



# SEEKING EXCELLENCE

45th ASSID AUSTRALASIAN CONFERENCE  
Hilton Brisbane, Queensland

Email: [assid2010@optusnet.com.au](mailto:assid2010@optusnet.com.au) Phone: 07 3163 2496 Fax: 07 3163 2445

## Key Note Speaker Abstracts

*Professor  
Chris Oliver*

**Cerebra Centre for  
Neurodevelopmental  
Disorders, University  
of Birmingham**

### Lessons from the Genes for Person-Environment Fit

The evolution of the research literature on behavioural phenotypes is characterised by increasing refinement of experimental design and method and the emergence of explicit gene-brain-cognition-behaviour-environment pathways. A developmental perspective has added another dimension to these pathways and, in combination with careful characterisation of the cognitive, emotional and behavioural outcomes, is likely to lead to an appraisal of the value of existing taxonomies. The problems experienced by people with intellectual disability caused by specific genetic disorders may differ from those evident in traditional symptom clusters and have different developmental trajectories. Research on these two facets of behavioural phenotypes has the merit of testing the utility of standard taxonomies for behavioural difference and disorder across the lifespan.

The challenge for researchers and practitioners is to translate the results of research in this area into effective and valued intervention and support. There are clear implications for services at the level of syndromes but there are also broader implications for all people with intellectual disability that can be derived from making the developmental gene-brain-cognition-behaviour-environment pathways explicit. These implications are described with reference to the physical and psychological characteristics and behavioural outcomes for people who have specific genetic disorders as a cause of intellectual disability and the environments they experience.

*Dr Jennifer  
Zarcone*

**University of  
Rochester, Rochester,  
United States**

### A Model for Training Effective PBS Practices in School and Service Settings

Training teaching teams or professionals to implement Positive Behaviour Support (PBS) for individuals with challenging behaviours can be a struggle. The first step is to provide information on the principles supporting the PBS approach. Then trainees are taught about the use of different tools and assessments. Finally, the training program must determine the trainee's competencies in implementing the approach. In this presentation, I will be describing the model developed by the Kansas Institute for Positive Behavior Support (KIPBS) at the University of Kansas to train professionals in the fields of intellectual disabilities, mental health, and child welfare to become independent PBS providers recognized by the state. Through this year-long training process, the Institute creates a unified network of professionals across the state that use systems change strategies to embed PBS processes into their organizations and who are now able to collaborate across a variety of organizations.

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*Professor  
Deb Keen*

**Associate Dean  
Research  
Australian Catholic  
University**

## It May be Interesting but Will it Help Me Learn? Identifying and Using Child Preferences to Enhance Engagement

There is strong evidence to show that engagement with the environment leads to better educational outcomes for children with developmental disabilities. Identifying and using objects and activities that gain and maintain the interest of children in order to increase engagement with the environment has been common practice for some time, particularly during educational instruction. Techniques for conducting preference assessments to identify these objects and activities have been investigated in the research literature. There is also a body of research that has considered how these objects can be used to increase engagement, decrease challenging behaviour and enhance learning outcomes. Typically, preferred objects and activities are used as reinforcers for appropriate or desired behaviour but they may also be embedded within an instructional context as teaching materials. In reviewing this literature, it is clear that many questions are yet to be answered if we are to utilise this technology to its greatest effect for children with autism. In this paper and with reference to my own research, I will review the literature, provide recommendations for practice based on this review, and highlight areas in need of further investigation.

*Clinical Assoc  
Prof Helen  
Leonard*

**Telethon Institute for  
Child Health  
Research, Perth**

## Using Epidemiology to Understand the Determinants of Intellectual Disability Disorders and Outcomes for Children and Their Families

In this presentation I will describe the infrastructure of a number of state, national and international data collections relating to intellectual disability in general as well as to specific disorders like Down syndrome and Rett syndrome as managed by our group at the Telethon Institute for Child Health Research in Western Australia. I shall cover three major areas of research: basic descriptive epidemiology –leading on to cause and prevention; natural history and how people are being affected over time especially in relation to their health; and finally the impact of the disorder on the person, their family and the community.

I shall provide some examples of the physical and medical problems associated with specific disorders and how they may be changing over time; describe the hospitalization experience of children with intellectual disability; provide some information on life expectancy in specific disorders; and finally demonstrate some ways in which we are trying to improve health outcomes for this population.

The third component of my presentation will look more broadly at the impact of having an intellectual disability or a specific disorder on the person, their family and the wider community. This will include presentation of data regarding the impact on their own health for mothers of children with Rett syndrome and Down syndrome and the economic costs for families. Finally I will mention the currently in-progress national transition study which aims to determine the experiences of young people with an intellectual disability moving from school to adult life and, determine what is a 'good' outcome for the individual and family. The underlying goal of our research is to maximise all aspects of quality of life for the affected individual and their family. For this to occur, it requires a supportive environment, optimal medical and therapy

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*Dianne  
Pendergast*

**Australian  
Guardianship and  
Administration  
Council**

interventions and close attention to the health and functioning of the whole family.  
**Alice and the Mad Liberian: Reflections of the Adult Guardian upon the Experience of Intellectual Disability in Queensland**

Dianne Pendergast was appointed as the Adult Guardian in Queensland in April 2006 with no previous experience working with adults with an intellectual disability. The Adult Guardian is appointed to make decisions for adults who do not have capacity to make their own decisions. Overwhelmingly those appointments are for young men with intellectual disability. What is it about our system that produces a result not seen in the rest of Australia?

Guardians follow the people they work with into hospitals, into mental health wards, into disability support services, into behavioural management, and into courts, and advocate and make decisions in the context of those systems. Dianne regards her own experience working within these systems as a time of significant personal growth and reflection, from Alice as she descended into this Wonderland, to the occasionally mad Liberian. This keynote address will explore that experience and ask how this impacts upon the pursuit of excellence for those with intellectual disability.

*Senator  
Sue Boyce*

**Senator For  
Queensland**

## From Parent to Senator

Parents of children with a disability almost immediately and intuitively become advocates for their own children. Parents follow various paths, based on their experiences, towards recognition of more formal advocacy and the development of formal advocacy skills. This paper presents the advocacy journey of Senator Sue Boyce, from mother to politician, within the framework of disability policy development and the maturation of the lobbying industry in Australia.

Senator Boyce reviews the history of political lobbying around disability issues in Australia, the continuing dominance of the Medical Model of disability in political discourse, and the effects on policy making and legislative decisions. Senator Boyce discusses examples of successful and unsuccessful political campaigns around disability. Finally, she examines the waxing and waning of political parties with a disability focus within Australia and the potential effect on the upcoming election.

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