

How to promote good health & optimise the healthcare of people with an intellectual disability

= Seminar report

by Hilary Johnson

ASIDVIC Member

This seminar was hosted by ASIDVIC in Melbourne on June 27th between 10-3pm. About 25 people attended from a range of areas including health professionals, students, family members and disability support workers. The speakers were experienced health professionals Professor Nick Lennox and Dr Jane Tracy. Professor Nick Lennox is the Director, University of Queensland's Centre for Intellectual & Developmental Disability based in the medical research institute at university of Queensland. He is also a fellow of ASID. He brought a range of skills to the seminar – those of researcher, educator, advocate and clinician. He has specialised in the health of adults with intellectual disability since 1992 and developed several interventions to improve the health of people with intellectual disability. They include the:

- CHAP (Comprehensive Health Assessment Program) health check
- Ask health diary
- First “whole of life” handbook on health for people with intellectual disability
- Online training for general practitioners & support workers
- 2016 Able X series of Massive Open Online Courses through Edx which focus on health and intellectual disability.

Dr Jane Tracy is the Director of the Centre for Developmental Disability Health, Monash Health and a medical practitioner who has worked for over 25 years with people with disabilities and their families. The CDDH works across the health and disability sectors to improve the healthcare of adults with intellectual disability through educational, clinical and service innovation activities. Jane brought her passion for health professional education, practical



Nick Lennox and Jane Tracy at the seminar

resources and her personal experience as a parent of adult son with intellectual and severe communication disability.

Nick opened the session by reminding us about the complexity of health and the many factors involved in being healthy. He cited a study with company directors that indicated they were healthier than their employees or managers, not simply due to economics but may also be due to having control. The issue of control is a taxing one in the health system as coordinated care for people with an intellectual disability often means involving a range of people and ensuring the person with an intellectual disability is as informed as possible and is supported to make decisions. Fortunately in Australia we have a good health care system, the third best system behind the UK and New Zealand. However people with a intellectual disability have a shorter life expectancy than the general population with people

continued page 10

... Seminar report

continued from page 9



with severe intellectual disability dying twenty years earlier. Between 16-40% of with a intellectual disability also have mental health issues. Unfortunately health promotion and disease prevention is lacking for this population. One example of this is screening for breast cancer. Women are identified to attend screening from the electoral role, however many women with an intellectual disability will not be on the role and may miss routine screening. Also some samples are tricky to organise (collecting faeces for a bowel screen) and people with an intellectual disability may find the reason for the test difficult to understand and so may not cooperate.

There is increased identification of health risks related to specific syndromes and a specific diagnoses may be very helpful in identifying health risks (e.g Down syndrome). There is also a high level of sensory issues with 50% of people having difficulties hearing and/or seeing. The main message of the day was the importance of continuity of care (for instance keeping the same GP) and ensuring people have a complete health story (e.g. updated health passport). It is important to have health care enablers who know the person well in place. Medical appointments should allow extra time; to provide a diagnoses and treatment plan (particularly if the patient has communication difficulties) and, to help medical professionals understand the supports they need to put into place to provide the same level of care that they would provide to people without an intellectual disability.

Jane provided various case studies that reinforced this message about continuity of care and the need for the GP to work like a detective. People tend to miss out on good care for the following reasons:

- Families do not know about the health assessment and case conferences which can be funded through Medicare
- They don't know about asking for a double appointment with GP remuneration
- Doctors don't know about the health assessment for people with and intellectual disability
- There may be limited physical access for an examination
- The person may have had previous negative experiences so reluctant to go
- Need for regular reviews (at least annual). This also assists the doctor to know how the person presents when s/he is well.

What to do

- Book a long appointment
- Take any medications currently in use
- Prioritise the appointment to be the best time for the person (avoid Monday and Fridays in GP practices)
- Organise a person who knows them well to accompany them

continued page 11

... Seminar report

continued from page 10



- Tell the GP in detail what observational changes you may have seen (if you nurture and inform your GP, you will get a better service)
- Provide communication information, for instance - how to ask yes/no questions and engage the person in the consultation. Model to the doctor how to communicate well
- Provide information if you have a rare syndrome
- Be prepared to ask questions of the GP
- Get health summary printed out from GP
- Use the Comprehensive Health Assessment Program (CHAP)

Additional reading

Newton, D. C., & McGillivray, J. A. (2017). Perspectives of carers of people with intellectual disability accessing general practice: "I'd travel to the ends of the earth for the right person". *Journal of Intellectual & Developmental Disability*, 1-9. doi:10.3109/13668250.2017.1310821. Access below:

[Perspectives of carers of people with intellectual disability accessing general practice: "I'd travel to the ends of the earth for the right person"](#)

Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in the middle: improving communication in primary health care consultations

with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 29(3), 211-225. doi:10.1080/13668250412331285163

Resources

www.cddh.monashhealth.org

<http://cddh-online.monash.org/> - online learning

- Free online resources for GPs, patients and carers
- Incl. Fact Sheets, booklets, Depression Checklist, online learning and much more information
- Telephone advice
- Clinical Assessments - reports with management recommendations.

Health Passport NZ:

www.hdc.org.nz/about-us/disability/health-passport/download-your-health-passport

Surrey Health Action:

<http://www.surreyhealthaction.org/a-to-z-of-health-information>

Easy Read Health Information:

www.easyhealth.org.uk

Nick's range of health resources and educational support

at <http://www.qcidd.com.au> ●