# Day 1 Thursday 3 July

# 8:15 - 9:00

Registration

# 9:00 - 9:10

Welcome to Country

* Uncle Chicka Madden, Metropolitan Local Aboriginal Land Council

# 9:10 - 9:15

MC Welcome

Conference Emcees Julian and Judy will welcome guests to the Conference.

* Julian Trollor, The Centre
* Judy Huett, The Centre

# 9:15 - 9:45

National Centre of Excellence Overview

Julian and Judy will give a short presentation about the Centre. A panel of team members from the Centre will talk about different parts of the work.

* Ricky Kremer, The Centre
* Patsie Frawley The Centre
* Laura Naing, Council for Intellectual Disability and National Centre of Excellence in Intellectual Disability Health
* Raylene Griffiths, Council for Intellectual Disability
* Rory Keyes, National Centre of Excellence in Intellectual Disability Health
* Lucy Reynhout, National Centre of Excellence in Intellectual Disability Health
* Ana Nguyen, Learn and Lead - National Centre of Excellence in Intellectual Disability Health

# 9:45 -10:30

Opening Address & Q&A

* Alastair McEwin, Professor of Practice UNSW and Former Commissioner -Disability Royal Commission

# 10:30 - 11:00

Morning Tea

# 11:00 - 12:30 Breakout sessions

# There are 4 breakout sessions to choose from

If you are joining online you can choose between the Blue Room and the Green Room

# 11:00 - 12:30 Blue Room

Driving Change – Advocacy on health for people with intellectual disability

This session is about systemic advocacy in intellectual disability health.

A panel of speakers from the National Centre of Excellence in Intellectual Disability Health will share their thoughts on progress and new directions for systemic advocacy in intellectual disability health.

Speakers:

* Sophie Howlett, Lead –Council for Intellectual Disability and the Centre, facilitator
* Simon Cotterell, Council for Intellectual Disability and the Centre
* Eileen Baldry, The Centre
* Kirsten Deane, Melbourne Disability Institute and The Centre
* Laura Naing, Council for Intellectual Disability and the Centre
* Darryl Steff –Down Syndrome Australia and Council for Intellectual Disability and the Centre

# 11:00 - 12:30 Theatre 120

Social, Sexual and Women’s Health

This session is about social and sexual health and women’s health. It will showcase some leading work and resources in this space that have been developed through a co design process. There will time for questions and discussion.

Facilitators:

* Patsie Frawley, National Centre of Excellence in Intellectual Disability Health (Co-Facilitator)
* Lucy Reynhout, National Centre of Excellence in Intellectual Disability Health (Co-Facilitator)

Speakers:

* Claire Bertholli, Women with Disability Australia (remote)
* Caroline Livanos, Jean Hailes for Women’s Health (remote)
* Dr Sheridan Kerr, Sexual Health ACT
* Mel Harrison, Sexual health ACT
* Dr Lauren Winkler, Syndey University

Interesting for family members, carers, supporters, researchers, academics and health professionals.

11:00 - 12:30 Orange Room Doric

Research Co Design in Intellectual Disability Health

This session is about co-design in research. Why it's important and how to do it well. There will be a practical activity at the end.

Facilitators:

* Josephine Wyborn, Centre for Disability Studies (Co-Facilitator)
* Suzie Jessep, Centre for Disability Studies (Co-Facilitator)

Speakers:

* Bruce O’Brien, Centre for Disability Studies
* Morag Kelly, Centre for Disability Studies
* Ellie Taylor, Centre for Disability Studies
* Wayne Wright, Centre for Disability Studies
* Erin Whittle, Centre for Disability Studies
* Iva Strnadova, UNSW GeneEQUAL
* Julie Loblinzk Refalo OAM, GeneEQUAL
* Caroline Hart, Scope (remote)
* Annie Loughens, Scope (remote)

 Interesting for researchers, academics and people with intellectual disability

11:00 - 12:30 Purple Room Corinthian

Workshop, Let’s Get Loud!

A workshop with the Learn and Lead Group about having your say!

Got something to say about healthcare?

Learn how to develop your key message in this fun and interactive workshop run by the Learn and Lead Group.

The Learn and Lead Group is a group of 10 people with intellectual disability who give advice to the Centre.

By the Learn and Lead Group

Interesting for people with intellectual disability

12:30 – 1:30 Banquet Hall

Lunchtime & Entertainment

Anthony 'the Piano Man' Minicino.

1:30 – 2:00 Spotlight Short Break Outs

1:30 – 2:00 Blue Room Grand Lodge

Health planning and peer facilitation for people with complex needs by Micro Boards Australia.

Micro boards Australia will talk about their project on health planning and navigation for people with complex needs.

Speaker:

* Rachel Skoss, Micro boards Australia

Interesting for families and supports, health professionals and disability professionals

1:30 – 2:00 Green Room Ionic, also live streamed

Intellectual disability and health - gaps and improvements – SACID

This presentation is sharing important information about accessing health services for people with an intellectual disability. Focussing on gaps in services and ways to address, in South Australia and beyond.

Speakers:

* Aaron Byrne, SACID
* Melinda Brown, SACID

Interesting for people with intellectual disability, families and supporters

1:30 – 2:00 Orange Room Doric

How to design workshops that include everyone bt Swinburn University

In this part workshop, part presentation, MedTech Vic /Swinburn will share learnings about co design processes and draw on the expertise in the room to further develop the process.

Speakers:

* Rachael McDonald, Swinburne University
* Paris Triantis, Swinburne University
* Claudia Bridge, Swinburne University
* Angus King, Actor

Interesting for health professionals, disability professionals, families and supporters

1:30 – 2:00 Purple Room Corinthian

Using your smart phone to make video messages and content

Sharing your story or message through film can be a powerful advocacy tool, and all you need is a smart phone! In, this workshop Angela Blake from Bus Stop Films and SP3 Smartphone festival will teach us how to use a smart phone or tablet to make a professional video or film! Participants can choose to screen their video screened at the conference.

Speakers:

* Angela Blake - SF3 Co-Founder, Festival Director and Filmmaker
* Bevan Garozzo - Award-winning filmmaker

Interesting for people with intellectual disability

2.10 – 3:10 Break Outs 60 Minutes

2.10 – 3:10 Blue Room Grand Lodge

Co Designing Online Spaces – Monash University and National Centre of Excellence in ID Health.

Monash Health used co design in the creation of an award-winning online information hub called MylivedID. [https://mylivedid.org.au](https://mylivedid.org.au/)

The Centre is co designing a complementary information hub called the KEH working with a co design network from around Australia.

Speakers will talk about the processes, the challenges and the lessons learned.

Facilitators:

* Rory Keyes National Centre of Excellence in Intellectual Disability Health
* Grace Sharlkey, National Centre of Excellence in Intellectual Disability Health

Speakers:

* Jen Xiang National Centre of Excellence in Intellectual Disability Health
* Patsie Frawley, National Centre of Excellence in Intellectual Disability Health
* Zoe Broadway, Valid Connect (remote)
* Mark Schiffer, Blick Creative (remote)
* Kellie Hammerstein, Monash Health

This session is interesting for researchers, academics, health professionals and disability professionals.

2.10 – 3:10 Green Room Ionic

Intellectual disability and mental health: From awareness to action

This session will include an update on what we know about mental health for people with intellectual disability.

It will explore ways to address gaps including specialist training and skills building health practitioners.

Facilitator:

* Rebecca Konz

Speakers:

* Prof. Julian Trollor, The Centre
* Mel Johnston, QCEAIHD
* Aimee Blackam, NSW Ministry of Health

You might like this session if you are a health professional, health professional, disability professional, academic or researcher.

2.10 – 3:10 Orange Room Doric

My Relationships Matter – CID. Lived Experience Panel.

This session will have 3 women with intellectual disability share their stories and experiences together.

The panel hope to help others feel more confident talking about their own sexual and reproductive health.

They will share how important it is to work together with people you trust.

Speakers:

* Leonie Mclean
* Pamela Darling
* Manon Bilawczuk
* Amanda Duell-Ferguson

This session is interesting for people with intellectual disability.

2.10 – 3:10 Purple Room Corinthian

Using your smartphone to make video messages and content – Continued

Sharing your story or message through film can be a powerful advocacy tool, and all you need is a smartphone! In this workshop Angela Blake from Bus Stop Films and SP3 Smartphone festival will teach us how to use a smartphone or tablet to make a professional video or film! Participants can choose to screen their video screened at the conference.

Speakers:

* Angela Blake - SF3 Co-Founder, Festival Director and Filmmaker
* Bevan Garozzo - Award-winning filmmaker

3.10 – 3:30

Afternoon Tea

3:30

MC’s welcome everyone back and introduce Michael Kidd

3:30 – 3.50

Professor Michael Kidd, Chief Medical Officer

3.50 - 4.50 Blue Room Grand Lodge

Culturally Safe and Inclusive approaches to ID Health

This session explores how culturally safe practices improve outcomes for Aboriginal and Torres Strait Islander people with intellectual disability.  Drawing on insights from diverse perspectives it will examine First Nations perspectives on ability, barriers to access, and the need for culturally safe services and practice.

Facilitator:

* John Gilroy, Sydney University

Speakers:

* Scott Avery, University of Technology Sydney
* Uncle Willie Prince, Advocate
* Samantha Cooms, University of Queensland

4:50

MC’s close

# Day 2 Friday 4 July

# 8:15 - 9:00

Registration

# 9:00 - 9:20

MC Welcome

Conference Emcees Julian and Judy will welcome guests to the Conference.

* Julian Trollor, The Centre
* Judy Huett, The Centre

# 9:20 – 10:30

Keynote Address

It has been 25years since Gloria Krahn published ‘Cascade of Disparities: Health and Health Care Access for people with intellectual disabilities’. Gloria will talk about health care for people with intellectual disability, 20 years on, how far have we come, and the priorities for change.

* Dr Gloria Krahn, Oregon State University

# 10:30 - 11:00

Morning Tea

# 11:00 - 12:30 Breakout sessions

# There are 4 breakout sessions to choose from

If you are joining online you can choose between the Blue Room and the Green Room.

# 11:00 - 12:30 Blue Room

Models of Care in Intellectual Disability Health

A model of care is the way health services are delivered. The panel will talk about the different health services they work at. The panel will also talk about how health services could do a better job in providing care for people with intellectual disability.

Facilitators:

* Kitty Foley, QCEIDH (co facilitator)
* Jenny Downs, The kids institute (co facilitator)

Speakers:

* Elizabeth O’Shannessy, Disability Access and Inclusion Lead, Alfred Hospital
* Melanie Johnston, Psychiatrist, Queensland Centre of Excellence in Autism and Intellectual Disability Health
* Dr Jessica Smith, Rehabilitation Physician Adelaide Disability Medical Services

Interesting for: Academics, Health professionals, disability professionals

# 11:00 - 12:30 Green Room Inconic

Lightning talks

10-15-minute talks sharing different ideas and perspectives, from personal journeys to new research, to the use of technology in ID Health. Speakers will take questions from our Live Stream audience at the end.

Facilitator:

* Ellen Skladzien

Presenters:

Partners in care - service experiences of carers of people with intellectual disability

* Lukas Hofstätter – Carers NSW

A Life of Ups and Downs: The Struggle Against Diagnostic Overshadowing of Rare Medical Conditions when you have Down Syndrome

* Dr Antonia Scott
* Victoria Scott

Hiding in plain sight: Using population research to better target policies to improve antenatal outcomes for mothers with intellectual disability and their children

* Susan Collings, Western Sydney University

Cancer survivorship for people with intellectual disability

* Jennifer Baldock, Cancer Council SA
* Michelle Bellon, Flinders University
* Timothy Cahalan, Flinders University

Don’t just tell me - show me: MyComms and the future of visual communication:

* Jess Shahbazi, MyComms
* Jennifer Winstone, MyComms

Interesting for: Families/carers/supports, academics, health professionals, disability professionals

11:00 - 12:30 Orange Room Doric

Palliative Care and Aging

In this session 4 presenters will share their work and lived experience in age related illness, end of life and palliative care. There will be a panel discussion and questions at the end.

Facilitator:

* Rebecca Koncz, UNSW (Facilitator)

Speakers

* Wendy Bruce, Fragile X Association of Australia
* Rachael Cvejic, National Centre of Excellence in Intellectual Disability Health
* Pamela Darling, Council of Intellectual disability
* David Pech, Council for intellectual disability

Interesting for: Families/carers/supports, academics, health professionals, disability professionals.

11:00 - 12:00 Purple Room Corinthian

Staying safe online: How to spot a scam and stay safe using apps and online platforms (30 mins)

The Down Syndrome Australia Digital Champions will run a short workshop on how to stay safe while using health apps such as MyGov and spotting scam emails.

Speakers:

* Elizabeth Willis, Project Manager Down syndrome Australia.
* Chris Bunton, Digital Champion
* Lachlan Gapes, Digital Champion
* Sarah Clarke, Digital Champion

It’s Doctor Time (30 mins)

Inclusion Australia

Inclusion Australia is working with the government to help increase the number of people with an intellectual disability having their Medicare-supported yearly health check. It’s Doctor Time! is about choosing a special time of year to book in a yearly health check. Doctor Time could be around a person’s birthday, in Autumn, during NAIDOC Week, AFL Grand Final week, or any other time that helps the person with intellectual disability remember to go to the GP around the same time every year. It’s Doctor Time! includes information and resources for people with intellectual disability, families, GPs and clinic staff, service providers and others.

Speakers:

* Catherine McAlpine, Inclusion Australia
* Luke Nelson, Inclusion Australia

Interesting for: People with intellectual disability, families’ carers supporters

12:30 – 1:30 Banquet Hall

Lunchtime & Entertainment

Caoimhe McCooey.

1:30 – 2:30 Break Outs

1:30 – 2:30 Blue Room Grand Lodge

Bus Stop Films Screening and Discussion.

In this session 4 films will be screened. A panel will talk about the films. The films are: Screen Me, What Was It Like, Not a Wallflower, Look the Part.

Facilitator: Kirsten Deane, University of Melbourne

* Jennifer Brennen, Centre for Disability Studies
* Julian Neuhaus*,* Bus Stop Films
* Ricky Kremer, National Centre of Excellence in Intellectual Disability Health and Documentary participant
* Estelle Kremer, Documentary participant

Interesting for: Everyone

1:30 – 2:30 Green Room Ionic

Lightning talks

Short talks sharing different ideas and perspectives, from personal journeys to new research, to the use of technology in ID Health. Speakers will take questions from our Live Stream audience at the end.

Facilitator:

* Grace Sharkey

VR in health care settings

* Stefan Michalski, UNSW

 Heart health for People with Intellectual Disability

* Emma Suzuki, UNSW
* Rory Keyes, UNSW, Heart Health Project

Outreach dental placement for people with disability

* Archana Pradhan
* Antonia Scott

Interesting for: Families, carers and supporters, health and disability professionals, academics and researchers

1:30 – 2:00 Orange Room Doric

Gloria Krahn Fireside Chat

Join our Keynote Speaker Gloria Krahn for a fireside chat

Facilitator:

* Mary-Ann O’Donovan

Interesting for: academics and researchers, health and disability professionals

1:30 – 2:30 Purple Room Corinthian

Amplifying Inclusion Though Art

Learn about inclusion from Inclusion Experts from across the Centre, while also learning new skills in pom-pom making, origami and performance! This session is in partnership with the Equity Through Art and is not to be missed!

Workshop Leads:

* Laura Naing, Council for Intellectual Disability and National Centre of Excellence in Intellectual Disability Health
* Raylene Griffiths, Council for Intellectual Disability

Interesting for people with intellectual disability, health professional

2:35 – 3:05 Break Outs 30 Minutes

2:35 – 3:05 Blue Room Grand Lodge

What can we learn from The Down Syndrome Australia Health Ambassadors?

The Health Ambassadors will talk about their work. They will share tips on how people with intellectual disability can play a key role training health worker.

Down Syndrome Australia Health Ambassadors:

* Olivia Sidhu
* Rohan Fullwood
* Naomi Lake
* Liz Evans

Interesting for people with intellectual disability, disability professionals and supporters

2:35 – 3:05 Green Room Ionic

Lightning talks

Two talks sharing different ideas and perspectives, from personal journeys to new research, to the use of technology in ID Health. Speakers will take questions from our Live Stream audience at the end.

Facilitator:

* Grace Sharkey

Healthy Discussions

* Tarli Sali, Office of the public advocate
* Lisa Brumtis, Office of the public advocate

Listening to people with intellectual disability to make genetic health care more inclusive, person-centred and respectful, GeneEQUAL

Interesting for: Families, carers and supporters, health professionals, disability professionals, academics and researchers

2:35 – 3:05 Orange Room Doric

Outcomes of a Hospital-Based Anaesthesia Service for People with Intellectual Disability

This presentation will talk about SAIDHS new Health Care Access Service and will share one woman's experience to describe the more health services will use our approach across Australia.

Speakers:

* Stephanie Searle, Senior Service Manager, SAIDHS
* Dr Farima Forooziya, Rehabilitation Consultant
* Michelle Bellon, SAIDHS Research Lead

Interesting for: Families, carers and supporters, health professionals, disability professionals, academics and researchers

2:35 – 3:05 Purple Room Corinthian

Meet up

Catch up with people you have met at the conference for a coffee and a chat.

3.05 – 3:30

Afternoon Tea

3:30 -4:30pm Blue Room Grand Lodge

That’s a Wrap

A panel of conference participants with different backgrounds and perspectives, and the audience, will reflect on the last two days. What is the vison for the future of health care? What does it mean to work together every step of the way to achieve it?

Our live visual storyteller will capture reflections in pictures, during the session.

Panellists:

* Dr Gloria Krahn, Oregon State University OSU
* Michelle Moss , QDN and the Centre
* Mandy Knight, Northern Territory Scholarship Recipient
* Others TBC

4:30pm Blue Room Grand Lodge

MCs close the conference