

Interview with Associate Professor Julian Trollor

*Chair, Intellectual Disability Mental Health
Head, Department of Developmental Disability Neuropsychiatry
Professor, School of Psychiatry
UNSW Medicine*



How did you become involved in intellectual disability psychiatry? And were there any key influences?

There were some key influences. A key opportunity came up in 2009 to pursue something I had always been passionate about. It was visionary that ADHC set aside funding for the new chair of intellectual disability mental health. When I saw that I was immediately interested in applying for that role because I could see that this was an area of quite substantial need and it provided a great sense of challenge to me. However, my interest goes back much further than taking on the role in 2009. I had some quite remarkable early mentors when I was training in psychiatry, in particular during my training in child and adolescent psychiatry I encour-

tered a senior and highly respected psychiatrist Dr Helen Molony.

At that stage Helen was partly funded by disability services to work in intellectual disability mental health seeing a broad range of clients. I sat in on some of her assessments and learnt a lot about assessing people with intellectual disability, adapting approaches and about working in a collaborative framework in a multidisciplinary team and indeed across service sector boundaries. She provided inspiration, so much so that some of the patients I saw with her as her trainee, I still see today.

After finishing psychiatric training I went straight into neuropsychiatry and trained in that specialty area. A core part of my work was seeing people with intellectual disability and complex neuropsychiatric disorders for evaluation in a tertiary setting. Some of those evaluations were inpatients and some were outpatients. That was a really significant experience that again reinforced the need for a very systematic approach for often very complex mental health and physical health problems. This background made me jump at the opportunity to contribute in the new role as Chair of Intellectual Disability Mental Health. Particularly as it was geared towards capacity building.

You hold the first formal chair of Intellectual Disability Psychiatry in Australia. What do you see as the role of the chair? How important are the developments in intellectual disability psychiatry for the welfare of people with intellectual disability?

The mental health needs of people with an intellectual disability are very significant and overall the burden of mental health problems are about 3-4 times of the general population. That tells us that really in order to uphold the basic human rights of a person with an intellectual disability it is very important that we address health and in particular mental health needs. In order to support a person or a population group to achieve a high standard of mental health and wellbeing, developments in this area are quite critical. Prior to taking on the role I now have, I am very much aware that there have been many initiatives and significant work in this area by others. Very broadly, I see the role of the chair as one of the national leadership of services, workforce and research initiatives in intellectual disability and mental health. This is divided into three main sections; ca-

capacity building, research and consultancy. For readers interested in the key projects we have in those areas, please refer to our website www.3dn.unsw.edu.au.

What are the main projects and research being undertaken with your team?

They fit into those three main areas of building capacity, research and consultancy. If I could take you through those current and future plans; firstly, in current projects for building capacity we have a very strong focus on intellectual disability mental health education. We completed staff surveys of confidence and learning needs with mental health staff in NSW. We have developed intellectual disability e-learning modules which keeps us very busy. We have conducted a local and then national audit of medical and nursing schools looking at intellectual disability health content with a view to developing minimum suggested content and a toolkit for curriculum enhancement in medical or nursing schools in Australia.

We have fostered the development of the workforce in various ways firstly by developing then launching the new national guide for mental health professionals in 2014. Also, more in the background we have had a collaborative role in a number of initiatives that others have led including the formation of a special interest group in the Royal Australian and New Zealand College of Psychiatry and including the development of some training initiatives for specialist training in this area. I have mentored each intellectual disability mental health fellow, have supervised many of them, and have assisted them in putting together a training experience so they can begin to contribute back to both the public and private mental health services. We are developing competencies for the public mental health workforce in intellectual disability mental health and we have assisted by consultation the development of some enhancements within the health setting.

In terms of research, current or completed has really been quite interesting. A lot of the research is centred on our surveys but there have been other initiatives. I have been privileged to be invited to collaborate with Professor Eileen Baldry and Associate Professor Leanne Dowse, Professor Patrick Dodson and others in a focus on Indigenous offenders with cognitive disorders including intellectual disability. The team has completed an ARC linkage grant and also conducted interviews with families and people with intellectual disability to understand their experience with the correctional system and the factors that have shaped those.

We have conducted a study that is still underway, of people with intellectual disability over the age of 40, trying to refine the approach to assessment and screening for cognitive decline for people with intellectual disability and to better understand the mental health needs as people age. This research also has a qualitative component where we interview professionals and carers who provide support for people with intellectual disability as they age to better understand gaps in service provision and how to address them.

I have also been involved in a lot of research in cognitive disorders in the general population including early onset

“In order to uphold the basic human rights of a person with an intellectual disability it is very important that we address health and in particular mental health needs...”

dementia. Also a study of both elderly twins and older people in the community in collaboration with the centre for healthy brain aging and the Dementia collaborative research centres. My main focus in these studies has been the cardiovascular metabolic inflammatory contributions to brain aging and also the relationship between health factors and brain imaging markers; particularly looking at longitudinal changes that we can see that occur in the brain that are linked to certain aspects of health.

We also have a research program that looks at Fragile X related disorders. Of particular interest to me are carriers of pre-mutation of the Fragile X gene. In collaboration with colleagues in Melbourne we have looked at males and females who are carriers of the pre-mutation to begin to understand the neuropsychiatric effects of this gene.

There is more research planned for the future.



I hope that our data-linkage work will be a real contributor to the sector in the future. We have managed to link for the first time in NSW the administrative datasets for disability, health, mental health and mortality so that we can see the health service characteristics of people with intellectual disability, the ambulatory mental health needs, the inpatient mental health needs, the emergency department presentations of people with intellectual disability and the reasons for their presentation, length of stay and the services that have been provided to those individual. We will also look at death rates and cause of death. This will certainly be a large part of our new research program in a NHMRC partnerships for the Better Health project grant that will run for the next four years.

In terms of consultancy we have been very active in legislative and policy reviews and made lots of submissions to both NSW and the Australian Government. We have reports to the National and NSW Mental Health Commission; making sure the needs for people with intellectual disability are considered within various documents. I have enjoyed having personal and written representation to Government.

I very much value my clinical work but regret I don't have the time for as much clinical work as previously. I currently run a tertiary clinic to support psychiatrists in their role as they assist people with intellectual disability and mental health. The clinic is available for referral of adults where the psychiatrist might wish for a second opinion or has a specific question about the diagnosis or the management of the person they are supporting.

The most exciting part of our capacity building work is the expansion of our IDMH eLearning with specialised modules and there are five new ones coming including the development of a carer module. Later we will develop a complete suite of modules for disability service workers.

The broadening of our work with data linkage and interrogation of access; barriers and enablers to access to services and our more strategic focus of developing a policy framework will ensure people with intellectual disability are better included in health services development.

Since the establishment of the Chair of Intellectual Disability Psychiatry, have we made any significant steps in this area of health?

Significant progress is really hard to quantify. What I have seen is a sector and a people who are working together in a really cohesive way to make a difference. It is a big task with lots of different components. I think there has been incremental progress. What we have seen at both a state and a national level is a recognition that this is a group with high mental health needs and inclusion of this group in policy and frameworks. This is beginning to happen partly because people are vigilant and are really motivated to respond to the consultation process for policies and frameworks.

Really pleasing is the development of the national guide which was released in 2014 This was created by a group of

“We have managed to link for the first time in NSW the administrative datasets for disability, health, mental health and mortality ...”

us, and provides a framework for mental health providers across all relevant jurisdictions whether it be primary care, private practice, public mental health space or specialist providers; there is something there for everyone.

We will capitalise in the next five years on the foundation that we have laid so far. As others do as well, as their work plans and research efforts mature we will see an acceleration of action in this space. For the moment though we have to be satisfied with incremental progress.

How much do you think the NDIS will change things for People with Intellectual/Developmental disability? Do you have concerns about the effects on the mental health needs of people with an intellectual disability?

The NDIS represents a significant change of service and funding model. It is something that has received great fanfare and acclaim as it has been introduced. There are really positive signs so far as the trial sites have done what they set out to do. There has been a high degree of satisfaction from people with intellectual disability other groups. It is not without teething problems but by and large it has been a positive introduction.

As the trial is rolled out and expanded and as the systems are rolled out as per the national plan I think there will be a remarkably transformed disability service sector. I will say that some aspects of the new system worry me; the issue around people with complex needs, for whom I think service provision is more complex. As service provision is shaped by market forces and there is obviously a dollar bottom line, I am concerned that people with complex needs who need extra levels of support may miss out. At the moment in NSW, some of those individuals are catered for by very highly skilled teams funded or heavily supported by the NSW Government (Aging, Disability and Home Care). My worry is that if we move to a less regulated market economy, the expertise and sharp focus on people with complex needs may be lost. I think there will be a lag before such capacity is developed in the private sector, and there will need to be a specific strategy that is developed to support its development and growth. I think people with intellectual disability and mental health fit within that more complex group and in particular some of those individuals have very high needs. We need to support the development of those capacities in the non-government sector and look for opportunities for NGO's to be taking the lead in service provision in those areas.

Do you have a vision of the future for Mental Health for peo-



ple with intellectual and developmental disabilities?

I think the primary vision is for the highest standard of health provision for people intellectual and developmental disabilities. The way we get there is by having a better understanding of the mental health needs, in children, adults and in older adults with intellectual and developmental disabilities. We need to have a very proactive approach to health care delivery and a proactive approach to prevention of mental health and health problems in this group. We need to see enhanced capacity developed in the mainstream so that mainstream health and mental health workforce feel equipped to provide a service. This needs to be backed up with specialist capacity so that mainstream mental health services are supported by specialists with high levels of expertise who can provide backup and consultation for those with more complex needs.

It is important that mental health workers in particular feel that people with mental health and intellectual disability are part of their core business. At the moment there is some distance from that but there is some increasing awareness of this group.

Some fun Questions:

What is your favourite book?

This is a difficult question for me as I don't sit long enough to read. I really prefer to be active. The inspirational book I would like to share is The Bible, that provides me with a backbone and underpinning that helps me understand life

and its purpose.

Some leisure reading I enjoy is an outdoor magazine called WILD. It allows me to remember some of the more extreme outdoor experiences I have had whether it be bushwalking, cross country skiing or canyoning.

A web-link you would like to share:

An interesting website is theconversation.com which is beginning to have a few articles on disability and intellectual disability. That would be another interesting one to look at.

What do you always take on holidays?

A sense of adventure.

Is there anything else you would like to add?

One of the joys and privileges in the last few years of work has been the tremendous support, encouragement and collaborative approach adopted by colleagues. I mean colleagues very broadly: academic colleagues, clinical colleagues, colleagues from the consumer and carers sector, colleagues from health administration and policy. It is wonderful to be part of that shared journey, and to strive together to improve the capacity of the health sector in this area. I think that the people that are working in this area are generally very passionate, knowledgeable and very open. That has been wonderful to witness, and I have certainly benefited greatly from that willingness to share and collaborate.