

# 16<sup>th</sup> International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Conference

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Scotland is renowned for many things...tartan, kilts, bagpipes, whisky, a certain loch ness monster and now for me the 16<sup>th</sup> International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Conference. IASSID promotes worldwide research and exchange of information on intellectual disabilities, and is co-sponsor of the Journal of Intellectual Disability Research (JIDR). This international conference was held in Glasgow from 5<sup>th</sup> to 9<sup>th</sup> August 2019 where we were welcomed daily by friendly volunteers, many of whom had an intellectual disability, to usher the crowds to our destinations. I have reviewed a couple presentations of interest and found a trip to Scotland was important to learn more about research from abroad and in our own back yard here in Australia.

## **Adapted DBT for ASD Clients**

I attended a pre-conference workshop at the University of Glasgow called “*Adapted Dialectical Behaviour Therapy (DBT) Coping Skills Training for Clients with Autism Spectrum Disorder (ASD) presenting with Challenging or Offending Behaviours*”. The presenters were Joseph Sakdalan, Yvonne Maxwell, and Sabine Visser from Australia and New Zealand.

They presented that there is currently a limited evidence base for the use of DBT with clients who have ASD. The existing evidence is primarily for people with Borderline Personality Disorder (BPD). The presenters suggest that many features of BPD and ASD overlap, including; issues around emotion dysregulation; impulse control problems/emotional reactivity; cognitive rigidity; poor interpersonal skills and poor problem solving skills; poor coping skills; poor distress tolerance and self-harm behaviours and some problems with empathy. They also suggest that both groups have had extensive traumatic histories and had longstanding exposure to invalidating environments (i.e. being bullied, abused, or rejected for example) and may have biological predispositions to emotional dysregulation and impulsivity.

Core strategies in DBT include a balance between problem solving and validation. Their adapted DBT Coping Skills Training for ASD clients is largely based on Linehan's DBT Groups Skills Training Program.



*Glasgow University on a beautiful summer day*



*Kelvingrove Art Gallery and Museum with 22 galleries , Glasgow*



Their adaption uses simpler terms, more visual aids, repetition, and focuses more on the use of coping skills to manage emotional dysregulation and distress tolerance, as the authors suggest these are major contributors to their challenging/offending behaviours. Their program uses mindfulness training as adapted for clients with ASD to move into their 'wise mind' to modulate sensory input and to reduce mental overload.

This was an interesting presentation that illustrated the practicalities of adapting a more mainstream mental health intervention to the ASD client group. Obviously a greater amount of evidence is required however the authors should be commended for their innovative practice. If you would like to read more: Sakdalan, J. (2010). Pilot study on the use of DBT groups skills training with forensic clients with ID. *Journal of Applied Research in Intellectual Disabilities*, 23(5).

**Inclusive Special Education**

Professor Garry Hornby from the University of Plymouth in his controversial keynote on inclusive special education suggested that total inclusion without a specialised setting was not, in his view, favourable. He suggested that choice is paramount- but preferred a more balanced approach to inclusion somewhere in between full inclusion and segregated special education. I agreed with Hornby that a student's sense of belonging, whether in special or mainstream environment's is important. Hornby highlighted that schools

“Their adaption uses simpler terms, more visual aids, repetition, and focuses more on the use of coping skills to manage emotional dysregulation”

should be using strong evidence based practices, strategies and interventions (such as direct instruction, parental involvement, building teacher/student rapport, functional behaviour analysis, metacognitive strategies, cooperative learning and peer tutoring), and to avoid those that don't. Similar to what I hear in NSW, Hornby explained that having staff who are well trained and experienced in inclusive special education share their expertise in mainstream and special schools is critical. He shared a personal experience from a few decades ago where he taught in a special school in New Zealand to highlight that inclusive special education should develop independence, employment skills and successful inclusion in society after school.

**Anxiety and ASD & ID**

Caitlin Murray from the University of Warwick presented on anxiety in children with intellectual disability with and without autism. In their UK data research Murray et al reviewed 648 children with ID, 50% of whom al-



# “Poverty and parental mental health may play a more important role in child anxiety”

so had ASD from the Cerebra longitudinal study. Initial findings indicated that children with ID and ASD have greater anxiety symptoms compared to children with ID only, which is in line with other research in this area. What was most interesting however is their suggestion that poverty and parental mental health may play a more important role in child anxiety than either autism diagnosis or ID severity. Her study measured parental mental distress using Kessler 6, and 23.5 % of parents scored above clinical rates of distress. Murray concluded that this had significance for targeting interventions at children of parents with poor parental mental health. This presentation made me reflect on the importance of parenting programs such as Triple P Stepping Stones which in our own research here at CHW reduced stress in parents by up to 50% and how this could potentially have a flow on affect to childhood anxiety.

Adam et al from Griffith University reported on a longitudinal study using the Anxiety Scale for Children with

Autism Spectrum Disorders (ASC-ASD). They reported on data from Years 2–4 of a community sample of 92 children aged 9–12 years on the autism spectrum. Parents completed the ASC-ASD at each time point. High rates of anxiety were found, with 60–63% of parents rating their children within the clinical range over time. 77 participants had complete data sets over the 3 time points. At time 1 the mean age was 11 years with 11.6% of the sample meeting criteria for an anxiety diagnosis, and by time 3 when participants had a mean age of 13 years this had increased to 57.1%. This highlights the need for early intervention in the primary school years.

## Self-Report Measures

I was impressed with the quantity of presentations on self-report measures for people with an intellectual disability- including our own research from the Children’s Hospital at Westmead on the translation of the Swedish Wellbeing in Special Education Questionnaire that I presented on. McElroy from The University of Newcastle, UK, presented on the development of a self-report scale for adults with ASD and ID called The Anxiety Scale for Autism – Adults with Intellectual Disabilities (ASA-AID).

Adams et al from Griffith University presented their research on a qualitative anxiety self-report survey for children (6-13 years) with ASD across home, school, and community settings (N=78). Nearly all children (98.7%) reported experiencing anxiety in at least one



Opening welcome was held at the Glasgow Science Centre





*Scottish Bagpipe band at the conference centre*

setting, with 41.9% of children reporting they experienced anxiety across the three contexts. There was wide variability in children's descriptions of their signs of anxiety (39 categories) which were classified under eight broad areas. The proportion of children who reported having someone to seek out to help reduce their anxiety differed across home (87%), school (74%), and community (48%) settings.

#### **School Attendance in Children with ASD & ID**

In two separate presentations the school attendance of children in Australia with ASD (Gray et al) and those with ID (Hastings et al) were presented and I have compared the findings here. Both were presented from data collected from Victoria Australia, with data from parents of children with ASD coming from the MySay community survey (n= 308) and from parents of children with ID (N=636) and their teachers (N= 376). In the last 20 school days, students with ASD were reported as missing 1.84 days versus students with ID who were reported as missing on average 1.6 days. 40% of children with ASD and 28% of children with ID missed more than 2 days of school in the 4 week sample.

For children with ASD the four most common types of nonattendance reported by their parents and were sickness (60%), refusal (21%), being kept home (16%), and medical appointments (16%). A greater number of

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**“A greater number of days away from school were associated with anxiety ”**

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days away from school were associated with anxiety and higher rates of parent mental health burden. The three most types of non-attendance for children with ID as reported by teachers and parents were illness, appointment and parent withdrawal of the child from school. These data provide a useful insight into reasons behind non-attendance in schools.

#### **Free access to abstracts**

A full list of the conference abstracts are available <https://onlinelibrary.wiley.com/toc/13652788/2019/63/7> . The abstracts are grouped into various topics including: Autism Spectrum Disorders; Challenging Behaviour and Mental Health; Communication; Down Syndrome; Ethics; Families; Inclusive Education; Profound Intellectual and Multiple Disabilities and several others.

