Health, Human Services & Sport, La Trobe University, Bundoora, VIC

3. Geography, Earth and Atmospheric Sciences, The University of Melbourne, Melbourne, VIC

#### **Main messages**

- Control over housing choices and information about housing are important to achieve housing goals.
  - Support that is relevant to the person can improve housing outcomes.
  - Housing policy can make a difference by fixing the issue that resources are not equal for people with intellectual disability.
- 

#### **Abstract**

**Background:** People like to have control of where they live and who they live with. But, people with intellectual disabilities do not have much choice when they want to move out of their family home.

**Method:** We did eight interviews with adults with intellectual disabilities and family members. We asked them what they want when they move out of the family home. We used something called a housing pathways framework to help us understand what people said.

**Results:** Adults with intellectual disabilities and their families told us they want housing close to people and places that are important to them. They also want to be able to choose who to live with. And they want help working out how to get what they need.

**Implications:** People with intellectual disability and their families need better support to know what housing is available. They need help to access this housing. It is important for housing to be what people need or want.

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#### **Presenter biography**

Irene is an experienced qualitative researcher with interests in ageing and disability, and ageing in culturally and linguistically diverse communities. She also has extensive experience in learning support and has been teaching at the university level for over 13 years.

## **SESSION 4: Housing and Leaving Home**

Wednesday, 22 November 2023

2pm - 4pm

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### **4.4 Living a good life in my own home**

Angela Walter<sup>1</sup>

1. Registered Social Worker, Self Employed, Auckland, Aotearoa/New Zealand

#### **Main messages**

- It is a big leap of faith for parents to contemplate their adult children leaving the family home
  - With the right government funding and support systems in place it can be successful
  - Adults with intellectual disability deserve the opportunity to live their best lives
- 

#### **Abstract**

Background: Many adults with intellectual disability continue to have little agency to decide how they want to live as adults. They often continue to live in “group homes.” My aim is to show that alternatives are possible.

Method: This is a personal reflection.

Results: In 2019, my 25-year-old adult autistic son, who also has an intellectual disability, moved into a state provided home paying income related rent. He continues to live semi-independently due to the good support structures around him and lives a rich and full life as an adult autistic man. The barriers and concerns raised by various government agencies were able to be worked through. An aim was and is, to educate and support other parents and caregivers that their person can also have this sort of living arrangement.

Implications: A good life living in the community is possible. Professionals should encourage people with intellectual disability and their families to pursue this option.

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#### **Presenter biography**

Angela Walter is a registered social worker from Aotearoa/New Zealand with a passion for supporting people with disabilities and their whanau. Angela is also a parent to three, now adult, children, two of whom were diagnosed as preschoolers as being on the autism spectrum.

## **SESSION 5: Inclusive Research**

Wednesday, 22 November 2023

2pm - 4pm

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### **5.1 A mental health support program for us by us**

Erin Louise Whittle<sup>1</sup>

1. Centre for Disability Studies, Camperdown, NSW

#### **Main messages**

- People with intellectual disability have a right to choose what research they are involved in from start to finish
  - We have learnt useful things about doing research as a group, especially about something sensitive like mental health
  - We are learning how to develop an intervention that is for people with intellectual disability by people with intellectual disability
- 

#### **Abstract**

Background: The Inclusive Research Network at the Centre for Disability Studies have worked together to do a project about people with intellectual disability supporting their peers with their mental health. We are developing a program for people with intellectual disability by people with intellectual disability.

Method: We are a co-designed project, using inclusive mixed methods.

Results: We are still doing the project. We will be talking about what we have learnt about mental health so far doing the project. We will also talk about what we have learnt about doing this kind of research.

Implications: This will help other people who would like to do this kind of research. It will also help people with their mental health.

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#### **Presenter biography**

Erin Louise Whittle is a researcher at the Centre for Disability Studies. She has an extensive research background in gender, intellectual disability and access to services. Previous work experience includes the Department of Developmental Disability and Neuropsychiatry, UNSW (3DN), the Black Dog Institute UNSW, and Faces in the Street, St Vincent's Hospital Sydney. She has a particular expertise in qualitative and mixed method research, in particular using various qualitative methods and the analysis of large scale lined data sets. She has an interest in inclusive research methods and has been a part of the CDS Inclusive Research Methods Network since 2021. She has published in a number of international journals.

## **SESSION 5: Inclusive Research**

Wednesday, 22 November 2023

2pm - 4pm

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### **5.2 The role of research in building agency with people with intellectual disability**

Morag Kelly<sup>1</sup>

1. Sydney Centre for Healthy Societies, Paddington, NSW

#### **Main messages**

- People with a disability are experts on their own lives.
  - Common research methods are not accessible to people with intellectual disability and people with communication delays.
  - Research on intellectual disability needs to include people with intellectual disability.
- 

#### **Abstract**

Background: People with disabilities are experts on their own lives. This means they should be involved in research about them.

Method: I wanted to understand how people with intellectual disability have been included in recent studies. I read many papers written within the last ten years that focused on intellectual disability to find out.

Results: There are a few studies that include people with intellectual disability. Studies usually include carers rather than people with intellectual disability. Most studies need participants to talk. This means that only people who communicate through talking are included.

Implications: Finding ways to include people with intellectual disability in research is important for inclusion. Common ways of doing research with people with disabilities need to be changed to actively include people with intellectual disability.

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#### **Presenter biography**

Morag is currently studying her PhD (Sociology) with the Sydney Centre for Healthy Societies at The University of Sydney. She is passionate about inclusion and agency within conversations about care for people with intellectual disability.

## **SESSION 5: Inclusive Research**

Wednesday, 22 November 2023

2pm - 4pm

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### **5.3 Lived experience: Profound intellectual disabilities and inclusion in research**

Michelle King<sup>1</sup>

1. School of Health and Rehabilitation Sciences, University of Queensland, Kelvin Grove

#### **Main messages**

- People with profound intellectual disabilities are not included in many research projects, and are almost never researchers themselves.
  - Michelle found that her lived experience made interviews into conversations: connection, emotion, and humour helped people talk about difficult problems and feelings.
  - The young person with profound intellectual disabilities being at the interview was very important, and having a young person with profound intellectual disabilities coming to an interview with the interviewer helped that interview be more inclusive.
- 

#### **Abstract**

Background: People with profound intellectual disabilities are not included in many research projects, and are almost never researchers themselves. We need more ways to include them.

Method: Michelle did research about law, decision-making, and people with profound intellectual disabilities. This research idea came from her experiences as a supporter of her daughter, Daelle, who has profound intellectual disabilities. In that research, Michelle did interviews with young adults with profound intellectual disabilities and their parents. Daelle also came to one interview.

Results: Michelle found that her lived experience made interviews into conversations: connection, emotion, and humour helped people talk about difficult problems and feelings. The young person being at the interview was very important. Daelle coming to an interview helped that interview be more inclusive.

Implications: These ideas can help researchers think about ways to include people with profound intellectual disabilities in research, and as researchers.

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#### **Presenter biography**

Michelle King is a sociologist and lawyer. She does research on decision-making and how law works for people who have all kinds of disabilities. Michelle is also an advocate and supporter of her 24 year old daughter who lives with profound intellectual and multiple disabilities.

## **SESSION 5: Inclusive Research**

Wednesday, 22 November 2023

2pm - 4pm

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### **5.4 The inclusion library**

Phillippa Carnemolla<sup>3</sup>, Jack Kelly<sup>1</sup>, Justine O'Neill<sup>1</sup>, Mary-Ann O'Donovan<sup>2</sup>, Clara Goossens<sup>2</sup>

1. Council for Intellectual Disability, Sydney, NSW
2. Centre for Disability Studies, University of Sydney, Sydney, NSW
3. UTS, Ultimo, NSW

#### **Main messages**

- The Inclusion Library is a new website that will collect and share knowledge and resources to include people with intellectual disability and show people how to include others.
  - The Inclusion Library is for anyone interested in making our communities, workplaces and cities more inclusive of people with intellectual disability.
  - We want to make it easier for people to learn how to be more inclusive by seeing what other people are doing, and we want to hear what you think we should share.
- 

#### **Abstract**

The Inclusion Library is a website. It is like a library online. We want the Inclusion Library to help people find information that includes people with intellectual disability and shows people how to include others. It has information from Australia and around the world. There are videos, written information, and information you can listen to.

Three groups are working on the Inclusion Library. They are the Centre for Disability Studies, the Council for Intellectual Disability, and the University of Technology Sydney. We will show you the kind of information we want to share because we think it is good. We will ask everyone what you think about the Inclusion Library and what sorts of things should be in it.

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#### **Presenter biographies**

Jack Kelly has worked in the disability research and advocacy sector since 2016. Jack is a project worker at the Council for Intellectual Disability and an Honorary Research Fellow at the University of Technology Sydney. Phillippa Carnemolla is a Senior Research Fellow at the University of Technology Sydney (UTS). She is interested in exploring what inclusive design and inclusive research really mean and how to do it well.

## **SESSION 6: Health Issues**

Wednesday, 22 November 2023

2pm - 4pm

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### **6.1 The healthy discussions project**

Michelle Wilcox<sup>1</sup>

1. Office of the Public Advocate, Carlton, VIC

#### **Main messages**

- The project is about helping health professionals get better at communicating with people with disability and understanding disability
  - There have been information sessions for health professionals delivered by people with disability
  - The HealthCARE Conversations video has tips for health professionals for better communication with people with disability
- 

#### **Abstract**

Background: The Office of the Public Advocate wants doctors and other health professionals to get better at understanding disability and how they communicate with patients with disability. The Healthy Discussions Project is led by people with intellectual disability.

Method: OPA has delivered information sessions to health professionals about people's rights to make decisions about their own health, lived experience of disability and ways to communicate well.

Results: The project has made a video called "HealthCARE Conversations". People with the lived experience of disability share tips on how health professionals can communicate with them. The project has also recorded audio interviews about people's lived experience of disability and human rights.

Implications: The HealthCARE Conversations video will help students at university who are learning to become doctors, nurses and other health professionals. OPA wants people with disability to have access to good healthcare.

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#### **Presenter biography**

Michelle Willcox is currently employed as a Policy and Engagement officer at the Victorian Office of the Public Advocate. She is a tenacious woman who has a Diploma in Community Services and has worked on various community development projects designed to improve long-term health outcomes for people with cognitive disability.

## SESSION 6: Health Issues

Thursday, 23 November 2023

4:30pm-5:30pm

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### 6.2 Enhancing preventive healthcare through service provider education

Clare Woods<sup>1</sup>, Jennifer Brennan<sup>1</sup>

1. Central and Eastern Sydney Primary Health Network, Mascot, NSW

#### Main messages

- The language used at the advent of the NDIS that 'health does health and disability does disability' has created a lot of confusion for both sectors.
  - To enable proactive preventative health you need to educate the individual, service provider and supporters.
  - Building accessible primary care services isn't enough if people do not know how or when to access them.
- 

#### Abstract

**Background:** A lot of healthcare for individuals with intellectual disability is reactive. Preventative healthcare has better outcomes and is cheaper for everyone. Disability providers have little education on how to support preventative health for their clients. GPs and disability providers lack an understanding of how each other work. This contributes to poor health outcomes for people with intellectual disability.

**Method:** Project GROW co-designed a process for annual health assessments. The process supports disability providers to improve planning for annual health, advocate for reasonable adjustments and preventative health, build relationships with, and understand and utilise GP management plans.

**Results:** Disability staff said they felt more confident to prepare for and advocate during appointments, appointments were better, and coordination between the disability provider and GP improved.

**Implications:** Training the disability sector on how to access primary care will create better preventative health for people with intellectual disability. We believe this is as important as making health services accessible.

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#### Presenter biography

Clare began developing resources and training on intellectual disability health at CID. She co-designed the My Health Matters folders that assist people to access health with minimal need for outside support. Clare began working for Central and Eastern Primary Health Network in 2021 on the Department of Health's Primary Care Enhancement Program, GROW.

## **SESSION 6: Health Issues**

Wednesday, 22 November 2023

2pm - 4pm

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### **6.3 Wellbeing Indicators for intellectually disabled New Zealanders**

Shara Turner<sup>2</sup>, Luisa Beltran-Castillon<sup>1</sup>, Keith McLeod<sup>1</sup>

1. Kōtātā Insight, Wellington, New Zealand
2. IHC, Wellington, Wellington, New Zealand

#### **Main messages**

- People with intellectual disability can have amazing outcomes if the right supports are in place.
  - The life expectancy of people with intellectual disability in New Zealand has increased a lot since 2011 without any help from the government, and could increase even more with support.
  - Intellectually disabled people should be a priority group for policy makers in New Zealand.
- 

#### **Abstract**

**Background:** Despite being a priority population for social policy, there is little reliable and up to date data on the experiences of intellectually disabled New Zealanders.

**Method:** In order to fill this gap, IHC formed a partnership with Kōtātā Insight to look into a dataset called the Integrated Data Infrastructure to find data on New Zealanders with intellectual disability. We are working on an Easy Read version of the executive statement that will be the basis of the presentation.

**Results:** The resulting data sheds light on the experiences of a group of New Zealanders who are too often made invisible by policy.

**Implications:** The results can be used as evidence for advocates and policy makers to design and prioritise more effective support, as well as enabling the country to report on progress against the priorities in the CRPD.

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#### **Presenter biography**

Shara Turner is a passionate advocate for people with intellectual disability and dedicated to creating an inclusive society where they can thrive and exercise their autonomy. Shara has a background in law but has for the last four years been working with IHC New Zealand as an advocate for people with intellectual disability, focusing mainly on systemic advocacy.

## **SESSION 6: Health Issues**

Wednesday, 22 November 2023

2pm - 4pm

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### **6.4 Transitioning from prison to community: Reflections from an NDIS OT**

Sally Lamshed<sup>1</sup>

1. Better Rehab, Moonee Ponds, VIC

#### **Main messages**

- Activities in prison are very different to activities in the community.
  - OT assessment and therapy can be effectively completed in prison.
  - NDIS participants with intellectual disability need OTs to advocate for their needs before being released.
- 

#### **Abstract**

Background: People with intellectual disability in prison are a vulnerable group who have often not had access to needed disability supports. Occupational therapists (OTs) working through NDIS play a key role in advocating for these needs, particularly for transition to the community.

Method: Information has been gathered through direct experience working with justice-involved participants in various settings in Victoria, both during their time in prison and post release.

Results: It's essential that OTs understand the activity demands of prison so they can effectively complete assessment and advocate for participants. There are limitations to assessments and therapy for NDIS participants in custody, however it is possible and necessary to work within these limitations to ensure this group are effectively supported to achieve their goals.

Implications: OTs require additional knowledge in forensic disability to provide the best quality of care to justice-involved NDIS participants with intellectual disability.

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#### **Presenter biography**

Sally Lamshed is a Senior Occupational Therapist working for Better Rehab in Melbourne. Sally works with NDIS participants with cognitive and psychosocial disabilities who are in contact with the justice system. She is passionate about the improvement and effective delivery of services for this group.

## **SESSION 7: Abuse Prevention**

Wednesday, 22 November 2023

4:30pm – 5:30pm

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### **7.1 Centering Lived Experience of Intellectual Disability in Violence Prevention**

Kirsty Hill<sup>1</sup> Alison Maclean<sup>1</sup>

1. WWILD Sexual Violence Prevention Association Inc, Lutwyche, QLD

#### **Main messages**

- People with intellectual disability have a valuable contribution to make to prevention work and have the right to full participation and leadership, not just consultation.
  - The process of engaging Lived Experience experts is just as important as the resource created.
  - Accessibility needs to be considered at the centre of the project design and implementation, alongside trauma informed practice.
- 

#### **Abstract**

Background: Although overrepresented as victims/survivors of domestic and family violence, people with intellectual disability are rarely meaningfully included in prevention work.

Method: Peer Workers who also have lived experience of intellectual disability and violence share the process we used to create violence prevention animations that centred the lived experience expertise of people with intellectual disability.

Results: We co-designed and co-created several animation videos with a group of women and non-binary people with intellectual disability. The animations explore popular myths about intellectual disability, which contribute to the high rates of domestic and family violence experienced by people with intellectual disability.

Implications: Insights about leading the project, providing creative input, creating safety and support in the project, and the impacts for project participants are important considerations for future work.

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#### **Presenter biographies**

Kirsty Hill is a peer worker. She has an intellectual disability and has gone through domestic violence. She is a member of the Resound Survivor Advocate Group at Brisbane Domestic Violence Service. Alison Maclean is a peer worker. She has lived experience of having an intellectual disability and volunteers for Queenslanders with Disability Network (QDN) 'Hot Topics'.

## **SESSION 7: Abuse Prevention**

Wednesday, 22 November 2023

4:30pm – 5:30pm

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### **7.2 Understanding everyday harm: a scoping review of abuse literature**

Sally Robinson<sup>1</sup>, Jan Idle<sup>1</sup>, Karen Fisher<sup>2</sup>, Ciara Smyth<sup>2</sup>, Heikki Ikaheimo<sup>3</sup>, Jung Yoon<sup>1</sup>

1. Flinders University, Bedford Park, SA

2. Social Policy Research Centre, UNSW, NSW

3. UNSW, Sydney, NSW

#### **Main messages**

- People with intellectual disability are often treated in ways that make them feel bad.
  - We looked at what other researchers have said about what causes this everyday harm.
  - More research needs to be done that asks people with intellectual disability what they think needs to change.
- 

#### **Abstract**

Background: The everyday harm experienced by people with intellectual disability is underexplored. Everyday harm indicates a lack of care, respect or value between people. These problems can leave people feeling uncomfortable, silenced, insulted or neglected.

Method: A scoping review of recent literature on microaggression and emotional and psychological abuse was completed to support a larger research project on everyday harm.

Results: The analysis showed that microaggression and emotional and psychological abuse occur between people and are also influenced by organisational structures and attitudes. Themes showed that harms occur routinely and are underpinned by ableist attitudes and stigma. Actions and omissions may or may not be intentional, can be subjective and have cumulative effects.

Implications: While the actions and omissions that cause everyday harm are acknowledged in the related literature, the experience and response to these harms by people with intellectual disability are not widely canvassed and require further research.

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#### **Presenter biography**

Sally Robinson does research with people with intellectual disability about things that help them to feel safe when life is difficult, and about how to improve services. She is a Professor at Flinders University in Disability and Community Inclusion.

## **SESSION 8: Parenting with Intellectual Disability**

Wednesday, 22 November 2023

4:30pm – 5:30pm

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### **8.1 Reframing parenting with intellectual disability: From problem to solution frame**

Susan Collings<sup>1</sup>, Margaret Spencer<sup>1</sup>

1. University of Sydney, Sydney, NSW

#### **Main messages**

- We have to challenge ableism in how we decide if parenting is 'good enough'.
  - Child protection needs to accept that 'parenting with support' is normal.
  - Governments need to ask: Can this parent be supported? If not, why not?
- 

#### **Abstract**

**Background:** Too many parents with intellectual disability have their children removed. But we know from research what helps these parents and children thrive.

**Method:** We ask six questions to find out why the situation has not improved for these families.

**Results:** We learnt that child protection uses unfair and ableist standards to judge parenting 'capacity'. Parents with intellectual disability are viewed as being dependent on others. Dependency is seen as a failure. If we reframe parenting as inter-dependent then we can value and respect diverse abilities. We can offer reasonable and necessary adjustments.

**Implications:** If it is normal to get help with parenting then the question for governments is: Can this parent be supported. If not, why not?

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#### **Presenter biography**

Susan Collings has an impressive track record for research to understand the systemic and environmental drivers of social disadvantage for vulnerable children and families, with a special interest in disability and child protection. Her co-design research with the child and family service sector, community groups and people with lived experience have contributed to policy and practice developments. As an experienced qualitative researcher, Susan has moved beyond conventional narrative methods to incorporate arts-based and visual storytelling modalities. Susan is a representative on several local and international committees working to overcome the inequalities faced by parents with intellectual disability and their children.

## **SESSION 8: Parenting with Intellectual Disability**

Wednesday, 22 November 2023

4:30pm - 5:30pm

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### **8.2 Disability or not, I am still a parent, sometimes I just need a little support**

Renee Mills<sup>1</sup>, Crystal Richardson

1. Community Living Association, Nundah, QLD

#### **Main messages**

- A parent with lived experience will share things that are hard, what makes them strong, and why good support is important
  - We will talk about how workers and parents found ways to work together and what we do to create change
- 

#### **Abstract**

**Background:** Community Living Association Inc., has worked alongside parents with intellectual disability for over 20 years, with these parents often beginning their families during their transition as young people through the Child Protection system.

**Method:** For the past four years, our social workers have worked alongside parents with intellectual disability to develop a practice that is genuinely person centred, holistic and responsive to the hopes and goals of the women and men with whom we work.

**Results:** This presentation will share the emerging practice framework that has developed alongside parents and the emerging outcomes of the work.

**Implications:** The practice framework aims to build a genuinely collaborative, person centred practice where parents thrive, ensure better outcomes for parents with intellectual disability, and address system and structural inequality and oppression.

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#### **Presenter biographies**

Renee Mills, is Team Leader of the Parenting Team at CLA. She has worked alongside young people at risk and people with disability for over twenty years. Crystal Richardson is a mother with an intellectual disability and three beautiful boys who are currently in out-of-home care. Crystal believes that all parents have the right to access the support they need to be the best parent they can be. Crystal strongly believes that there should be better ways to share care of children when they are in out-of-home care.

## **SESSION 9: Co-Production**

Wednesday, 22 November 2023

4:30pm – 5:30pm

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### **9.1 CID's Working Together Framework: Making co-production easy**

Catalina Voroneanu<sup>1</sup>, Jack Kelly<sup>1</sup>, Kerry Watson<sup>1</sup>,

1. NSW Council for Intellectual Disability, Surry Hills, NSW

#### **Main messages**

- It is important to make co-production easy
  - Making things easy can be hard but is important for accessibility
  - Creating new ways of working together to do things differently is fun and pioneering
- 

#### **Abstract**

Background: CID is an organisation led by people with intellectual disability. This presentation will share CID's Working Together Framework including how it was co-created with people with lived experience.

Method: CID wanted to get clear how they work with people with lived experience in their roles as Board Directors, employees and members. A team was set up to run focus groups with staff to help CID find out what words people used, what they were doing together, what was working, what needed to change, and what co-production means.

Results: The team co-created CID's Working Together Framework. It includes easy words to describe different types of teamwork in action, all the parts of co-production, CID's Principles for Co-production, and an example of an entire co-production process.

Implications: The Framework helps CID be consistent in how they work together with people with lived experience within CID and describe how they work together to others outside CID. It is important to help CID decide what they need to model inclusive practices.

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#### **Presenter biographies**

Catalina is Manager, Inclusion Projects at CID who helped lead the team to co-create CID's Working Together Framework. Catalina has experience leading a number of projects and teams within Australia and internationally. Jack is an Inclusion Projects Worker at CID with lived experience of intellectual disability who worked on the team to co-create CID's Working Together Framework. Jack works in the Health team at CID and has contributed his expertise in many other project priorities within and external to CID. This has included engaging with high profile people including speaking up at the Disability Royal Commission.

## **SESSION 9: Co-Production**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **9.2 Co-designing hospital education for healthcare workers about intellectual disability**

Cathy Beck<sup>1</sup>, Katie Brooker<sup>1</sup>, Catrin Culla<sup>1</sup>

1. Mater Intellectual Disability and Autism Service , Mater, South Brisbane , QLD

#### **Main messages**

- We codesigned education for hospital staff about intellectual disability and autism
  - We made the education brief and powerful to suit busy hospital staff
  - Feedback shows staff are more confident and knowledgeable about intellectual disability health
- 

#### **Abstract**

Background: People with intellectual disability and autistic people experience barriers to accessing healthcare and, as a result, die earlier than the general population. Part of the problem is there is little or no training in our health professionals training about disability. Our aim was to create training for health staff.

Method: We interviewed people with intellectual disability, autistic people and their supporters about their experiences accessing mainstream health services. Mainstream staff were surveyed and interviewed to determine their confidence, knowledge and attitudes about intellectual disability and autism.

Results: With this information we designed an online course for hospital staff. The education was co-designed and developed with a creative arts company with actors with disability.

Implications: We are evaluating the impact of this training on the confidence, knowledge, and attitudes of health workers in three hospital settings. Our goal is to roll this out as mandatory education in all healthcare settings.

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#### **Presenter biographies**

Katie is a health and disability researcher. She did an undergraduate degree in health sciences. She was motivated to make a change after learning about the significant health gap experienced by people with intellectual disability. Catrin is a research assistant at the Mater Intellectual Disability and Autism Service. Catrin has worked on a project to make education for hospital staff since 2020. Cathy Beck is the Program Manager at the Mater Intellectual Disability and Autism Service. She has a background in Occupational Therapy and health management.

## **SESSION 11: Health Information**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **11.1 Roadmap for Improving the health of people with intellectual disability**

Nicholas Lennox<sup>1</sup>, Anthony Lark<sup>2</sup>

1. University of Queensland, Anstead, QLD

2. Department of Health & Aged Care, Primary Care Division, Canberra, ACT

#### **Main messages**

- The Roadmap helps people with intellectual disability and their supporters to improve healthcare.
  - Under the Roadmap, a National Centre of Excellence will be established and yearly health checks will become easier to access.
  - The Roadmap aims to improve the education of health professionals and support better research.
- 

#### **Abstract**

**Background:** The health of people with intellectual disability is poor when compared to other Australians. There was no national strategy to better the health of people with intellectual disability in Australia until August 2021.

**Method:** The Department of Health and Aged Care made a 10-year plan to improve the health of people with intellectual disability. They worked closely with people with intellectual disability, their families, and supporters to make this plan called the Roadmap.

**Results:** The Roadmap helps people with intellectual disability and their supporters to improve healthcare. Under the Roadmap a National Centre of Excellence will be established and yearly health checks will become easier to access. The Roadmap aims to improve the education of health professionals and support better research.

**Implications:** The Roadmap aims to improve the health of people with intellectual disability.

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#### **Presenter biographies**

Nick Lennox trained as a general practitioner and also has a PhD. He was Director of a Centre of Excellence, and currently is a Medical Advisory to the Australian Government Department of Health and Aged Care. Anthony Lark is an Assistant Director in the Australian Government Department of Health and Aged Care. He has worked on health and disability policy in the department for three years. Anthony previously worked in legal research for the New South Wales Industrial Relations Commission and the University of Sydney.

## **SESSION 11: Health Information**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **11.2 Co-designing a healthy cooking program for adults with intellectual disability**

Roberta Asher<sup>1</sup>, Vanessa Shrewsbury<sup>1</sup>, Beth Innes<sup>2</sup>, Sarah Simmonds<sup>1</sup>, Arron Fitzpatrick<sup>1</sup>, Clare Collins<sup>1</sup>

1. School of Health Sciences, The University of Newcastle, Callaghan, NSW

2. Sports 4 All, Newcastle, NSW

#### **Main messages**

- Healthy cooking can support good health and wellbeing.
  - FLIP is a healthy cooking program made with and for people with intellectual disability.
  - People with intellectual disability play an important role in delivering FLIP.
- 

#### **Abstract**

Background: Programs that teach healthy cooking and meal planning skills can promote good health and wellbeing. This presentation describes the initial development of a healthy cooking program called FLIP. FLIP is the Food and Lifestyle Information Program.

Method: A disability service provider, university researchers and two co-researchers with intellectual disability created FLIP curriculum and materials. They also created a plan to evaluate whether FLIP was acceptable to participants and feasible to deliver. Two groups of adults with mild to moderate intellectual disability participated in FLIP.

Results: FLIP is an eight-week program. Sessions included nutrition education, cooking activity using pictorial recipes, and shared meals. A university researcher led FLIP sessions. Co-researchers with intellectual disability attended FLIP to support program delivery. Overall FLIP was enjoyed by participants and was feasible to run.

Implications: Future studies can evaluate whether FLIP can improve participants' cooking and meal planning skills, diet quality, health and wellbeing.

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#### **Presenter biography**

Roberta Asher is an Accredited Practising Dietitian and qualified chef. Roberta has worked as a clinical dietitian and community culinary nutrition educator. In 2019, Roberta commenced her PhD at the University of Newcastle researching cooking skill development and nutrition education for people with disability using co-design and inclusive research principles.

## **SESSION 11: Health Information**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **11.3 Just include me: Co-produced easy read healthy literacy resources**

Laura Naing<sup>1</sup>, Jack Kelly<sup>1</sup>, Nicole Ascaino<sup>1</sup>, Pablo Garcia Guzman<sup>1</sup>

1. Council for Intellectual Disability, Surry Hills, NSW

#### **Main messages**

- Work intended to support people with intellectual disability can inadvertently cause disempowerment and additional barriers when they are not involved in the design process.
  - Involving people with intellectual disability in resource design leads to meeting the needs of the community addressing gaps in the healthcare system.
  - Better communication facilitates comprehensive assessment and treatment, leading to better health care provision.
- 

#### **Abstract**

Background: Effective communication is essential for equitable access to healthcare. CID co-produced resources with people with intellectual disability to address disparities in health care outcomes.

Method: We conducted focus groups and individual semi-structured interviews with people with intellectual disability, supporters, health professionals, and academics. Iterative changes were made in response to consultation with people with intellectual disability via focus groups and testing.

Results: Participatory processes resulted in the co-production of a number of Easy Read resources for people with intellectual disability and for health professionals.

Implications: New versions My Health Matters Folder, My Health Cards to facilitate health conversations, and easy read factsheets for health professionals were produced.

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#### **Presenter biographies**

Laura Naing and Jack Kelly are Inclusion Projects Workers at CID. Laura is a member of the Australian Commission on Safety and Quality in Health Care Advisory Group and Jack is also an Honorary Research Fellow at UTS. Nicole Ascaino is an inclusion project officer for the Health team at Council for Intellectual Disability. Nicole is also a social worker and yoga teacher.

## **SESSION 12: Assessing Needs**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **12.1 Women with intellectual disability and mental health disorders**

Erin Louise Whittle<sup>1</sup>

1. Centre for Disability Studies, Camperdown, NSW

#### **Main messages**

- We don't know enough about what women with intellectual disability need for their mental health.
  - This research tells us more about what stops women from getting the help they need
  - It also tells us some ways that we can make it easier for women with mental health issues to get the right kind of support and help with their mental health
- 

#### **Abstract**

Background: We do not know much about what women with intellectual disability need when they want help for their mental health. We know that women and men use mental health services in different ways. They sometimes need help for different things.

Method: I used a mixture of methods. I spoke to 3 women with intellectual disability and their supporters about their stories. I asked what made it harder for them to get help and what made it easier. I also looked at information from hospitals and mental health services.

Results: I analysed both sets of data. I looked at the different ways people with and without intellectual disability used services. Using all the information helped me to understand how women need more help to get the services they need.

Implications: This information can help to make sure that women with intellectual disability get help when they need it.

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#### **Presenter biography**

Erin Louise Whittle is a researcher at the Centre for Disability Studies. She has an extensive research background in gender, intellectual disability and access to services. She has also worked at the Department of Developmental Disability and Neuropsychiatry, UNSW (3DN), the Black Dog Institute UNSW, and Faces in the Street, St Vincent's Hospital Sydney. She has a particular expertise in qualitative and mixed method research and the analysis of large scale data sets. She has an interest in inclusive research methods and has been a part of the CDS Inclusive Research Methods Network since 2021. She has published in a number of international journals.

## **SESSION 12: Assessing Needs**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **12.2 Scoping review: Comparison of proxy and self-reports of internal states**

Kristen Webb<sup>1</sup>

1. Applied Research Centre for Disability and Wellbeing, Hobart, TAS

#### **Main messages**

- Internal states are usually measured through self-report
  - Self-report can be difficult for people with cognitive or communication impairments, so we often use a proxy
  - This presentation examines the research evidence regarding proxy measures of internal states
- 

#### **Abstract**

Background: Assessing the emotional state of people with intellectual disabilities can be difficult. Usually, self-report measures are used, but they can be hard for some people. So sometimes, other people are asked to answer for them. However, some studies have questioned if this is a good way to understand their feelings. This review looks at the evidence about using other people to answer questions about how people with intellectual disabilities feel. It aims to give advice to practitioners working with them.

Method: The researchers refined an existing method.

Results: The results show mixed findings. The results also tell us what kind of person is best at answering for someone else.

Implications: Using other people's answers can give us useful information about how people with intellectual disabilities feel, but we need to think about how to use it carefully.

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#### **Presenter biography**

Kristen is a PhD student with the Applied Research Centre for Disability and Wellbeing. She is a psychologist and is currently employed as the Clinical Director of a national team of allied health professionals. Kristen has a master's and doctorate in health, where her research focused on alternatives to the use of restrictive interventions.

## **SESSION 12: Assessing Needs**

Thursday, 23 November 2023

11:30am – 1:00pm

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### **12.3 Lived experience of the fetal alcohol spectrum disorder diagnostic assessment**

Kerryn Bagley<sup>1</sup>

1. La Trobe University Living with Disability Research Centre, Melbourne, VIC

#### **Main messages**

- The design and development of diagnosis guidelines should consider the experiences of people with the disability.
  - Receiving a fetal alcohol spectrum disorder diagnosis can come with mixed emotions so professionals should offer suitable support and think about the good aspects of diagnosis and the challenges that people might face.
  - The diagnostic process should address concerns that arise before diagnosis, the experience of getting the diagnosis, and the needs after assessment.
- 

#### **Abstract**

Background: Fetal Alcohol Spectrum Disorder (FASD) affects 2–5% of the population and is a known cause of intellectual disability. In this presentation, we'll talk about what we found in a systematic review on how people experience getting diagnosed with FASD. The goal was to help improve the Australian Guide to the Diagnosis of FASD.

Method: We looked at studies about people's experiences of FASD diagnosis. We used thematic analysis to find the main themes in their stories.

Results: The review revealed a number of important findings. Caregivers felt that doctors didn't take their worries seriously. People said it's important to have safe and non-judgmental support. They also wanted diagnostic reports to focus on the person's strengths. Getting a diagnosis brought mixed feelings, with hope and worries about the future. People talked about the challenges of getting the right support.

Implications: The findings from this review will help update the FASD diagnostic guidelines, leading to more understanding and supportive ways of diagnosing FASD.

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#### **Presenter biography**

Dr Kerryn Bagley is researcher at the La Trobe Living with a Disability Research Centre and a lecturer in Social Work at La Trobe University Australia. Her research interest stems from her social work practice experience of working alongside people with Fetal Alcohol Spectrum Disorder (FASD) and their families.

## **SESSION 13: Group Homes**

Thursday, 23 November 2023

2pm-4pm

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### **13.1 Ageing residents in group homes: Exploring staff experiences**

Tal Araten-Bergman<sup>1</sup>, Christine Bigby<sup>1</sup>

1. Living with disability research centre, La Trobe University, Melbourne, VIC

#### **Main messages**

- Group home staff have a limited understanding of the support needs of people ageing with intellectual disabilities.
  - Group home staff and managers think that the NDIS presents both new opportunities and challenges for ageing residents to have a good quality of life.
  - Policymakers and service providers should develop clear guidelines on how to best support ageing residents with intellectual disabilities living in group homes.
- 

#### **Abstract**

Background: The study aimed to learn a) what staff and managers think about the support needs of older people living in group homes b) How staff support older people in group homes and how this support has changed with the introduction of the National Disability Insurance Scheme.

Method: We talked with 21 group home staff and managers about their experience supporting older residents with intellectual disabilities.

Results: Analysis revealed four main themes: The first was about how staff understand ageing and the support needs of older residents. The second explored how staff adjusted their services to meet this group's needs. The third focused on staff hopes for the older people they support, and the fourth looked at their experiences of providing support in the changing policy context

Implications: Findings can help policymakers and service providers develop better policies and strategies to support older residents with intellectual disabilities, ensuring they experience a good quality of life as they age.

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#### **Presenter biography**

Tal Araten-Bergman is a Research Fellow in the Living with Disability Research Centre and a Senior Lecturer in Social Work & Social Policy at La Trobe University. Her research has focussed on key determinants of human rights realisation for people with disabilities and their families.

## **SESSION 13: Group Homes**

Thursday, 23 November 2023

2pm-4pm

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### **13.2 Support model for seven people living in shared accommodation**

Melanie Ingham<sup>1</sup>

1. Community Living Options, Edwardstown, SA

#### **Main messages**

- Person centred support can be effectively provided within a group home model of service.
  - Understanding the benefits and positive outcomes of living and working within a “group home” environment can reduce stigma.
  - Human rights, safeguarding and quality support can be maintained within a group home service model.
- 

#### **Abstract**

Background: Community Living Options deliver shared living supports. We use a practice led, person-centred, active support model. We support seven participants with intellectual disability within one group home to have a voice in the service, increase their independence and skills, to make life choices, and to provide practice leadership.

Method: Family members, participants and staff completed quantitative assessments and qualitative interviews pre-entry and after 6 months.

Results: The data suggest that 7 people can be supported in a group home. The model needs the right mix of residents, type of property and a specific service delivery model. Skill development, human rights, and quality of life can be maintained and increased. The data show there is a reduced staff turnover and increased job satisfaction. This provides stability for the residents.

Implications: This model relies on residents who choose to live in a shared living arrangement, the training of support workers, and property availability.

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#### **Presenter biography**

Melanie Ingham is a General Manager for Community Living Options (CLO), an organisation providing services to people with disabilities and their families. Melanie has a bachelor's degree in Disability Studies and Masters in Social Work. Her passions are in advocacy, inclusion and the upholding of human rights for people with disabilities.

## **SESSION 13: Group Homes**

Thursday, 23 November 2023

2pm-4pm

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### **13.3 Checking if services are good and safe for people with intellectual disability**

Jade McEwen<sup>1</sup>

1. Australian Institute of Family Studies, Eltham, VIC

#### **Main messages**

- The way we check services is as important as what we check - e.g., a standard about human rights can never be checked by looking at paperwork alone.
  - The experience of the people who receive services and the staff who support them has to be the most important focus of checks about service quality and safety.
  - Checks need to be made by people who know what they are looking for and they need to be regular and not rushed.
- 

#### **Abstract**

Background: The Disability Royal Commission shows that people with intellectual disability still receive poor quality services and experience abuse and neglect. New ways of checking that people receive good, safe services are needed. This talk explores ways that services can be checked to ensure they are good and safe.

Method: Papers other people had written about what good, safe services are for people with intellectual disability were read. Staff and leaders who support people with intellectual disability were spoken to and observed.

Results: The way services are checked now is mostly by looking at paperwork written by disability service staff. Findings show that services should be checked by talking to people who receive services and by looking at the way staff support them.

Implications: It is important to check how people receive services, rather than reading about it in paperwork.

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#### **Presenter biography**

Dr Jade McEwen has worked in the disability sector for 22 years. Jade completed her PhD with La Trobe's Living with Disability Research Centre in 2022, which focused on understanding what good and poor service quality look like, and how services can be better regulated to identify abuse and neglect.

## **SESSION 13: Group Homes**

Thursday, 23 November 2023

2pm-4pm

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### **13.4 Changes in quality of support in group homes**

Christine Bigby<sup>1</sup>, Aron Jackson<sup>1</sup>, Lincoln Humphreys<sup>1</sup>, Jelena Stojic<sup>1</sup>, Lauren De Losa<sup>1</sup>, Christopher Cott<sup>1</sup>

1. La Trobe University, Living with Disability Research Centre, Bundoora, VIC

#### **Main messages**

- The quality of support by group homes has dropped since 2013
  - The time for the tasks of frontline practice leadership, which is a key enabler of good Active Support, is being eroded by increased paperwork.
  - Organisations managing group homes must focus more strongly and consistently on good practice if people with intellectual disabilities are to have a good quality of life.
- 

#### **Abstract**

**Background:** The quality of support affects the quality of life of people with intellectual disabilities living in group homes. When staff use Active Support people have better outcomes. We tracked the use of Active Support in group homes between 2009 - 2022.

**Method:** We observed the support given to 382 people with intellectual disabilities from 119 group homes managed by 12 organisations. We spoke to 70 frontline managers and observed their practice.

**Results:** Use of Active Support and strength of frontline practice leadership was increasing but has declined since 2018. People living in group homes are spending more time watching TV and less time doing household activities and leisure. Frontline managers report increased paperwork making it difficult to find time to lead good practice.

**Implications:** Good support is fragile. Factors such as NDIS paperwork, compliance requirements, staff shortages, and COVID appear to have shifted attention away from practice.

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#### **Presenter biography**

Christine Bigby is Director of the Living with Disability Research Centre at LaTrobe University. She has led multiple projects and published extensively on the social inclusion of adults with intellectual disabilities and the translation of policy intent into good practice.

## SESSION 14: Health Research

Thursday, 23 November 2023

2pm-4pm

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### 14.1 Collecting healthcare experience information from people with intellectual disability

Bronwyn Newman<sup>1</sup>, Reema Harrison<sup>1</sup>, Laurel Mimmo<sup>2</sup>, Rebecca Mitchell<sup>1</sup>, Elizabeth Manias<sup>3</sup>, Corey Adams<sup>1</sup>, Megan Alston<sup>4</sup>, Anne Marie Hadley<sup>4</sup>

1. Macquarie University Sydney Australia, Macquarie University, NSW
2. Sydney Children's Hospital , Randwick , NSW
3. Monash University, Melbourne, VIC
4. Patient Experience and System Performance, NSW Health, St Leonards, NSW

#### Main messages

- People with intellectual disability are not always included in the system-wide collection of patient experiences.
  - There are methods that work well for people with intellectual disability being asked about their healthcare experiences but these are not used for collecting health system-wide patient experience information.
  - We need to make systems that can collect and use health system-wide patient experience information for people with intellectual disability.
- 

#### Abstract

**Background:** The ways that services ask patients about their experiences are not always accessible for everyone. NSW Health funded this review about how people with intellectual disability are asked about their healthcare experience.

**Method:** Our team searched and reviewed journal articles, reports, and websites to find information about how people with intellectual disability are asked about health care.

**Results:** We found 48 examples of how health services ask people with intellectual disability about their experiences, like short surveys or interviews. We only found examples about specific services or clinics, not health system-wide experience measures.

**Implications:** Health services can use the methods we found to make system-wide collection of patient experiences accessible for people with intellectual disability.

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#### Presenter biography

Bronwyn Newman is a researcher at Macquarie University. Bronwyn has worked as a Social Worker in disability services and has worked on many different research projects including her PhD about accessible mental health information for people with intellectual disability. She is interested in research that makes health care more accessible for all people.

## **SESSION 14: Health Research**

Thursday, 23 November 2023

2pm-4pm

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### **14.2 Improving the delivery of annual health assessments**

Nicholas Lennox<sup>1</sup>, Anthony Lark<sup>1</sup>

1. Department of Health & Aged Care, Health & Disability Interface Section, Primary Care Division, Canberra, ACT

#### **Main messages**

- Why get a yearly health assessment
  - What is involved in getting a health assessment
  - How we are working with people with intellectual disability, their families, supporters, and health practitioners to improve the use of annual health assessments.
- 

#### **Abstract**

Background: The general practice healthcare of people with intellectual disability is improved if they are involved in annual health assessments using the revised Comprehensive Health Assessment Program (CHAP).

Method: The Australian Government is investing \$6.7 million to improve delivery of the revised Comprehensive Health Assessment Program (CHAP). This forms a key part of the Roadmap to Improve the Health of People with Intellectual Disability.

Results: We will present why yearly CHAP health assessments are needed and what they involve, and how we are working with people with intellectual disability, their families, supporters, and health practitioners to improve the ease of use of CHAP.

Implications: Increased and easier use of the updated CHAP annual health assessment will improve healthcare delivery.

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#### **Presenter biographies**

Nick Lennox trained as a general practitioner and also has a PhD. He was Director of a Centre of Excellence, and currently is a Medical Advisory to the Australian Government Department of Health and Aged Care. He has developed several innovative strategies, including the Comprehensive Health Assessment Program (CHAP). Anthony Lark is an Assistant Director in the Australian Government Department of Health and Aged Care. He has worked on health and disability policy in the department for three years. Anthony previously worked in legal research for the New South Wales Industrial Relations Commission and the University of Sydney.

## **SESSION 14: Health Research**

Thursday, 23 November 2023

2pm-4pm

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### **14.3 Falls in people with intellectual disability who live in group homes**

Caroline Hart<sup>1</sup>, Stella Koritsas<sup>1</sup>, Aislinn Lalor<sup>2,3</sup>, Keith Hill<sup>2</sup>, Libby Callaway<sup>2,3</sup>, Natasha Layton<sup>2</sup>, Prue Morgan<sup>4</sup>, Leigh Hale<sup>5</sup>, Megan Clark-Ash<sup>2</sup>

1. Scope, Melbourne, VIC

2. Rehabilitation, Ageing and Independent Living (RAIL) Research Centre, Monash University

3. Department of Occupational Therapy, Monash University, Melbourne, VIC

4. Department of Physiotherapy, Monash University, Melbourne, VIC

5. School of Physiotherapy, University of Otago, Dunedin, New Zealand

#### **Main messages**

- We do not know much about why some people with intellectual disability fall or what to do to stop people from falling either.
  - The research looked at things that might contribute to people with intellectual disability falling.
  - The results will help us better understand why people with intellectual disability might fall and help us think of ways to prevent falls in group homes.
- 

#### **Abstract**

Background: We do not know much about why some people with intellectual disability fall. We do not know much about what to do to stop people from falling either. The research looked at risks related to falling for people with intellectual disability in group homes.

Method: The research used a survey that looked at things that might contribute to people falling. It looked at information from a database about when people had fallen. The researchers also went to group homes to see what else might cause falls.

Results: We found that there are many things that can cause falls, for example a person's health. Hazards in the home can also cause falls.

Implications: The research helps us better understand why people with intellectual disability might fall. It helps us think of ways to help prevent falls in group homes.

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#### **Presenter biographies**

Dr Caroline Hart is a Research Officer at Scope. Caroline has 20 years of experience conducting research with people with disability. Dr Stella Koritsas is Head of Research at Scope and Honorary Associate Professor at the University of Melbourne.

## **SESSION 14: Health Research**

Thursday, 23 November 2023

2pm-4pm

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### **14.4 Resources for strengthening hospital inclusion of people with intellectual disabilities**

Teresa Iacono<sup>1</sup>, Christine Bigby<sup>1</sup>, Jo Spong<sup>1</sup>, Charity Sims-Jenkins<sup>1</sup>, Ana Garcia-Melgar<sup>1</sup>, William Crisp<sup>1</sup>

1. Living with Disability Research Centre, La Trobe University, Melbourne, VIC

#### **Main messages**

- Quality Hospital Care for People with Intellectual Disabilities is a website with information and videos about supporting people when they go to hospital.
  - The information on the website comes from good hospital practices we learned about in a study about the experiences of people with intellectual disabilities when they went to hospital.
  - The website shows hospital staff, disability staff, and families sharing information and working together to provide good care to people with intellectual disabilities when they come to and spend time in hospital.
- 

#### **Abstract**

Background: People with intellectual disabilities often go to hospital but have poor experiences. We developed a framework of processes for hospital staff, families and disability staff from previous research. We demonstrate the framework on a website with learning resources. We aim to find out how relevant and useful they are for people involved in the hospital journeys of people with intellectual disabilities.

Method: The online resources include videos of people with intellectual disabilities in hospital and how the framework can be used. We are asking people who might use the resources to evaluate it by completing a survey. Some people will be interviewed.

Results: We will analyse the information descriptively and qualitatively.

Implications: The evaluation will show changes we need to make to the resources. They will then be freely available to help people involved in hospital journeys of people with intellectual disability ensure they receive good care and outcomes.

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#### **Presenter biography**

Teresa Iacono is Professor of Rural and Regional Allied Health and a member of the Living with Disability Research Centre, La Trobe University. Teresa is a speech pathologist and has worked for many years in research and university teaching. Her focus has been on supporting people with complex communication needs.

## **SESSION 15: Being Included**

Thursday, 23 November 2023

2pm-4pm

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### **15.1 Towards inclusive practice: Reflections on why inclusive practice matters**

Luke Nelson<sup>1</sup>, Jamie Bannister, Riley Buchanan<sup>1</sup>

1. Inclusion Australia, Nunawading, VIC

#### **Main messages**

- Inclusive practice benefits everybody.
  - Inclusive practice helps Australia meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities.
- 

#### **Abstract**

Background: Most Government systems and processes are not easy to navigate. This is especially so for people with an intellectual disability. People with an intellectual disability also have very few ways to tell the Government what matters.

Method: In February 2021, Inclusion Australia launched the Towards Inclusive Practice project. This was done by working with a network of people with an intellectual disability across Australia to give advice to the Government on how to be more inclusive of people with an intellectual disability.

Findings: The project showed that the government needs to listen to people with an intellectual disability and work with us to make their systems more accessible for everyone. It also helps Australia's efforts to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities.

Implications: The presentation will share some of the project findings and reflect on the power of inclusive practice.

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#### **Presenter biography**

Luke Nelson is a Policy Officer at Inclusion Australia. Luke has a wealth of experience working in the disability advocacy sector, bringing his lived experience and passion to work to elevate the human rights of people with disability in Australia.

## **SESSION 15: Being Included**

Thursday, 23 November 2023

2pm-4pm

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### **15.2 The practical application of the Inclusive Governance Projects findings**

Bernadette Curryer<sup>1</sup>, Will Harding<sup>1</sup>

1. Side By Side Advocacy Inc, West Ryde, NSW

#### **Main messages**

- Involvement of people with an intellectual disability at a governance level adds to the value of Board discussions and decision-making.
  - An organisation that includes people with intellectual disability throughout the organisation is in the best position to practise inclusive governance.
  - Moving towards inclusive governance can be guided by the principles that emerged from the research.
- 

#### **Abstract**

Background: The Inclusive Governance Project has explored how people with intellectual disability can be included on Boards and committees of community organisations. This presentation will provide ideas for developing a practical action plan, to guide organisations towards inclusive governance

Method: We interviewed Board members and people who work with Boards. We asked them about their experience of the inclusion of people with intellectual disability.

Results: The themes emerging from the research have led to 5 Principles of Inclusive Governance. These principles are about valuing inclusion, creating a pathway to inclusion, ensuring accessible Board activities, providing individual support, and making a commitment.

Implications: These principles can be used by organisations to create an action plan to make changes that will support people with intellectual disability to be included throughout their organisation, including at a governance level.

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#### **Presenter biographies**

Bernadette Curryer has been involved in the disability sector as a parent, advocate, and researcher. She completed a doctorate on self-determination of adults with intellectual disability and is on the ASID Board. Will Harding works as a co-researcher with the Inclusive Governance Project. He also does bush regeneration and has been a member of the Consumer Representative Group at his workplace. He is involved in the local cricket club, managing the 2nd grade team. His message is “focus on your ability, not your disability”.

## **SESSION 15: Being Included**

Thursday, 23 November 2023

2pm-4pm

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### **15.3 TEDx for everyone: People with intellectual disability speaking up**

Kathy Ellem<sup>1</sup>, Donna Best<sup>2</sup>

1. The University Of Queensland, St Lucia, QLD

2. Queenslanders with Disability Network, QLD

#### **Main messages**

- TEDx talks are a great way to get your message across.
  - People with intellectual disability have lots to offer as TEDx speakers.
  - Donna and Kathy talk about their experience giving a TEDx talk.
- 

#### **Abstract**

Background: TEDx talks are talks where people share important ideas. Speakers are asked to talk for no longer than 18 minutes. Usually there is only one speaker on stage.

Method: The University of Queensland asked Dr Kathy Ellem to do a TEDx talk about stories about people with intellectual disability. Kathy said she wouldn't do it without a person with intellectual disability. Donna Best, a self-advocate, agreed to speak with Kathy.

Results: The University of Queensland has not supported people with intellectual disability to do TEDx talks before. Kathy and Donna had to change some of the TED rules to make their talk happen. They share what they did.

Implications: TEDx talks need to include people with intellectual disability as speakers. Donna and Kathy want other people with intellectual disability to know that they can do TEDx talks too.

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#### **Presenter biographies**

Dr Kathy Ellem is a Senior Lecturer in Social Work at The University of Queensland. Kathy enjoys doing inclusive research with people with intellectual disability as research partners. She has an interest in self-advocacy; people with disability in the criminal justice system; and relationship-based practice with people with intellectual disability. Donna Best is a leader in self-advocacy in Queensland. She is the peer leader of Hot Topics, a self-advocacy group for people with intellectual disabilities in Queensland, based at Queenslanders with Disability Network. Donna has been a keynote speaker at many different conferences.

## **SESSION 15: Being Included**

Thursday, 23 November 2023

2pm-4pm

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### **15.4 The Silos Project: Working together helps students with intellectual disabilities to get jobs**

Janice O'Connor<sup>1</sup>

1. The Onemda Association, Doncaster East, VIC

#### **Main messages**

- Schools, families, and employment supports need to work together to help students with intellectual disabilities to get jobs.
  - An independent person is needed to provide support and connect everyone together.
  - Students with intellectual disabilities who have opportunities for work whilst at school get better employment outcomes when they finish school.
- 

#### **Abstract**

Background: This project is important as employment rates are low for youth with intellectual disabilities. The Silos project is about working together to create job opportunities for young people with intellectual disabilities whilst they are still at school.

Method: In 2020 the Silos Team met with young people with intellectual disability, families, school staff, employers, and industry representatives to develop a model of support for students who want to get a job.

Results: The model has three key parts: (1) student and family must be valued and placed at the centre, (2) an independent person working directly with the student and the important people in their life to connect everyone, get things up and going, and provide support as needed, and (3) commitment to working together..

Implications: The Silos model is currently working with students and Special Schools in Melbourne and regional VIC and is achieving great employment outcomes for students

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#### **Presenter biography**

Janice O'Connor is the Research & Innovation Manager at Onemda, a disability service in Melbourne with over 20 years' experience collaborating and driving projects with people with a disability, their families, and carers. Janice enjoys working with others to challenge traditional therapy and learning models through collaboration and co-design.

## **SESSION 16: Families and group homes**

Thursday, 23 November 2023

4:30pm–5:30pm

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### **16.1 Family's experience supporting adults in group homes during COVID-19**

Tal Araten-Bergman<sup>1</sup>, Carmit Noa Shpigelman<sup>2</sup>

1. La Trobe University, Melbourne, VIC

2. Department of community mental Health, University of Haifa, Israel

#### **Main messages**

- Family engagement is important for the health, well-being and safety of adults with intellectual disabilities residing in group homes.
  - COVID-19 and lockdown policy impacted the quality of life of residents with intellectual disabilities and their families.
  - Policymakers and service providers should consider flexible policy and individualised responses to meet the support needs of group-home residents and their families during a health crisis
- 

#### **Abstract**

**Background:** COVID-19 and the rules made to keep everyone safe have changed the daily routines of people with intellectual disabilities living in group homes. It is important that families are involved in keeping people safe, healthy, and happy. Our study wants to learn how COVID-19 changed things for families, the people they support, and the services they received.

**Method:** 108 Israeli family members answered questions online, we also talked with 19 people in more detail about their experiences.

**Results:** Families shared stories about how they stayed in touch with their loved ones and communicated with the staff during lockdown. They also told us how the lockdown affected the services they got and their outcomes.

**Implications:** Our findings can help policymakers and service providers to make better plans. They can make sure that people with intellectual disabilities and their families get the right support during future health crises.

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#### **Presenter biography**

Tal Araten-Bergman is a Research Fellow at the Living with Disability Research Centre and Senior Lecturer in the discipline of social work at the School of Allied Health, Human Services and Sports La Trobe University.

## **SESSION 16: Families and group homes**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **16.2 Family perspectives on support in group homes**

Christine Bigby<sup>1</sup>

1. La Trobe University, Living with Disability Research Centre, Bundoora, VIC

#### **Main messages**

- Families have important perspectives on the quality of support in group homes.
  - Finding ways to improve consistency of staff support in group homes is important.
  - Improving communication between families, group home staff and more senior organisational managers is important to families and ensuring issues for people with intellectual disabilities are addressed.
- 

#### **Abstract**

Background: Families are only often the only people who know people with more severe intellectual disabilities well and advocate for them with service providers.

Method: We interviewed 34 family members of people with severe intellectual disabilities living in group homes. They were families of people involved in an observation study of group homes. We asked families their perspectives about what was important for their family member to have a good quality of life.

Results: Families' satisfaction with group homes ranged from very happy to very unhappy. Families valued their person being known by staff and knowing staff, being supported to engage in activities, open communication and collaboration with staff and committed supervisors. They were concerned about inconsistent and uncertain quality of support across time.

Implications: Families' views aligned with some findings from the observational study of their family members' group home but provided additional insights about ways of improving group homes.

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#### **Presenter biography**

Christine Bigby is Director of the Living with Disability Research Centre at LaTrobe University. She has led multiple projects and published extensively on the social inclusion of adults with intellectual disabilities and the translation of policy intent into good practice.

## **SESSION 17: Parenting Experience**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **17.1 Exploring student-parent experiences of a postgraduate disability studies program**

Sian Anderson<sup>1</sup>

1. Living with Disability Research Centre, La Trobe University, Bundoora, VIC

#### **Main messages**

- Disability studies programmes expose students to key concepts in disability including human rights.
  - Students who are parents of people with disabilities spend a great deal of time and effort managing their family's relationships with the NDIS and individual providers and they use study as an opportunity to deepen their understanding of the systems they are dealing with, and as an opportunity to have time to themselves.
  - Student-parents use their disability studies knowledge to become stronger advocates for their family members with disabilities.
- 

#### **Abstract**

**Background:** The discipline of disability studies and related academic streams in disability practice and disability and inclusion can provide a framework for examining the ongoing exclusion of people with intellectual disabilities from the social, economic and cultural life of communities. Students who are parents of people with disabilities bring their own experiences and perspectives to their studies.

**Method:** Six student-parents were interviewed about their experience of a postgraduate disability studies course and the data was analysed.

**Results:** The participants found that the course had given them a new language to talk about intellectual disability and developed their skills and knowledge as advocates.

**Implications:** Disability studies programs should be accessible to student-parents and their focus on rights-based approaches to support have potential to improve the quality of life for people with intellectual disabilities.

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#### **Presenter biography**

Sian Anderson is a Senior Lecturer in the Living with Disability Research Centre at La Trobe University, Melbourne. She is the course coordinator of the Disability Practice program and an experienced researcher with publications about self-advocates and self-advocacy groups, community participation and supported living.

## **SESSION 17: Parenting Experience**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **17.2 Enduring strength from a labour of love: Family life with disability**

Murray Rieck<sup>1</sup>

1. School of Psychology and Counselling, Faculty of Health, Queensland University of Technology, Brisbane, QLD

#### **Main messages**

- Giving parents a voice for them to tell their story is crucial
  - The Enduring Strength from a Labour of Love model is useful to illustrate and understand parents' lived experience and family life
  - Life is complex, multidimensional, dynamic and everchanging; not a static one-dimensional existence.
- 

#### **Abstract**

Background: There haven't been many in-depth studies of the lived experience of parents of a young adult with intellectual disability living with them at home.

Method: Six parents were interviewed about their family life many times for about an hour each time. The researcher then analysed the interviews looking for meaning and themes to understand parents' lives

Results: Even though these parents faced many difficulties and struggles in their lives, they also had many rewarding experiences. A model called the 'Enduring Strength from a Labour of Love' of understanding family life with intellectual disability came out of their stories.

Implications: Knowing parents' views might help people supporting families with a person with intellectual disability to better understand what their life is like.

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#### **Presenter biography**

Murray Rieck is a registered psychologist and clinical leader in disability, forensic disability, and mental health. His PhD examined the lives of parents of young adults with intellectual disability, from which the 'Enduring Strength from Labour of Love' theoretical model emerged. He has presented this work at national and international conferences.

## **SESSION 18: Outcomes**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **18.1 Contribution: A different perspective on measuring outcomes**

Samuel Arnold<sup>1</sup>, Sarah Butler

1. Western Sydney University, Bankstown, NSW

#### **Main messages**

- People with intellectual disability told us that contribution is good.
  - Using a Grounded Delphi study, people have agreed what contribution means.
  - We are building contribution assessment tools.
- 

#### **Abstract**

Background: We are making an assessment tool that measures contribution by people with intellectual disability. Contribution can mean helping your family or friends. It can mean helping the community, society, the economy, or helping the planet. No one has tried to measure contribution before. We think that people with intellectual disability should get good support that helps them to contribute.

Method: We talked to people with intellectual disability first. Together we made the Contribution Photovoice gallery. Next we did a Grounded Delphi study. This means we did 3 surveys with family members, clinicians, service providers and people with disability. We asked them to agree on a definition of contribution.

Results: We had 21 people agree what contribution means. We agreed what questions we should include in our new assessment tool.

Implications: Assessing contribution will make service providers focus on supporting people with intellectual disability to have a contributing life.

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#### **Presenter biography**

Dr Samuel Arnold is a lecturer at Western Sydney University. He used to work at 3DN UNSW Sydney. He is a registered psychologist with a background in supporting autistic adults and adults with intellectual disability.

## **SESSION 18: Outcomes**

Thursday, 23 November 2023

4:30pm-5:30pm

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### **18.2 Implementation of a toolkit for planning and supporting new living arrangements**

Micaela Goldsmith<sup>1</sup>

1. IDEA Services, Wellington CBD, Wellington, New Zealand

#### **Main messages**

- Where we live with and who we live with has a big impact on our wellbeing. However, Tāngata Whaikaha are often not included in this decision making process.
  - The goal was to create a process for assessing flatmate compatibility in a large NZ residential disability provider that puts Tāngata Whaikaha at the centre.
  - This is a step towards self-determined flatmate selection in the future as Aotearoa's disability sector transforms.
- 

#### **Abstract**

Background: The Toolkit for Planning and Supporting New Living Arrangements is a resource designed to identify the preferences of potential flatmates, guide the decision-making process, identify incompatibilities, problem-solve, and support successful transitions for people with an intellectual disability.

Method: After a research and development phase, a draft version was piloted. Feedback from this pilot was incorporated, creating the toolkit in its current format.

Results: To date anecdotal feedback has been positive. Results from an audit of the toolkit will be shared.

Implications: Being able to make choices is linked to better quality of life, as is compatibility between flatmates. Therefore, supporting individuals to make choices about their living situations not only fits in with New Zealand's Enabling Good Lives Principles, but can positively impact the happiness and wellbeing of people with intellectual disabilities.

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#### **Presenter biography**

Micaela has more than a decade's experience in the disability sector. She works as part of the National Services Support Team for IDEA Services as a Programme Lead Psychologist. She is responsible for various programmes including the development and implementation of the Toolkit for Planning and Supporting New Living Arrangements.

## **SESSION 19: Decision Support Research**

Friday, 24 November 2023

11:30am-1pm

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### **19.1 Supported decision making: There is no 'except who'**

Leanne Pearman<sup>1</sup>, Shewani Shilkar<sup>1</sup>

1. Western Australia's Individualised Services, West Perth, WA

#### **Main messages**

- All people have the ability to make and implement their decisions with the right support.
  - Quality support may be the difference between someone being able to exercise their legal capacity and lead their life or not.
  - We are all responsible for supporting each other to become valued and contributing citizens.
- 

#### **Abstract**

Background: People with complex communication access needs and intellectual disability are under-represented in research about supported decision making.

Method: This presentation is about the Decision Making Possibilities project. People who have been judged not to have capacity have shown their ability to learn and grow in decision making capability.

Results: The project showed that people with complex communication access needs and intellectual disability can make decisions about their lives when their supporters believe and expect this is possible.

Implications: The outcomes should provide a catalyst and an imperative to consider how best to support people with decision making.

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#### **Presenter biography**

Leanne has been involved in the lives of children, people with disability, and their families, together with people who have been marginalised by society for more than 30 years. This has created in her a deep understanding and commitment to all people being able to exercise their rights as full citizens in our community. Shewani is 28 and a very loved daughter. She has autism and sometimes it's really hard for her to control her body. People need to be heard and they need more quality support. Supported decision making is part of that.

## **SESSION 19: Decision Support Research**

Friday, 24 November 2023

11:30am-1pm

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### **19.2 Targeting feeling in choice and control workshops for staff**

Charity Sims-Jenkins<sup>1</sup>, Kathryn Bartlett<sup>1</sup>, Rachael Walters<sup>1</sup>, Christine Bigby<sup>1</sup>, Tal Araten Bergman<sup>1</sup>

1. La Trobe University, Bundoora, VIC

2. New Wave Gippsland Self Advocacy Group, Gippsland, VIC

#### **Main messages**

- We made a workshop with video stories for disability support staff
  - The stories showed how bad people feel if staff don't support their choice and control
  - We will talk about what we did and what we learned from the staff who went to the workshop
- 

#### **Abstract**

Background: Adults with intellectual disabilities have the right to be in charge of their lives. But sometimes there is not enough support.

Method: We co-developed a workshop to help disability support staff think differently about supporting choice and control. Our workshop used story videos of adults with intellectual disabilities telling how it feels when unsupported with choice and control. We developed theory from the literature to understand how this could work. We interviewed staff before and after the workshop to find out.

Results: We will present what staff got from the workshop and what changed for them.

Implications: We hope this will help others making workshops to decide if they should focus on feelings, and to get ideas for how to do it.

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#### **Presenter biography**

Charity Sims-Jenkins is a PhD candidate with the La Trobe University Living with Disability Research Centre. Charity is an experienced social worker who has been a project worker for the New Wave Gippsland Self Advocacy group. Kathryn Bartlett is a peer leader with the New Wave Gippsland Self Advocacy Group. Kathryn is a co-researcher on research projects with the La Trobe University Living with Disability Research Centre. Rachael Walters is a peer leader with the New Wave Gippsland Self Advocacy Group. Rachael is a coordinator assistant and peer educator for the Safer Lives and Sexual Relationships program.

## **SESSION 20: Support Practice**

Friday, 24 November 2023

11:30am-1pm

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### **20.1 Making moves in disability support work**

Catherine Maitland<sup>1</sup>

1. Relational Learning, Sydney, NSW

#### **Main messages**

- Support workers are sometimes overwhelmed by operational tasks and it's difficult for them to find time to reflect on their work.
  - Attending workshops to learn how to apply a practical, evidence based tool helped support workers to gain insights into "how" they work with people with intellectual disability.
  - Support workers became more skilled at asking themselves questions while on the job.
- 

#### **Abstract**

Background: Support workers are sometimes overwhelmed by operational tasks and it's difficult for them to find time to reflect on their work.

Method: People with intellectual disability shared photographs and stories about their world. Support workers talked about their work. From this data, Catherine developed a way of talking about care that is based on four moves of disability support work. Then she developed workshops for support workers.

Results: They said they now feel less afraid to try new things, and find it easier to figure out new ways to relate to clients. They feel empowered to speak up to managers and coworkers when they see poor practice.

Implications: The workshops helped support workers to realise when they were standing over or controlling, rather than standing with, people with intellectual disability.

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#### **Presenter biography**

Catherine is a consultant in her own business, Relational Learning. She delivers workshops and does research. She is also a part-time researcher at Australian Network on Disability (AND). Catherine has 15 years experience working in the disability field. Catherine has a PhD. She writes about social justice, participatory research methodologies, and relational ethical support practices.

## **SESSION 20: Support Practice**

Friday, 24 November 2023

11:30am-1pm

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### **20.2 He is just like a two-year old: Controversial?**

Sheridan Forster<sup>1</sup>

1. Private practitioner, Eltham, VIC

#### **Main messages**

- People with severe and profound intellectual disability need to be individually understood.
  - Using age analogies may or may not be helpful for understanding individual experiences.
  - Using age analogies is a complex, contentious issue.
- 

#### **Abstract**

Background: People with severe or profound intellectual disability have different cognitive and communication skills from their age equivalent peers: different perspectives that, in line with the conference theme, need to be valued.

Method: Systematic exploration of features of the problem, including “what informs understanding of infant communication: from societal tacit views to contemporary infant mental health?” and “how might an age equivalence contribute to everyday support?”.

Results: The supports that people with severe or profound intellectual disability need from others for a good life differ from supports needed by most adults. Some skills may be more similar to those of infants and young children. However, whether we use age analogies to understand and communicate an individual’s experience is a very contentious issue.

Implications: Decisions regarding use of age of analogies can be informed by analysis of the issue, and can be shared with other support providers.

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#### **Presenter biography**

Dr Sheridan Forster is a speech therapist, researcher, and person with an acquired disability, with an interest in people with severe and profound intellectual disability. She has a PhD looking at interactions between adults with profound intellectual and multiple disability and disability support workers. She continues to be curious, writing and contributing to knowledge of interactions that occur without speech.

## **SESSION 21: Advocacy, rights and peer work**

Friday, 24 November 2023

11:30am-1pm

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### **21.1 Raising awareness of self advocacy**

David Corner

1. IHC New Zealand, Wellington, New Zealand

#### **Main messages**

- Staff are there to support people to have their say. It is not the staffs' place to have their say as they are in a support role.
  - It's important for people to be supported and encouraged to have their say. Their voice matters to ensure that they get a good quality of service and a good life.
  - As people with an intellectual disability say: "nothing about us without us".
- 

#### **Abstract**

Self-advocacy is very important for everyone as it enables people to speak up and have a voice and say about things that are important to them in their own way with the help, support, and equipment they need to participate.

For a long time, it has seemed to me that the voice of people with an intellectual disability in services seems to be silenced, and people are not encouraged to speak like how they used to.

After talking to a group of people, myself and others updated some self-advocacy presentations and decided to set up some self-advocacy webinars. I want to talk about the issues I experienced and how important self-advocacy is.

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#### **Presenter biography**

David Corner is an inspiring advocate for people with intellectual disabilities. He has been a self-advocate for over 26 years, dedicating his career at IHC to teaching and supporting others in the intellectual disability community. David uses his experiences as a person with intellectual disability and autism to fuel his advocacy for people with intellectual disabilities, working to ensure that their voices are heard, and they are included. David lives in his own house in Wellington and has graduated from Polytechnic with a Certificate in Teaching People with Disabilities.

## **SESSION 21: Advocacy, rights and peer work**

Friday, 24 November 2023

11:30am-1pm

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### **21.2 Being equally valued in economic life**

Ben Alexander<sup>1</sup>, Raylene Griffiths<sup>1</sup>

1. Council for Intellectual Disability, Surry Hills, NSW

#### **Main messages**

- Lived experience leadership drives a call to action to expand open employment opportunities for people with intellectual disability.
  - People with intellectual disability have the right to actively participate in social and economic life.
  - By embracing the diverse talents and perspectives of people with intellectual disability in the workforce, we can foster a stronger sense of community, enriching workplaces and society.
- 

#### **Abstract**

Background: People with intellectual disability have the right to actively participate in social and economic life.

Method: The presenters share their experiences of open employment.

Results: They focus on capacity building for employers and workshops for jobseekers with intellectual disability, using person-centred tools for career planning.

Implications: Their confidence and awareness drives employers as leaders in change, while also serving as role models for job seekers. This fosters confidence amongst their peers and promotes the right to meaningful employment opportunities.

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#### **Presenter biography**

Raylene Griffiths and Ben Alexander are Inclusion Project Workers at the Council for Intellectual Disability. Raylene co-produces and facilitates training on inclusive employment for councils in NSW and co-leads a peer mentoring program. Ben has presented in countless workshops on disability inclusion. Ben has become a trusted pillar of knowledge within his team, and a strong advocate for inclusive employment.

## **SESSION 21: Advocacy, rights and peer work**

Friday, 24 November 2023

11:30am-1pm

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### **21.3 Doing peer work with people with intellectual disability**

Louisa Smith<sup>1</sup>, Jarrold Sandell-Hay<sup>1</sup>

1. Deakin University, Melbourne, VIC

#### **Main messages**

- People with intellectual disability were happier living in disability group homes when peer workers helped them to find activities they enjoyed.
  - Peer workers needed time to get to know their peers with intellectual disability and to help them to experience new things.
  - Peer workers needed support to use their unique skills and experience to benefit their peers with intellectual disability living in group homes.
- 

#### **Abstract**

Background: Some people with intellectual disability who live in disability group homes are lonely.

Method: Peer workers with disability visited people with intellectual disability in group homes to find out what they enjoyed doing. They tried to find things for them to do and places for them to go to meet people.

Results: Peer workers found ways to talk to their peers about what they liked doing. They found places their peers could go to with a support worker and activities they could do with other people. Peer workers found many ways for people to leave their home and enjoy themselves with other people.

Implications: Peer workers with disability can help people with intellectual disability living in group homes to enjoy activities with other people in their communities.

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#### **Presenter biography**

Jarrold Sandell-Hay is a proud disabled man. He is a Project Coordinator at Community Disability Alliance Hunter. Jarrold enjoys finding ways to help people with disability connect with their community. Louisa Smith is a Senior Lecturer in Disability and Inclusion at Deakin University. Louisa has a PhD. She writes about how people with disability and dementia experiences changes. Louisa likes to do inclusive arts-based research.

## **SESSION 22: Families**

Friday, 24 November 2023

2pm-3:00pm

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### **22.1 The role of the family in finding meaningful employment**

Jack Kruger<sup>1</sup>, Jan Kruger<sup>1</sup>

1. Imagine More, Canberra, ACT

#### **Main messages**

- Learn about customised employment
  - Discover what the person is interested in
  - Use your networks to find meaningful employment, you don't have to do this alone.
- 

#### **Abstract**

Background: Society has low expectations of people with intellectual disability to find work. So Jan started early to get her son, Jack, work using customised employment.

Method: Jan learned about customised employment. We held a Circle of Support gathering. People told Jack what they thought he was interested in, what conditions a workplace would need to have for Jack to be successful and what he could contribute to a workplace.

Results: Since Jack was 14 he has done 3 work experiences. Jack has had 6 paid jobs and one volunteer job. He is now 21.

Implications: Jan learned about customised employment through a School to Work project. Jan employed a job coach and found Jack jobs that matched his interests.

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#### **Presenter biography**

Jack Kruger is a world traveller, movie enthusiast, employee, Learner driver, and friend. Jack also has Down syndrome. Jack finished school in 2020. Jack has had six jobs since he was 14. Jack is now crafting a meaningful week of work, study, sport and leisure. Jan is a wife to Paul and mother to 4 fabulous young adults. Jack is her youngest child. Jan has been using customised employment principles to find and maintain meaningful paid work roles for Jack. Jan is also the Executive Director of Imagine More, a family-led organisation in Canberra.

## **SESSION 22: Families**

Friday, 24 November 2023

2pm-3:00pm

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### **22.2 Family roles in adults' lives: Views of service managers**

Monica Cuskelly<sup>1</sup>

1. Applied Research Centre for Disability and Wellbeing, Launceston, TAS

#### **Main messages**

- Managers have different views of family roles.
  - Views are based on beliefs and experiences.
  - Managers have an important role in influencing organisational culture.
- 

#### **Abstract**

Background: Families often talk to the people who work with their adult child with intellectual disability. These people may decide on things the adult does. Some managers of services might think the adult should decide. Other managers might think families should decide. Managers can help adults make their own decisions. Understanding managers' views could help change services.

Method: We spoke to 28 managers. They worked in a service for adults with intellectual disability. We asked them what they thought about families and the way they helped their adult child make decisions.

Results: Managers had different views about families. Some thought families were most important. Others thought families made too many decisions. Not all adults with intellectual disability have families who care for them.

Implications: Managers and families could work together. They could help adults to make their own decisions. Managers need to understand how to work with families.

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#### **Presenter biography**

Monica Cuskelly is the Director of Research at the Applied Research Centre for Disability and Wellbeing (ARCDW). The ARCDW is a joint initiative of Possability Group and the University of Tasmania. Monica has published on a number of aspects of the lives of individuals with intellectual disability.

## **SESSION 23: Employment**

Friday, 24 November 2023

2pm-3:00pm

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### **23.1 The NDIS and disability employment: A customised approach**

Peter Smith<sup>1</sup>

1. Centre for Disability Employment Research and Practice, Docklands, VIC

#### **Main messages**

- The NDIS funds individualised customised approaches to disability employment.
  - Discovery is a universal model of employment that supports anyone with barriers to employment.
  - Customised employment requires extensive training for service delivery with fidelity
- 

#### **Abstract**

Background: This presentation will examine the role of workplace counselling in the NDIS and its role in building personal capacity.

Method: We examine a practice solution that uses workplace counselling to develop self-determination and self-advocacy skills as part of the process of creating employment opportunities.

Results: Self-determination and self-advocacy skills are vital ingredients to successful employment that support the NDIS goal in increasing participant choice and control. Evidence from practice in Australia and overseas highlights the benefits of building this capability.

Implications: Self-determination and self-advocacy skills are essential ingredients for long term meaningful employment supported by participant choice and control. While the process may take longer, the evidence shows that these skills are important ingredients that underpin successful life transitions

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#### **Presenter biography**

Peter works for the Centre for Disability Employment Research and Practice. He works across Australia and internationally and has twenty years of experience. Peter has a PhD, published extensively, and has written disability employment practice guides.

## **SESSION 23: Employment**

Friday, 24 November 2023

2pm-3:00pm

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### **23.2 NDIS workplace counselling and capacity building**

Peter Smith<sup>1</sup>, Lauren Pavlidis<sup>1</sup>

1. Centre for Disability Employment Research and Practice, Docklands, VIC

#### **Main messages**

*Details to come.*

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#### **Abstract**

**Background:** This presentation will examine the role of workplace counselling and the NDIS and its role in building personal capacity.

**Method:** We examine a practice solution that uses workplace counselling to develop self-determination and self-advocacy skills as part of the process of creating employment opportunities.

**Results:** Self-determination and self-advocacy skills are vital ingredients to successful employment that support the NDIS goal in increasing participant choice and control. Evidence from practice in Australia and overseas highlights the benefits of building this capability.

**Implications:** Self-determination and self-advocacy skills are essential ingredients for long term meaningful employment supported by participant choice and control. While the process may take longer, the evidence shows that these skills are important ingredients that underpin successful life transitions.

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#### **Presenter biography**

Peter works for the Centre for Disability Employment Research and Practice. He works across Australia and internationally and has twenty years of experience. Peter has a PhD, published extensively, and has written disability employment practice guides. Lauren is the COO of CDERP, has a degree in psychology and runs the Work First program along with the school transition and employment hub projects. In her role Lauren also works with individual clients supporting their capacity building.

## **SESSION 24: Making Decisions**

Friday, 24 November 2023

2pm-3:00pm

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### **24.1 A new way to make choices about the end of life**

Nicola McKenzie<sup>1</sup>

1. Centre for Postgraduate Nursing, University of Otago, Christchurch, New Zealand

#### **Main messages**

- People with intellectual disabilities can say what they want if they are sick or dying.
  - Everyone should be supported to make choices about the end of their life.
  - You can use our model to get started.
- 

#### **Abstract**

Background: Everyone should be able to make choices if they get sick or are dying. People's wishes can be written in a plan. People with intellectual disabilities don't always get good support to make their wishes known. We wanted to improve this.

Method: People with learning disabilities and disability service managers were part of the research team. We found out how plans are made now for people who are sick or dying. We developed a better way of planning and tested this.

Results: People with intellectual disabilities made high-quality plans. Doctors and nurses trusted the plans. We developed a model to explain the systems and tools, processes, and values that made planning successful.

Implications: We are starting to use the new model in New Zealand. People with intellectual disabilities will have more choice and control when they are sick or dying.

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#### **Presenter biography**

Nic McKenzie trained as a speech-language therapist but now works with various disability services as a consultant. Most of her work relates to staff education, service quality, accessible communication, and policy. She has just finished a PhD and has published about advance care planning.

## **SESSION 24: Making Decisions**

Friday, 24 November 2023

2pm-3:00pm

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### **24.2 Deciding with support: Bringing supported decision-making to positive behaviour support**

Sally Robinson<sup>1</sup>, Sabrina Forte<sup>2</sup>

1. Flinders University, Bedford Park, SA
2. Council for Intellectual Disability, Parramatta, NSW

#### **Main messages**

- This talk is about a new website. The website has information to help people make decisions about their behaviour support plans. It is called Deciding with Support.
  - People with disability were involved in making the website. It has lots of easy read and video information.
  - The website aims to help everyone feel more confident supporting people with disability to make more decisions about their behaviour support plans.
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#### **Abstract**

Background: Supported decision-making is important to make sure the person is involved in their behaviour support in the way that they want. Deciding with Support is the first toolkit of resources on supported decision-making for everyone involved in positive behaviour support.

Method: The resources are evidence based, informed by reviews of literature and policy. They were co-designed with people with disability, behaviour support practitioners, and service providers.

Results: The resources have been developed for different users, including people with disability, supporters, behaviour support practitioners and service providers. Resources are available to everyone on an accessible website.

Implications: The website can help people with intellectual disability have more choice and control in their lives, including how their behaviour support is provided. Over time, this may help improve people's quality of life and reduce the need for them to have restrictive practices and/or behaviour support.

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#### **Presenter biography**

Sally Robinson does research with people with intellectual disability about things that help them to feel safe when life is difficult, and about how to improve services. She is a Professor at Flinders University in Disability and Community Inclusion.