Bringing together Australian families’ experiences of FASD

Session E8
We would like to acknowledge that we are gathered today on the territory of the Musqueam, Squamish and Tsleil-Waututh peoples, as well as acknowledge the land from which we come, and its Indigenous elders, nations, people and cultures, whose land it was and will always be.

Acknowledgement of country
Disclosure

• No speakers have any conflicts of interest

• We do not have any affiliations (financial or otherwise) with a pharmaceutical, medical device or communications organization.

• We therefore have no biases.
Overview

This session presents Australian families’ experiences of FASD assessment, diagnosis and support by combining caregiver and support organisation perspectives with research from three of Australia’s specialist FASD diagnostic clinics.

We aim to illuminate pathways to better, FASD-informed service provision and caregiver support.
Learning objectives:

• To understand what parents want and need for their family members with FASD
• To identify ways to better incorporate patient experience in clinical FASD practice
  • To inform planning of FASD related diagnostic and support services
• To empower individuals, parents and families to continue engaging in research about living with FASD
Session Flow

Parent experience

Research into family experience

Family support in the digital age

Conversation
Connections & Intersections
Themes

• The impact of FASD on child quality of life and family functioning
• The importance of timing and quality of the diagnostic process and feedback to caregiver experience, including provision of information regarding a range of supports and health issues
• Limitations in and difficulties accessing health care services for children with FASD
• Caregiver engagement in and with FASD clinical service and research
Cheryl Dedman
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Conversations
Connections
Intersections
Thank you