

*conference keynote profile:*

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## **What led you to begin researching in this area?**

My interest in intellectual disability began when I was asked by the Queensland Department of Education to be part of the team set up to establish several early intervention services for children not yet of school age, who might be at risk of failure in the regular system. The majority of children who attended these services had a developmental disability, many with intellectual disability. Parents, almost always mothers, were central to the ways in which many of these services operated and so this experience was also the originating source of my interest in families of children with intellectual disability. My life as a researcher did not begin until a number of years after this initial experience; however, when I did return to study I chose to focus my research on children with Down syndrome and their families.

By great good luck, my first academic job was at the Fred and Eleanor Schonell Special Education Research Centre at the University of Queensland. One of the projects being carried out at the Schonell Centre was a longitudinal study of the development of children with Down syndrome. This program began by recruiting families when their child with Down syndrome had just been born and these individuals, many of who remain in the study, will be 40 years old in 2018. I became a member of the team with carriage of this project and this has remained central to my research over the years.

Longitudinal work is slow to produce results but is crucial to understanding how development proceeds and what influences developmental change(s). Recent analyses of the data from the Down syn-

drome longitudinal study have revealed important aspects of cognitive and language development in those with Down syndrome. While cognition and language development have been central to the ongoing project, the focus has always adapted to reflect the current issues facing the participants. We are currently engaged in a new tranche of data collection which is collecting information about mental health along with cognitive and language performance.

My research has included other investigations related to functioning of individuals with Down syndrome separate from the longitudinal study, family functioning when there is a family member with intellectual disability, and, most recently, aspirations for the future held by individuals with intellectual disability and their families.

## **What have been your highs in doing research?**

Relationships are at the core of successful longitudinal studies. While the originators of the Down syndrome longitudinal study cemented the relationships between the research team and the families who participated, I have benefitted from these initial bonds and have had the opportunity to also build important connections with a number of families.

Being a researcher is a role in which one is always learning and this is one of the aspects that I find most satisfying. In addition to the longitudinal research mentioned above I have conducted research on a number of topics that have been absorbing, including the impact of having a sibling with a disability on children, self-regulation and mastery motivation of children with Down syndrome, and parenting.

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## How does your research change practice and what needs to change?

Some research, while contributing to knowledge, does not immediately translate into practice or policy, and much of my research is focussed on understanding the developmental trajectories of important aspects of functioning. Understanding development is useful in itself, as is building a solid understanding of behavioural phenotypes even though knowledge of these things does not lead directly to practice implications.

## What does ASID need to do to facilitate the implementation of your findings?

The annual conference organised by ASID is a useful beginning to overcoming the gap between research and practice, as it is often attended by practitioners.

This may become less useful in the future unless the NDIA and service providers are able to agree on the importance of funding ongoing professional development for staff working in services for individuals with a disability. Another useful activity is the publication of the journal *Research and Practice in Intellectual and Developmental Disabilities (RAPIDD)*, a journal which has the specific intent of reporting research in a way that makes clear how findings might be translated into policy and practice.

Developing strong relationships with government and other organisations that provide information or take on advocacy roles should continue, with strong representation about the need for decisions to be made on the basis of evidence. This is a role that ASID should (and does) embrace. ●

The image is a screenshot of the ASID Facebook page. At the top, there is a dark blue navigation bar with the Facebook logo on the left and login fields for 'Email or Phone' and 'Password' on the right, along with a 'Log In' button and a 'Keep me logged in' checkbox. Below the navigation bar is a green banner with the text '6 GREAT REASONS TO JOIN ASID'. The banner contains six icons and their corresponding descriptions: 1. A globe icon for 'Strong and active local and national community'. 2. A group of people icon for 'Annual conferences featuring leading international speakers'. 3. A book icon for 'Regular journals, magazines and publications'. 4. A network of three nodes icon for 'Networks for pursuing areas of special interest'. 5. A globe icon for 'Workshops, seminars, conferences, seminars, workshops & social gatherings'. 6. A globe icon for 'ASID is on Facebook. To connect with ASID, sign up for Facebook today.' This last item includes 'Sign Up' and 'Log In' buttons. In the bottom left corner of the banner, the ASID logo is displayed with the tagline 'research to practice' and the text 'ASID Non-Profit Organization'.