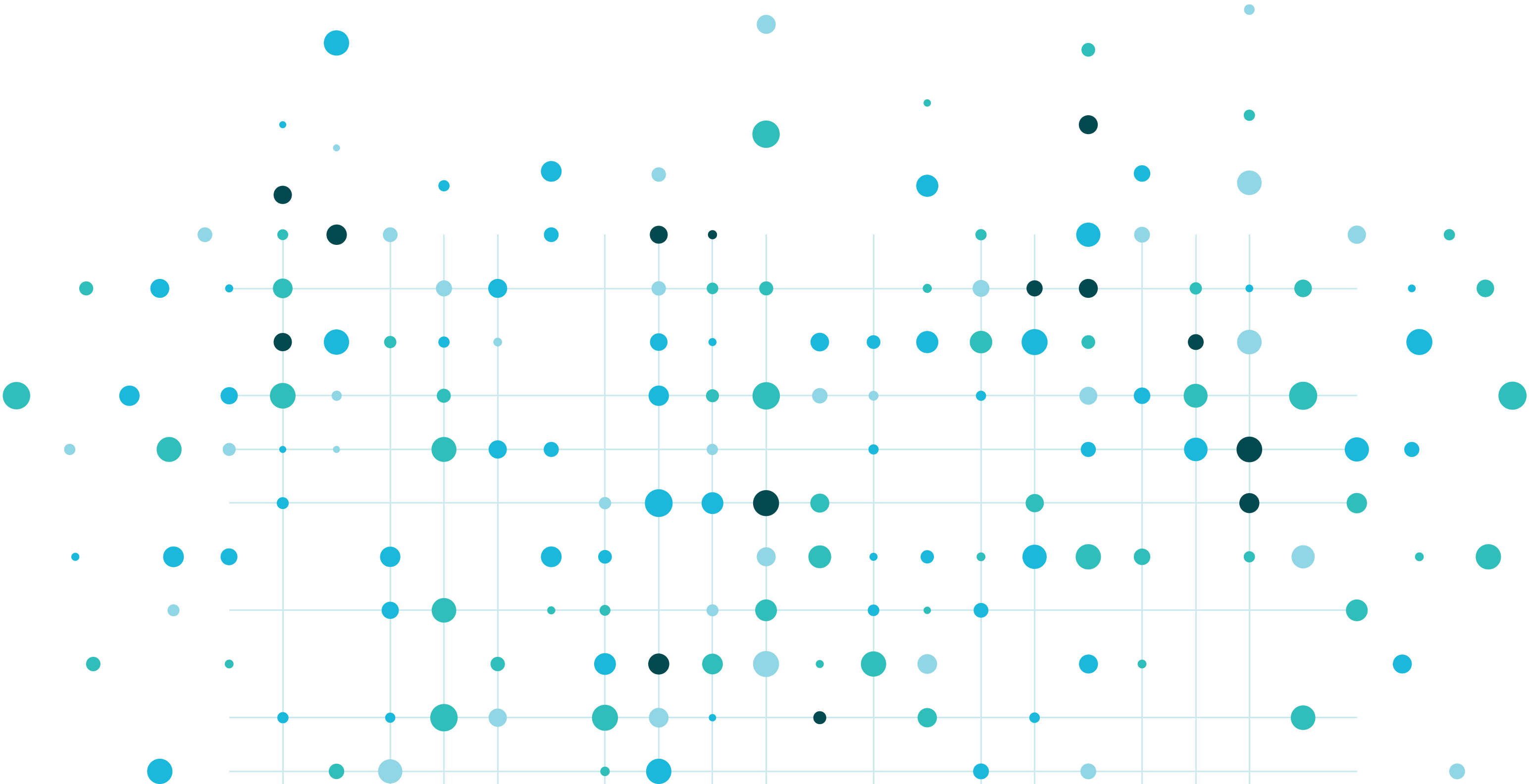
ASID
Aotearoa
New Zealand
Division

Data, Design and Delivery:

Research to Support People with an Intellectual (Learning) Disability

One-day Conference

Monday 17th March 2025 • Shed 22, Wellington



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Programme overview

Time	Session	
8:30 – 9:00	Registrations at venue, Shed 22, Wellington	
9:00 – 9:15	Opening	
9:15 – 10:00	**Keynote Address** - **Plenary Room** - Recognising and responding to the grief experience for people with intellectual disabilities: Using research to contribute to understanding and support *Suzanne Guerin - Professor of Research Design & Analysis, University College School of Psychology, Dublin*	
10:05 – 10:30	**Stream 1 – Wellbeing**	**Stream 2 - Adverse events**
	1.1 – **Plenary Room** Measuring what matters: Using data to maximise wellbeing *Victoria Ross and Michelle Macaskill*	2.1 – **The Loft -** Your tails of the tail – focus for the future: Pandemic and other events *Dr Henrietta Trip, Dr Hemant Thakkar, Hamish Taverner, Assoc Prof Brigit Mirfin-Veitch*
10:30 – 11:00	Morning Tea	
11:00 – 11:45	**Keynote Address** - **Plenary Room** - From data to dignity and beyond: Creating change through data *Luisa Beltran-Castillon (Principal, Kōtata Insight), and Shara Turner (Advocate, IHC)*	

	Stream 3 - Using data in services	**Stream 4: Co-research**
11:50 – 12:15	3.1 - **Plenary Room** - NZCL people experiences survey *Sarah Lean and Mallory Quail*	4.1 - **The Loft -** My experience learning to be a research assistant with learning disability *Julia Young (Donald Beasley Institute)*
12:20 -12:45	3.2 - **Plenary Room** - One source of truth: a journey from accessing one record at a time to seeing the bigger picture *Eilish Montgomery and Susan Rae*	4.2 - **The Loft -** Working together as co-researchers in an equal role *David Corner and Adelaide Jasonsmith*
12:45 – 1:30	Lunch	
	Stream 5 – Technology	**Stream 6 – Accessible information**
1:30 – 1:55	5.1 - **Plenary Room** - Supporting digital citizenship *Sarah Kinley and Arnah Trelease*	6.1 - **The Loft -** Telling people what I want if I get sick or am dying *Dr Nic McKenzie, Dr Henrietta Trip, Associate Professor Brigit Mirfin-Veitch, Dr Jenny Conder*
2:00 – 2:25	5.2 - **The Loft -** Online safety and avoiding scams – ‘Safety Net Cyber Cards’: An educational resource	6.2 - **Plenary Room** - Research informed easy read delivery

	Ben Healey and Rosie Zyskowski	*Dr Nicolina Newcombe and David Corner*
2:30 – 2:55	5.3 - **Plenary Room** - Moving forward with Volition: tools and strategies to support self-determination and decision-making *Erika Butters and Neville Pugh*	6.3 - **The Loft -** Rainbow easy read: From consultation to creation *Andi Buchanan, Rozlyn Gielink, and AJ Fitzwater*
2:55 – 3:15	Afternoon Tea	
	Stream 7 – Wellbeing	**Stream 8 (40 minutes) – Communication**
3:15 – 3:40	7.1 - **Plenary Room** - Managing and making my own decisions about my health and wellbeing *Assoc Prof Brigit Mirfin-Veitch, Julia Young, Dr Nic McKenzie, Patrick Doherty, Jason Donovan, Dr Henrietta Trip*	8.1 - **The Loft -** Communication access: what does that mean for you? *Michelle Bonetti and Bridget McArthur*
3:45 – 4:10	7.2 – **Plenary Room** - Safeguarding adults from abuse: A research informed response *Sue Hobbs and Dr Debbie Hager*	

4:15 – 4:30	Dance performance from Wellington Inclusive Dance
4:30 – 4:40	Acknowledgements and closing karakia

PRESENTATION DESCRIPTIONS

Key Note 1 - Recognising and responding to the grief experience for people with intellectual disabilities: Using research to contribute to understanding and support

Suzanne Guerin (Professor of Research and Design Analysis, School of Psychology, University College Dublin, Ireland)

Suzanne is visiting Aotearoa New Zealand from Ireland. She is going to talk about the topic of grief.

When a person experiences the death of a loved one, feelings of sadness are common. Most people are able to cope with these feelings and over time, the sadness can be less. A small number of people can feel a stronger sadness, one that lasts longer than might be expected. It may impact their ability to go to school or work, or even how they feel about other people in their lives. It is important that we can understand the feelings people have after the death of a loved one.

Researchers have done studies to get a better understanding of the different feelings people can have after someone dies. These studies have helped us to develop ways of supporting people after a loved one had died. In this talk, Suzanne will share some of the things she has learned from working with professionals and people with disabilities.

Key Note 2 - From data to dignity and beyond: Creating change through data

Luisa Beltran-Castillon (Principal, Kōtata Insight), and
Shara Turner (Advocate, IHC)

Join Luisa and Shara as they explore the transformative potential of data in improving the lives of disabled individuals. Building on the key insights from the Data to Dignity report, this session will unpack the latest findings, delve into crucial unanswered questions, and highlight how we can move from research to practical real-world impact.

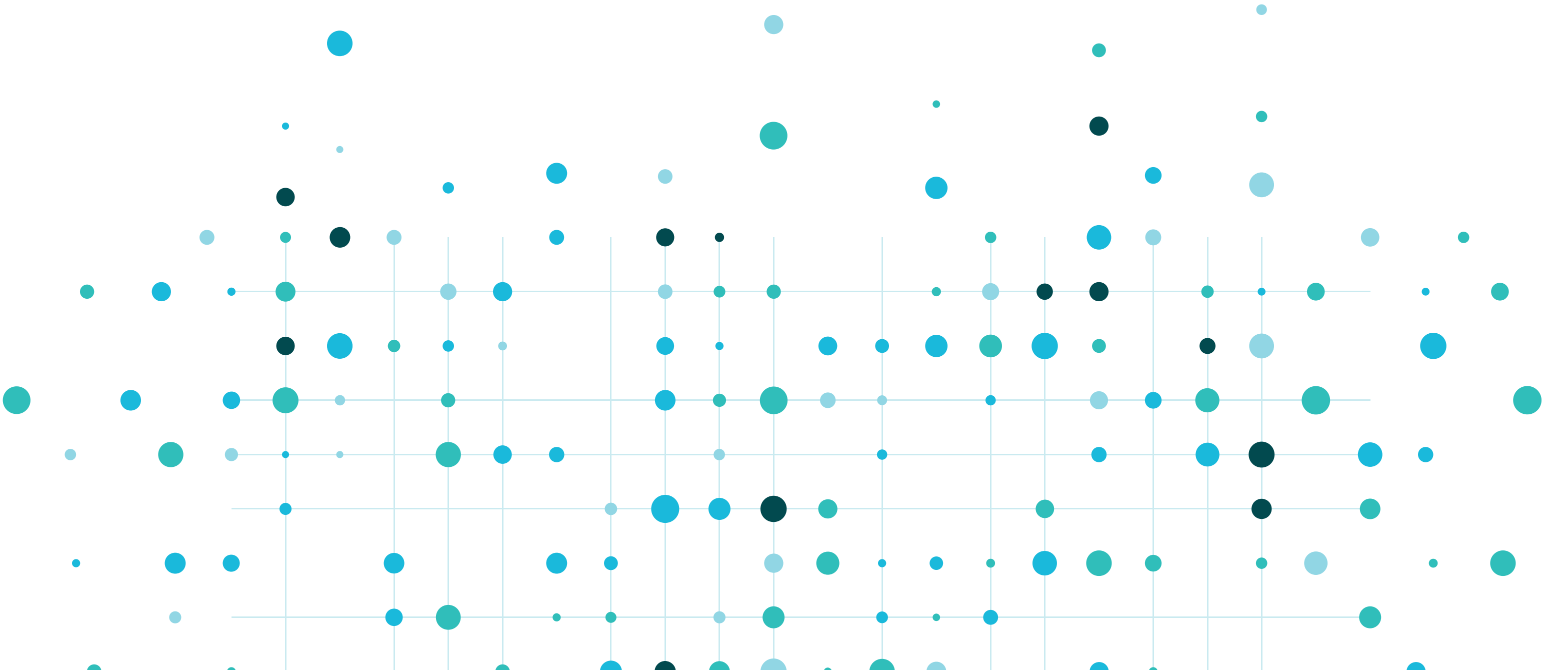
Luisa and Shara will focus on:

Breaking Down the Data: What are the trends, and why do people with intellectual disabilities face worse health outcomes? We'll take a closer look at the underlying causes and discuss the urgent need for change.

Practical Recommendations: How can we translate the data into action? We'll outline clear, actionable steps for improving health services and support systems based on the report's findings.

Driving Change with Data: Explore how data from the Integrated Data Infrastructure (IDI) can serve as a powerful tool for improving services and shaping more equitable social policies. We'll also introduce the concept of social investment thinking and how it plays a role in creating lasting, positive outcomes.

This session is a must for those who want to see how research can drive real change in health services and disability rights.



1.1 Measuring what matters: Using data to maximise wellbeing

Victoria Ross (SkillWise) and Michelle Macaskill (Huber Social)

In this presentation we will describe a research project about wellbeing that we carried out at SkillWise. In the research we wanted to explore:

- **areas of community strength**
- **how to use our resources to improve the wellbeing of the people we serve and their whānau (family).**

We will talk about:

- **the process of co-creating and carrying out a baseline survey to measure wellbeing**
- **what we measured in the survey**
- **how we made the survey accessible**
- **how the data from the survey has helped us understand people's needs and wishes**
- **what we are doing to maximise wellbeing and overcome some of the challenges.**

2.1 Your tails of the tail – focus for the future: Pandemic and other events

Dr Henrietta Trip (University of Otago), Dr Hemant Thakkar (Taikura Trust), Hamish Taverner (SAMS), Assoc Prof Brigit Mirfin-Veitch (Donald Beasley Institute, University of Otago)

Sometimes there are events that are out of our control that can impact our lives. This includes natural disasters and the COVID-19 pandemic, for example. It is important to understand what helps people to cope with these types of situations.

In 2023 the New Zealand division of the Australasian Society for Intellectual Disability (ASID) held 2 workshops with people with intellectual disability, and their supporters. We talked about their experiences of unexpected events.

In this presentation we will talk about what we learned about how to support people with intellectual disability to be resilient. Resilient means to adapt to change. This information could help people who are planning for natural disasters, pandemics, and in disability services on a daily basis.

3.1 NZCL people experiences survey

Sarah Lean and Mallory Quail (NZCL)

This presentation discusses the NZCL People Experience Survey. The survey tool was designed with individuals who have lived disability experience. The tool was also designed in line with the hui process. It was developed so that kiritaki / people could have a voice. It tells us how well NZCL is meeting the Enabling Good Lives (EGL) principles in residential homes.

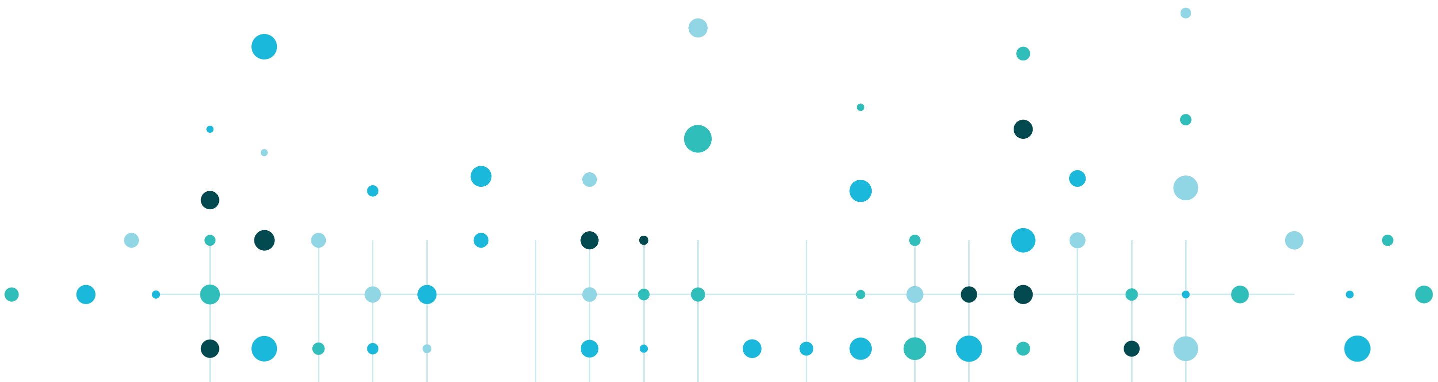
In the presentation we will talk about:
- **How we developed the survey with stakeholders**
- **The innovative conversational approach that we used**
- **What we learned**
- **How we are using the data from the survey to change what we do**
- **The importance of evidence-based approaches in service delivery.**

3.2 One source of truth: a journey from accessing one record at a time to seeing the bigger picture

Eilish Montgomery and Susan Rae (Spectrum Foundation)

This presentation is about how Spectrum Care have started using data from our Customer Relationship Management (CRM) system in innovative ways to improve the way that we support people with intellectual disability.

We will talk about:
- **how the data helps us to meet the Enabling Good Lives (EGL) principles of person-centred, ordinary life outcomes, mana-enhancing, and easy to use.**
- **the data visualisation software we use (PowerBI) and how it helps us**
- **what we have learnt from using this approach**
- **how the data impacts our clinical processes and the way that we support people with intellectual disability.**



4.1 My experience learning to be a research assistant with learning disability

Julia Young (Donald Beasley Institute)

Just over one year ago I started in my first paid job as a Research Assistant with the Donald Beasley Institute. In this presentation I am going to tell you:

- **How I came to be interested in research**
- **What my job involves**
- **How I am learning research skills**
- **How I work within a team.**

I will also talk about the things that are exciting and the things that are hard about being a disability researcher.

4.2 Working together as co-researchers in an equal role

David Corner (IHC) and Adelaide Jasonsmith (Victoria University of Wellington)

David is a person with an intellectual disability and Autism who works for IHC as the national self-advocacy advisor and is a life member of People First New Zealand | Ngā Tāngata Tuatahi. Adelaide is a PhD student who works at PSAID at Te Whatu Ora Waitaha.

We will talk about how we first met to work together, and our role as co-researchers and the work we have done so far.

We will talk about what we hope to achieve over time and how it will help people with an intellectual disability to have better healthcare from health professionals.

We will also talk about the unconscious bias and how over time we can remove the myth and stigmas that doctors and nurses have toward people with an intellectual disability.

5.1 Supporting digital citizenship

Sarah Kinley and Arnah Trelease (Hōhepa Canterbury)

In 2023 we worked to design a framework to support people with intellectual disability to use technology in a way that is safe and supports their wellbeing. The framework focuses on 5 areas of digital citizenship:

- **support / safeguarding**
- **values and attitudes**
- **cyber safety awareness**
- **digital literacy**
- **digital fluency.**

The framework and its associated tools support, educate, and empower people with intellectual disability (and whānau and supporters) to thrive and become successful digital citizens.

In this presentation we will:

- **talk about how we developed the framework**
- **show you what the framework looks like and how it works**
- **explain how people have been using the framework, and the outcomes of that**

5.2 Online safety and avoiding scams – 'Safety Net Cyber Cards': An educational resource

Ben Healey and Rosie Zyskowski (People First New Zealand | Ngā Tāngata Tuatahi)

We will present an educational resource that was developed through a co-design process led by people with an intellectual disability. The resource created is designed to support staying safe on-line and is called 'Safety Net Cyber Cards.' It includes Easy Read documents that explain how to play the game, as well as information about online scams.

We will explain how the need was identified and the co-design process (led by people with intellectual disability) that followed. We will also demonstrate how to use the game cards.

5.3 Moving forward with Volition: tools and strategies to support self-determination and decision-making

Erika Butters and Neville Pugh (Volition)

We will discuss the foundations of supported decision-making, and the importance of promoting rights, will and preference.

We will then introduce Volition, a new accessible app that is a digital preference bank. Volition enables decision makers to:
- **say what is important to them**
- **say how they want to receive support**
- **share the information with people who support them**

We will explore our innovation, lay bare our challenges, and share and learnings and next steps.

6.1 Telling people what I want if I get sick or am dying

Dr Nic McKenzie (Disability sector consultant), Dr Henrietta Trip (University of Otago), Associate Professor Brigit Mirfin-Veitch (Donald Beasley Institute, University of Otago), Dr Jenny Conder (University of Otago)

It is really important for people to know what we want if we get ill or are dying. This is called Advance Care Planning. People with intellectual disability are often left out of this type of planning, and others make decisions for them.

This presentation will share a way of Advance Care Planning that was developed in Aotearoa New Zealand. The resources were co-designed with people with intellectual disability and have been tried out and tested. They can help people with intellectual disability to have choice and control at the end of life.

This session is for people with intellectual disability, whānau and supporters.

6.2 Research informed easy read delivery

Dr Nicolina Newcombe and David Corner (IHC)

Nicolina's doctoral research explored intellectual disability as a culture, highlighting cultural literacy practices that are unique to them. One key practice is Easy Read. Easy Read uses simple words, short active sentences, descriptive pictures, and enhanced visual accessibility to make information easier to understand.

This talk will discuss Easy Read as an element of learning disability culture and how IHC uses Easy Read throughout our organisation.

Nicolina and David will talk about how we work together to create these helpful resources. We will show the Easy Read Employment Pack as an example of developing both translated and co-designed information. This pack includes a job description template, welcome letter, and form for identifying reasonable accommodations at work. Printed copies will be available for people to take home and use.

6.3 Rainbow Easy Read: From consultation to creation

Andi Buchanan, Rozlyn Gielink, and AJ Fitzwater (People First New Zealand | Ngā Tāngata Tuatahi)

With funding from the Rule Foundation, People First NZ translators worked together with People First NZ members to create a suite of Easy Reads for and about rainbow (LGBTTQIA+) communities and identities.

These Easy Reads cover topics including:
- **rainbow identities**
- **coming out**
- **how to support your rainbow friends and whānau (family).**

This presentation describes the design process, including recruitment of People First NZ members as advisors, idea sharing meetings, safeguarding and wellbeing concerns, and the processes used for feedback on draft Easy Read documents. We will also discuss the insights gained from this consultation and co-design approach and how we created and edited the Easy Reads based on feedback. We look at the challenges faced along the way, and future possibilities for co-design and shared decision making.

7.1 Managing and making my own decisions about my health and wellbeing

Assoc Prof Brigit Mirfin-Veitch (Donald Beasley Institute, University of Otago), Julia Young (Donald Beasley Institute), Dr Nic McKenzie (Understandable), Patrick Doherty (People First New Zealand | Ngā Tāngata Tuatahi), Jason Donovan (People First New Zealand | Ngā Tāngata Tuatahi), Dr Henrietta Trip (University of Otago)

The Donald Beasley Institute is doing a research project called 'managing and making my own decisions about my health and wellbeing.' We are doing this research in partnership with People First New Zealand | Ngā Tāngata Tuatahi.

In this presentation we are going to talk about:

- **what this research is about**
- **why it is important to do it**
- **how we are working together**
- **how people with a learning disability are leading the research process**
- **what we want to come out of the research.**

7.2 Safeguarding adults from abuse: A research informed response

Sue Hobbs and Dr Debbie Hager (VisAble)

This presentation is about safeguarding. Safeguarding goes beyond protection. It is the actions that promote and protect human rights, decision-making, choice and control, well-being, cultural considerations, citizenship, and quality of life.

We will talk about an evaluation of previous work keeping adults safe from harm in Waitematā. The research showed that disabled people face significantly more abuse and harm than non-disabled people, and that people with intellectual disabilities are the most at risk. Furthermore, the current family and sexual violence systems do not meet their needs well.
We will explain how we are using this learning at VisAble, to develop and implement a new way of supporting disabled people to live safely.

8.1 (Plenary session) - Communication access: what does that mean for you?

Michelle Bonetti and Bridget McArthur (Moretalk Communication Assistance)

Since 2012, Moretalk Communication Assistants have worked within New Zealand’s justice system, supporting effective communication in:
- **courts**
- **police interviews**
- **Oranga Tamariki meetings**
- **Corrections environments.**

Our mission is to ensure everyone can understand, participate, and have their voice heard, even in highly stressful situations.

In this presentation we will talk about important things we have learnt, including:
- **how to identify hidden communication challenges**
- **how to ask the right questions**
- **how to advocate to access communication**
- **practical strategies to support effective communication and ensure participation.**

Join us to explore how understanding individual needs and implementing accommodations can make justice and other complex communication situations more effective and equitable for everyone.

Are you a member yet?

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Ko Wai Tatou - Who Are We?

Australasian Society for Intellectual Disability (ASID) is a peak body in intellectual disability research in Australia and New Zealand.

- Research gives us good evidence.
- Good evidence helps to make good policy and practice.
- Good policy and practice help people with learning (intellectual) disabilities to have better lives.

Why Join Us?

As an ASID member, you:

- Can make a difference to the lives of people with learning (intellectual) disabilities
- Get to attend informative webinars, workshops, and conferences for free or at discounted rates
- Can build strong local, national and international networks
- Get free access to online national and international research journals
- Get discounted publications from Taylor & Francis

How do I Join?

You can become an Individual Member or Organisational Member of the ASID by visiting: https://asid.asn.au/join/

I need more information before I join:

- You can contact the ASID Secretariat on info@asid.asn.au OR
- Contact the Chair of ASID New Zealand division, Hemant Thakkar, by email: hemant.thakkar@taikura.org.nz or phone: 0272991520.

What did you think about the conference?

Thank you for coming to the conference.

We would like to know what you thought about the conference.

For each question, please circle 1 answer.

1. How interesting were the presentations?

very good   good   ok   bad   really bad

2. How useful did you find the presentations?

very good   good   ok   bad   really bad

3. How well organised was the conference?

very good   good   ok   bad   really bad

4. How was the venue (comfort, access, catering)?

very good	good	ok	bad	really bad

5. What did you like the most about the conference? Write your answer here.

6. What didn’t you like about the conference? Write your answer here.