



## Bringing developmental disability into focus.

by David Dossetor

The Australian Association of Developmental Disability Medicine (AADDM) was founded in 2002. In its first ten years, AADDM has had a significant leadership role in the betterment of the health and mental health of people with an intellectual disability.

The core of AADDM's work includes advocacy, research, education and service development at both national and state levels. The 2012, AADDM conference brought all this to the fore.

Although people who work in this area often feel (like their clients) that they are in an unheard minority, this 3 day conference held at University of NSW, brought together people with an intellectual disability, carers, advocates, academics, clinicians, managers, administrators and politicians from health, disability, Education, NGOs and government.

This generated an energy and an optimism that together we can change attitudes, understanding, access, knowledge, circumstances and outcomes, albeit through multifaceted incremental change.

Kevin Humphries, NSW Minister for Mental Health and Healthy Lifestyles opened the conference. He expects the NSW Mental Health Commission to be able to bring

a focus on the needs of people with mental health problems, including those with intellectual disability and those most vulnerable in the care systems such as those from the criminal justice system.

Andrew Constance NSW Minister for Aging Disability and Home Care, emphasised the coming of individualised packaging of funding, increasing the power of choice to the client and family over their priority of services.

Jane Halton, Secretary from the Department of Health and Aging, described the significance of the Health Care Agreement (HCA). The HCA committed the Federal Government to sharing the funding of the future expansion of health care services with the states. She also highlighted the importance of the interagency agreement for the collaboration between hospital based services and community based services such as Medicare Centrals.

Prof Tony Holland, at the inaugural Trevor Parmenter lecture, described the evolution in UK of the legal framework to enable people with disability to be supported to make their own decisions with sensitivity to the task and context, and a framework for protection through the development of Safeguard of Vulnerable Adults Boards. The UK reports on abuse, neglect and lack of access to health care led to the Mental Capacity Act of 2005 and a rights framework. Thus Prof. Holland contended, the recognition of rights of autonomy and a legal framework for this complex area has

done more in promoting the wellbeing of people with an intellectual disability than the more highly publicised advances of science.

Prof Eric Emerson, from comprehensive British birth cohort data, demonstrated the extent to which intellectual disability is associated with poverty, adverse life events, other adversities and poorer access to health care.

One example is marked increased rates of weekly bullying in school. These adverse environmental circumstances account for more than half of the variance in poor health, emotion and behaviour problems, obesity etc.

Improved access to health care such as annual checks can help, as can a range of prevention initiatives, including building resilience and changing social attitudes with inclusive approaches eg to employment. The Medicare Item for annual GP health check ups is one such success here in Australia.

Curiously the risk of persistent conduct disorder in those with Autistic Spectrum Disorder (ASD) was not related to these environmental drivers! Prof Bruce Tonge presented data from the Australian longitudinal data of those with ID, also illustrating that ASD has even higher rates of disturbance than ID alone, with a peak in problems in social relating and depression in ASD in adolescence, while hyperactivity declines over time in both groups. A mental health examination of a cohort with ID at 20 years found psychiatric disorder in 42% which was related to early childhood family environment, a range of adverse life events and a family history of depression (in those with depression).

In those with ASD evidence is mounting on the need for transition planning for secondary school or leaving school to reduce rates of disturbance.

Drs David Mowat, Caroline Ellaway and Tony Holland gave stimulating presentations on the future potential of new targeted treatments for Tuberous Sclerosis, Rett's Syndrome and Dementia in Downs, and how these conditions help us to understand the complexity of the genetic and metabolic pathways of the brain and their relationship to cognition and behaviour. Yet where is the specialist service capacity for each genetic phenotype, especially when they become adults?



Prof Les White presented on the NSW health initiatives over the last 7 years leading to the development of the Agency of Clinical Innovation Disability Network and the 3 pilot sites of specialist health services for ID. David Coyne from the Office of the Senior Practitioner of ADHC, NSW Family and Community Services reported on the initial experience of the Memorandum of Understanding between Mental Health and ADHC with encouraging signs of increased collaboration at a senior managerial level. This was supported by some joint clinical presentations at a local service level and the establishment of joint systems of data analysis. The presentation from SW Sydney illustrated how complex some of these cases are, but how collaboration over a few years can still reap good outcomes.

Maria Heaton, parent and co-chair of the ACI Disability Network Executive Committee gave a beautiful, illustrated presentation on how family compassion and love, and dogged persistence really gave her son Tristan a great quality of life, despite his rare severely disabling condition that included deafness, blindness and no verbal communication skills. This achievement has been in the face of inaccurate medical advice and pessimism and a lack of person centredness in disability service provision.

A presentation on medical education illustrated a similar point whereby a young person with a disability presented to medical students, not about her disability, but her pleasures and expectations in life. One medical student responded by say-

ing that her aims for fulfilment were the same as his; something no professional could teach!

Fiona McKenzie, the chair of the Council for Intellectual Disability, who has an intellectual disability (ID) gave a talk on how she goes about consulting on others' experience in order to speak up on behalf of people with ID and mental health problems.

Brian Smyth King, Head of Disability for the NSW Department of Education and Community, described the changing challenge of getting the special skills of managing complex disability into the classroom. Over time, increased educational demands on children has drawn attention to disability of different sorts eg ASD, yet more parents want their child to be appropriately educated in mainstream classrooms.

Prof Julian Trollor, the inaugural chair of Mental Health and Intellectual Disability at UNSW, described how the last 2 years working with people with intellectual disability, their carers and advocates had shaped his understanding of some of the components needed to improve the mental health of people with ID. This includes concerted changes in workforce and service development, policy, research and clinical processes. People with intellectual disability need to be specifically considered in every mental health strategy. A key component is education and attitudinal change to face the challenge to hear and understand the needs of those with disability: for doctors of all types, other

caring professions, including teachers, and indeed the wider community.

Perhaps with the web-based and videoconferencing learning it is becoming feasible to give access to the advancing knowledge and skills to meet the needs. Conversely the attitude and skill to relate to and engage with disadvantaged members on our community including the indigenous people, the homeless, those with mental health problems as well as those with intellectual disability is something anyone entrusted with authority should have and indeed should be expected as a right.

I cannot do justice to the 100 presentations over 3 days (including from our CHW school-link team), which for the curious is currently available on the website: <http://www.aaddm2012.com>. ●



The Reach Out Teachers Network is a free site, originally launched in 2007 in response to the growing need to support teachers to understand the mental health issues impacting on young people they were working with. The site was re-launched in 2010 with an expanded focus on delivering teachers more quality teaching resources for use in their work.

Our site provides educators with access to up-to-date information on a range of mental health issues that may affect the students they are working with as well as fact sheets and curriculum resources and lesson ideas on a wide range of issues that young people may experience that can impact on their health and wellbeing, including alcohol and drugs, sexuality, leaving home and cyberbullying.

The Reach Out Teachers Network is an accredited professional development provider and has developed and delivered a range of training sessions at schools and conferences throughout Australia. The Network has developed a series of self-paced online training modules that you can view any time, any place. Our site provides a place to explore ideas and opinions around youth mental health issues with other educators through our online blog. We are pleased to have guest bloggers joining the team from the education sector, mental health field, as well as young people.

Become a member now and stay up to date with all the new content, conversations and resources that are being developed. Not only can you stay up to date with the Teachers Network through the website, you can also follow us on Twitter and Facebook. By joining the network you will also receive the monthly eNewsletter - *HeadsUp*.

Visit <http://teachers.reachoutpro.com.au/> or contact [sarah@inspire.org.au](mailto:sarah@inspire.org.au) (National Manager Schools) for more information