

Profound Autism Symposium | 2025

State Library of NSW, 17-18 November 2025



Program

DAY 1 | Monday 17 November

8:45 – 9:15am

Registration

9:15 – 9:20am

Welcome

9:20 – 10:05am

Keynote: Conversations around profound autism – Compassion. Clarity. Progress

Speaker: Judith Ursitti (USA)

The term profound autism is intended to provide clarity to help further support a subset of the autism population. Concerns have been expressed about potential stigma, while excitement has been expressed by those who feel validated. Learn about the history of the development of the term, related research, and the path forward as part of the broader autism community.

10:05 – 10:50am

Presentation: Autism and emergency services – Building safer responses

Speaker: Kathrine Peereboom

Encounters with police, paramedics, or hospitals can be life-changing, even life-threatening for the autistic community. This session will explore safer responses in emergencies, from navigating frontline interactions to safeguarding against abuse and reducing trauma through better preparedness. This conversation is about more than awareness. It is about protecting and saving lives.

10:50 – 11:15am

Morning tea

11:15am – 12:00pm

Keynote: When acceptance ignores reality – Life with profound autism

Speaker: Eileen Lamb (USA)

As both an autistic adult and mother to a profoundly autistic son, Eileen sees every day how awareness and acceptance fall short when the realities of profound autism are ignored. In this talk, she shares personal stories that reveal the daily challenges – like safety, self-injury, elopement and lack of resources – that families like hers face. Eileen highlights why these experiences matter, how they've been erased from the broader autism conversation, and what true inclusion looks like for those with the highest support needs.

12:00 – 12:55pm

Panel: Housing futures – Building better options for profound disability

Speakers: Brent Woolgar (DSC), Libby Ellis (Mable), Lydia Dockrill (Housing Hub) | **Moderator:** Nicole Rogerson

Housing remains one of the greatest challenges for people with profound autism. In this expert panel, leaders in disability housing will share proven approaches, highlight barriers, and offer practical strategies to help families and practitioners make informed choices.

12:55 – 1:30pm

Lunch

1:30 – 2:00pm

Panel: Bridging research and practice – What do we know about profound autism in an Australian cohort?

Speakers: Dr Rebecca Sutherland, Dr Kelsie Boulton, Dr Antoinette Hodge | **Host:** Prof Andrew Whitehouse

While the term, *profound autism*, is increasingly recognised internationally, little is known about how it presents in Australia. This panel will share new insights from a multidisciplinary hospital clinic study examining the clinical and demographic features of children referred for autism assessment. The discussion will explore the characteristics of those who did and did not meet criteria for profound autism, as well as younger children likely to do so by age eight. The panel will also cover what these findings reveal about future diagnosis, service planning, and support policy within the Australian context.

2:00 – 2:50pm

Panel: Parent voices – Living with profound autism

Panel: Kathrine Peereboom, Judith Ursitti, Tim Pryde, Bob Buckley | **Moderator:** Nicole Rogerson

In this open conversation, parents share their personal stories of raising children with profound autism, across different ages and stages. Candid, heartfelt, and deeply relatable, this session offers insights into the daily realities, challenges and joys of family life.

2:50 – 3:15pm

Afternoon tea

3:15 – 4:00pm

Presentation: The light, the dark and the lasting – Supporting ourselves as families and carers through the profound autism experience

Speakers: Meredith Coote, Briana Blackett

Caring for someone with profound autism is a lifelong journey that brings deep moments of challenge and joy. In this honest and intimate fireside chat, seasoned carers will share what sustains them, what works, what doesn't, and explore practical ways families can look after themselves and each other along the way.

4:00 – 4:45pm	Panel: When the system says no – Families, rights and the NDIS Speakers: Shannon Eeles, Bob Buckley Navigating the NDIS can be one of the most challenging parts of raising or supporting someone with profound autism. This session looks at what to do when the system says no – how to build strong evidence, write clear and achievable goals, and prepare for plan reviews or appeals. Our experts will share practical advice to help families understand their rights and the NDIA's review and appeal processes.
4:45 – 4:50pm	Closing
5:00 – 7:00pm	Networking event, proudly sponsored by DexuS

DAY 2 | Tuesday 18 November

8:45 – 9:15am	Registration
9:15 – 9:20am	Welcome
9:20 – 10:00am	Keynote: The representation wars – Media portrayals, language debates, and advocacy in the autism community Speaker: Amy Lutz (USA) Representation is a word with multiple meanings in the autism community: who is allowed to speak for profoundly autistic people who can't self-advocate? What words are we allowed to use to describe our profoundly autistic loved ones, clients, patients, and research subjects, and who gets to decide? How is autism portrayed in the media and in public discourse more broadly? This talk will explore all these different issues, as well as the very real material impacts that different kinds of representation can have on the supports and services available to profoundly autistic people.
10:00 – 10:50am	Panel: Overlooked and underserved – Healthcare for profound autism Speakers: Dr Peter Smith, Dr James Best, Dr Rummana Afreen Moderator: Kathrine Peerboom Why is accessing healthcare so hard for those with profound autism? This session looks at the structural failures and everyday barriers that families encounter, from diagnostic overshadowing to inadequate support in emergency settings. Expert clinicians will offer practical solutions and share examples of services that are making a difference.
10:50 – 11:15am	Morning tea
11:15am – 12:00pm	Presentation: Planning for a good life – Beyond services, towards connection and possibility Speaker: Leanne Pearman This session will explore how genuine person-centred planning supports building a good life and how it helps families build strong, natural safeguards that keep people safer, connected, and valued. By recognising the different types of "capital" each person holds: social, material, knowledge, and personal, families can build stronger foundations for belonging, trust, and contribution. This session offers a practical and positive approach to planning that focuses on relationships and community as the heart of safeguarding and living a good life.
12:00 – 12:45pm	Presentation: Where should we begin? – Understanding and teaching the essential skills to live a happy and healthy life Speaker: Karen McKinnon Time is precious, resources are stretched, and there's a seemingly endless list of goals we should be working on with children and young adults with high support needs. So, how do we determine and prioritise the most important skills to teach? This presentation outlines the essential skills we can teach to support a child to live a happy and healthy life. To achieve these essential goals, a framework for evaluating progress will be suggested, emphasising the importance of collaboration between professionals and parents/caregivers to ensure success.
12:45 – 1:30pm	Lunch
1:30 – 2:20pm	Presentation: Securing the future of your family member with a profound disability – Estate planning for families Speaker: Jonathan Harris Planning ahead is essential but often overwhelming. This session will cover the essentials, from guardianship and powers of attorney to disability trusts, Centrelink considerations, and strategies for providing for your family member with a profound disability and your other family members. Families will leave with a clearer sense of the steps they can take to safeguard their loved one's future.
2:20 – 3:30pm	Panel: The road ahead – Building a national voice for profound autism Panel: Bob Buckley, James Morton, Shannon Eeles, Tim Pryde Moderator: Nicole Rogerson Real reform requires persistence, courage and a united voice. This final panel brings together leading advocates to reflect on where we've come from, the change that's urgently needed, and how to build momentum from here. With a focus on politics, policy and the NDIS, the session will close the Symposium on a note of hope and determination, reminding us all why speaking up – and standing together – matters.
3:30 – 3:40pm	Closing
3:40pm	Afternoon tea

Shared experience. Real connection.