

# Developmental Disabilities, Challenging Behaviour and Mental Health: Research to Practice and Policy – Conference Review

Rowan Keighran  
Psychiatry Fellow  
*Intellectual Disability and Mental Health*

The *Developmental Disabilities, Challenging Behaviour and Mental Health: Research to Practice and Policy* conference was held at the Footbridge Theatre at the University of Sydney on 7/11/2014. There was an enthusiastic turnout representing the full gamut of the Intellectual Disability (ID) workforce. The topics were diverse and catered to medical professionals as well as those working in allied and non-clinical roles. This was the third annual one day conference on challenging behaviour with a great line up of speakers.

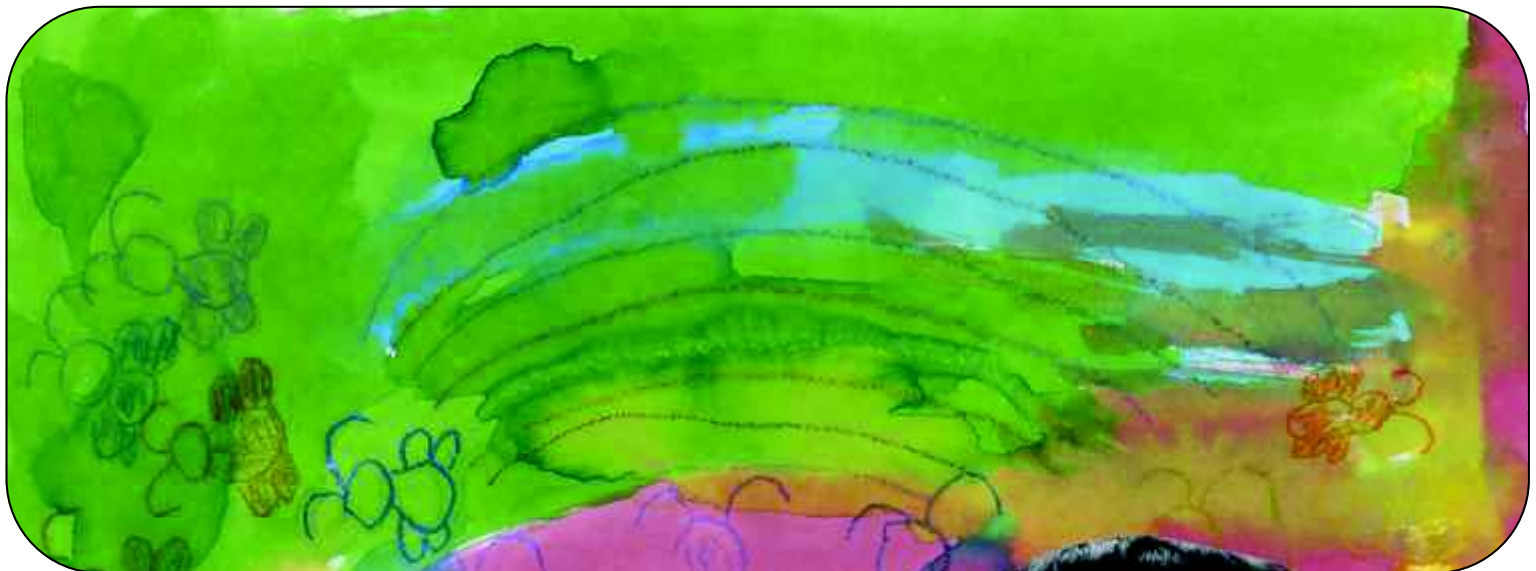
The day's events were divided into four sessions, each with a distinctive theme related to ID: (1) population perspectives, (2) brain functioning in developmental disability, (3) interventions for challenging behaviours, and (4) advancing policy.

## 1: Population perspectives

Eric Emerson began with '**Challenging behaviour: A community issue**'. The talk grappled with the definition of what 'challenging behaviour' actually is and also what it is not: it is not an illness or health condition but rather something of a 'catch-all' term. In this regard, the exact prevalence of challenging behaviour in the community depends on where one draws the line. It is believed that around 10% of children with an ID and 5-15% of adults with an ID who use or who are known to services have challenging behaviour. However, there is an unknown 'hidden majority' of adults with mild ID who do not use or who are not known to services. Some groups are more vulnerable than others: people with certain specific syndromes associated with ID

(such as Autism), people with more restricted opportunities to control their environment, and children in families exposed to environmental adversity (such as poverty). Addressing challenging behaviour is a matter of social justice but also a significant clinical issue and it was suggested that the way we approach challenging behaviour might be a good litmus test of our services.

Kerim Munir discussed '**Autism in human populations**' which began with an overview of the development of the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) in its approach to Autism and the new term of Autism Spectrum Disorders (ASD). This provided space for historical reflection and it was noted that the first edition of the DSM had no description for Autism or even Pervasive Developmental Disorder; rather, 'Schizophrenic Reaction (childhood type)' was the closest diagnosis. In fact ASD is currently viewed as a set of complex neurodevelopmental health conditions that vary enormously in their presentation from severely impaired individuals at one end of the spectrum to verbally fluent and academically gifted individuals at the other. However, there are difficulties in trying to encapsulate this in the current classification system and the much broader 'Autism phenotype' has not been included in the DSM-5 despite growing evidence on its existence and relevance. The comment was made that the new diagnosis of 'Social Communication Disorder' does not adequately capture this. Mention was made of the Autism and Developmental Disability Monitoring Network (ADDMN) and the current prevalence rates for ASD of 1 in 42 boys and 1 in 189 girls. However, there is clearly a need for



more prospective representative epidemiological studies.

To conclude the first session, Pat Howlin provided a brief overview of the new book *Communication in Autism* which is edited by Joanne Arciuli and Jon Brock. The book appears to be a sophisticated tome discussing this highly variable domain in ASD.

## 2: Brain functioning in developmental disability

Michael Brammer began this session with '**Developments in brain imaging in developmental disabilities**'. This was a medically oriented presentation which evaluated traditional ('univariate') versus more modern ('multivariate') approaches to neuroimaging in ID. In essence, the traditional voxel-based approach has remained the standard to date and more than 95% of the literature refers to this method of imaging. Data is generally easier to understand but the clinical usefulness is debatable. For example, despite having access to univariate modalities such as fMRI for many years, it is rarely used in a day-to-day clinical context. The more modern approach tends to view the brain as a whole and may be able to provide far more detailed information. This way of approaching neuroimaging has only been available for the last five to ten years and as a result researchers are much less familiar with it. 'Maps' of the brain can be created but are not easy to produce and localisation information may not be readily understood. The focus of such multivariate methods presently is on diagnosis: brain scans from a neurotypical group can be compared with a group of patients with ASD and a computer can be trained to separate the two groups and later to apply these learnt rules to other individuals in order to predict diagnosis. Such an approach has already been licensed for assisting in the recognition of Alzheimer's dementia in the USA where early small structural changes can be detected and processed. The method is being used in the diagnosis of Depression, Schizophrenia, Autism, and Attention Deficit Hyperactivity Disorder (ADHD) with a reported accuracy of 75-95% although it is still obviously in its infancy and is expensive. Some concluding cautionary remarks were made about possible ethical, insurance, and family issues associated with computer diagnoses as well as current limitations concerning specificity and sensitivity.

Roshel Lenroot presented on '**New treatment approaches for behavioural problems in developmental disabilities**' which began with a discussion on 'synaptopathies' (neuronal synapse abnormalities) and the imbalance between excitatory and inhibitory neuronal activity which is proposed to be at the core of developmental disabilities. Down syndrome was reviewed in this context where synaptic plasticity has been explored in animal models and potential treatment targets subsequently identified, including GABA<sub>A</sub> antagonists such as pentylentetrazole. This medication has a history of use in humans and is available as a cough syrup for children in Europe; however, its usefulness in Down syndrome is only just beginning to be explored with clinical trials underway across Australia. Fragile X syndrome was also reviewed in light of the possible benefits of GABA agonists such as arbaclofen and

acamprosate and mGluR5 negative modulators such as fenobam. Developments in the treatment of tuberous sclerosis have been marked and rapamycin (mTOR inhibitor) has had favourable results in humans. The 'Autisms' are also being increasingly explored and the above treatment pathways are being translated, although it remains difficult to account for the significant heterogeneity and pathophysiology associated with ASD. Timing of any intervention is an important consideration and it is generally thought that the earlier the treatment the better the outcome. However, neurodevelopmental disorders can become apparent at different ages and thus treatment effects may vary depending on the stage of development. This is interesting given that most current studies focus on adults and then attempt to translate the findings onto younger age group- trialing medications in children presents an ethically challenging hurdle. However, with the conceptual possibility of prenatal treatment for Autism on the therapeutic horizon, it is apparent that exciting progress is afoot.

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**“Parent-mediated treatment programs may improve outcomes for infants and toddlers at high risk of developing Autism...”**

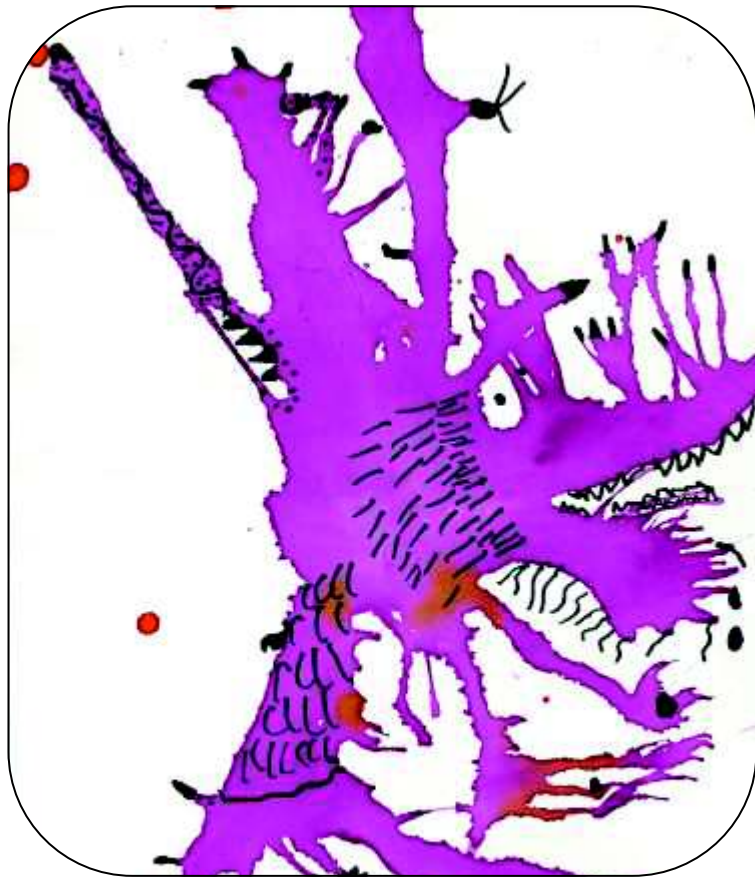
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Roger Stancliffe presented on '**Mental Health support for older people with developmental disabilities**' and reviewed some of the experiences of adults with ID. These included the high rates of depression, loneliness, and adverse life events as well as low levels of employment and participation in domestic and community activities. Observational studies have found that 33-42% of residents in group homes have very low average levels of participation which is vastly atypical compared to the general population where 99% of adults spend their waking time engaged in activities. Low participation levels have been correlated with poorer physical and mental health. With this in mind, the *Active Support* interventional approach was explored. This aims to increase staff support, resident participation, and adaptive behaviour and decrease levels of depression, self-injury, stereotyped behaviour, and withdrawal. *Transition to Retirement* is a program which applies these concepts to mainstream communities and involves facilitating individuals to participate in the community group of their choice where they can receive support from volunteer mentors. In the program, mentors are trained to provide effective social support and ensure activities are available. The approach is very much person-centred and there is generally one person with a disability per group. Video clips were shown which followed an individual engaging in a group and demonstrated these principles well.

## 3: Interventions for challenging behaviours

Pat Howlin commenced the third session for the day with '**Effective interventions for Autism: what does the latest evidence show?**' This talk began by warning of internet-





promoted therapies that are often unsupported, expensive, and dangerous. The central theme of the talk was on psychosocial interventions for families with autistic children. The focus on the early years (one to six years) holds relevance given the plasticity in early brain development. Here the goal is to avoid the development of maladaptive behaviours (in parents and children) and set children off on more 'normal' trajectories. Preliminary evidence has suggested that parent-mediated treatment programs may improve outcomes for infants and toddlers at high risk of developing Autism. Specifically, early intensive behaviour intervention (EIBI) is an intensive strategy with moderate to large effect sizes in most. Behaviourally based training for parents varies in its results but can lead to significant improvements in parents' stress, mental health, knowledge of Autism, ability to carry out the program, perception of control, and quality of life.

James Harris's presentation on the '**DSM-5 and ICD for people with developmental disabilities**' provided an involved and informative overview of the DSM-5 categorisation of neurodevelopmental disorders and the co-occurrence of certain diagnoses, for instance ASD and ADHD. The current DSM criteria for ID (deficits in both intellectual and adaptive functioning with onset in the developmental period) were detailed, as were the inherent problems associated with trying to subcategorise these disorders meaningfully, given their profound heterogeneity. Another problem is the strict age limit definitions of the 'developmental period' given that the brain continues to mature well beyond the previously accepted and rather arbitrary 18-year-old cut-off. In ASD, the transition from three core criteria to two in moving from DSM-IV to DSM-5 was highlighted. Further, the recognition of Autism being a spectrum of disorders (in favour of

the older classification which attempted to segregate out Asperger disorder) is seen as an important step in improving the accessibility of services in the USA.

Stewart Einfeld concluded the session with '**Community-wide approaches to interventions for behavioural problems**'. This began with the statistic that children with an ID have a three- to four-fold increase in behavioural and emotional problems. The *Australian Child to Adult Developmental Study* found that only 10% of children with severe behavioural and emotional problems received expert help and most do not gain access to appropriate evidence-based treatment. The *Stepping Stones Triple P Program* was reviewed and there appears to be growing evidence for its efficacy. The creation of carer resources for seven specific behavioural phenotypes (Down syndrome, Fragile X syndrome, Foetal Alcohol Spectrum disorders, Williams syndrome, Prader-Willi syndrome, ASD, and Velo-cardio-facial syndrome) represents an impressive advance in the field.

#### 4: Advancing policy

Holly Proddis offered the final session with '**Supporting families affected by developmental disabilities**'. Holly spoke about the Luke Priddis Foundation, of which she is the Director and co-founder. The Foundation emphasises the importance of social support for families of children with ASD. This was quite a personal talk, as Holly's own son was diagnosed with ASD in childhood. Holly spoke of how the family struggled with limited information and support. Stories were shared about young people and their families who had attended the Foundation's various activities which provided an individualised context to people living with disabilities.

Julian Trollor prescribed '**The need for a national guide**' and provided an overview of the sociopolitical context of challenging behaviours, services, and supports as well as funding and policy considerations. Historically, a disconnect has existed between health and disabilities funding but ideally care will start to move towards more individualised, multi-disciplinary services which are not based on funding boundaries. The talk addressed progress with ID being incorporated into mental health policies in recent years, as well as the recognition of elevated rates of mental health problems in ID. However, the translation into practice is far from complete. The development of ID mental health educational resources and research at 3DN was outlined.

The day's events concluded with the NSW launch of *The Guide: Accessible Mental Health Services for People with an Intellectual Disability (A Guide for Providers)* which was very well-received by all. *The Guide* is a landmark document (available in print and online at [www.3dn.unsw.edu.au](http://www.3dn.unsw.edu.au)) which offers a framework for mental health professionals to improve the accessibility and quality of mental health care for people with an ID. Julian Trollor, Holly Priddis, and the NSW Mental Health Commissioner, Mr John Feneley, spoke at the launch which provided both an enjoyable and optimistic finale to the day.