

# Services for adults with intellectual disability in Aotearoa New Zealand

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**Aotearoa New Zealand is a country of just under 5 million people with a diverse population, the main ethnic groups being of European descent and Maori. There are well-developed public and private healthcare systems. As in other countries, Aotearoa New Zealand has closed the large institutions and developed community-based services for people with intellectual disability. Aotearoa New Zealand has specific legislation for people with intellectual disability presenting to the criminal justice system and has unusually and explicitly excluded people with intellectual disability from mental health legislation since 1992. Partly as a result, most health professional training schemes have little focus on issues for people with intellectual and developmental disabilities. Therefore, one of the main challenges over the coming decade will be to ensure there is a sufficient workforce of psychiatrists and other professionals who have the training and expertise to work with people with intellectual disability requiring mental health and forensic services.**

## Healthcare in Aotearoa New Zealand

The current population of Aotearoa New Zealand is estimated to be just over 4.75 million, with a Human Development Index (HDI) in the very high range. The HDI is a composite statistic of life expectancy, education and per capita income reported by the United Nations. For 2017, New Zealand was ranked 16<sup>th</sup> and the UK 14<sup>th</sup>, with Norway first (United Nations Development Programme, 2018). The population is predominately bicultural; by ethnic group, 74% identify as being of European descent, and 14.9% as Maori. Other major ethnic groups include Asian (11.8%) and Pacific peoples (7.4%). Maori are the indigenous people of Aotearoa New Zealand, descended from the ocean-going navigators of Te Moana nui a Kiwa, the Pacific Ocean.

Aotearoa New Zealand has both a private and a public healthcare system, the latter of which is managed under the Ministry of Health. The government-funded public healthcare system works on a community-oriented model and includes District Health Boards that are funded by the government and are responsible for providing or funding health and disability services

in their district, including mental health and addiction services. Primary healthcare covers a broad range of out-of-hospital services, including first-level services such as general practice, mobile nursing and community health services.

## Services and policy for adults with intellectual disability

For over 40 years, many countries including Aotearoa New Zealand have implemented the closure of large hospitals and the development of community-based services for adults with intellectual disability. The past two decades have seen polices, mainly in more developed countries, that have encouraged choice and independence and improved access to services for people with intellectual disability (Tsakanikos & McCarthy, 2014).

Around the world, mortality and morbidity are reported to be higher in people with intellectual disability (O'Hara *et al*, 2010). There is no register or database of people with intellectual disability in Aotearoa New Zealand, so tracking increased mortality and morbidity is not routinely undertaken. Figures from a 2011 report led by the Ministry of Health found that life expectancy was significantly reduced in the three most recent years for which data were available, from 2006 to 2009 (Ministry of Health, 2011). The life expectancy for males with intellectual disability was 59.7 years, compared with 78.4 years for *all* New Zealand males – a difference of 18.7 years. The life expectancy for females with intellectual disability was 59.5 years, compared with 82.4 years for *all* New Zealand females – a difference of 22.9 years. The ethnicity of the person with intellectual disability may influence their experience of health services, as is seen in the wider population of Aotearoa New Zealand, for example, in the recognition of an autism spectrum disorder (ASD). Recent research also funded by the New Zealand Ministry of Health highlighted the influence of ethnicity on recognition and access to services of people with ASD, which commonly occurs with intellectual disability (Broadstock, 2018).

There is increasing recognition of the mental health needs of people with intellectual disability across Australasia (Trollor, 2014) and specifically in Aotearoa New Zealand as part of the national enquiry into Mental Health and Addiction Services. The New Zealand representation of the Section of Psychiatry of Intellectual & Developmental Disabilities in consultation with members of the Royal Australian and New

Zealand College of Psychiatrists from Australia have recently put forward a number of key recommendations to improve outcomes for people with intellectual disability and mental health needs (RANZCP, 2018). The recommendations are summarised below.

- Consideration of the mental health needs of adults with neurodevelopmental disabilities in relevant policy development and implementation.
- Review of training and support for all front-line health staff across all disciplines. It is critical to ensure that training in neurodevelopmental disorders is part of both undergraduate and postgraduate courses for all health disciplines.
- Development of clear clinical pathways with broader intake criteria in secondary mental health services for patients with neurodevelopmental disorders.
- Development of multidisciplinary specialist mental health teams, with the specific functions of managing the mental health needs of people with intellectual disability and autism who also present with comorbid mental illness.
- Development of centres of excellence in this area with strong links to academic institutions, leading to the expansion of leadership in regard to training and research.

Recent research looking at the mental health needs of those with neurodevelopmental disorders in Aotearoa New Zealand has highlighted the overlapping nature of these disorders, with levels of attention-deficit hyperactivity disorder increasing with severity of intellectual disability and ASD symptoms (Matthews *et al.*, 2018).

## Legislation

In Aotearoa New Zealand, prior to 1992, people with intellectual disability who presented to the criminal justice system with identified risks to self or others could be managed under mental health legislation. The Mental Health (Compulsory Assessment and Treatment) Act (MH (CAT) Act) 1992 intentionally excluded people who had an intellectual disability and no coexisting mental health problems. This created a legislative gap that significantly limited the options available to the courts for management of offenders with intellectual disability and further closed a civil entry for people with intellectual disability who might present with risk behaviours not necessarily escalating to the criminal justice system. The legal system was left with the options of sending people with intellectual disability to prison or leaving them in the community, or, in the case of a very high level of offending behaviour, such a patient could be admitted to a forensic hospital as a special patient. Once the patient no longer required management as a special patient, no legal framework existed to offer ongoing compulsory supervision in the community.

As a result of this gap in legislation, the Intellectual Disability (Compulsory Care and

Rehabilitation) Act (IDCCR Act) 2003 was enacted in 2004 (Ministry of Health, 2003). The IDCCR Act established a scheme which authorised the provisions of compulsory care and rehabilitation to individuals with an intellectual disability who had been charged with or convicted of an imprisonable offence. The Act created two categories of care recipient: special care recipients, who must always receive care and rehabilitation in a secure facility, invariably a hospital; and care recipients, who can receive care in a secure facility or in a supervised setting. The IDCCR Act created a variety of new roles and services. The earlier models envisaged a more seamless range of tailored services, from high-level secure care to supported independent living. There are currently four levels of secure care operating alongside community-based forensic teams: national secure hospital care, regional secure hospital care, community secure care, and community supervised care. The regional community forensic ID teams vary in their arrangements, but invariably have nursing, occupational therapy, psychology and psychiatry input. These teams focus on those under the IDCCR Act in the community, as well as those in transition from hospital to community care.

Currently, little is known about the effects of the IDCCR Act on outcomes for offenders with intellectual disability across Aotearoa New Zealand. Although there is routine screening for mental health issues for people remanded to prison, with a model of care that supports mental illness, no screening for intellectual or developmental disabilities occurs (Pillai *et al.*, 2016). Qualitative research has highlighted tensions between upholding the rights of people with intellectual disability who come to the attention of the criminal justice system and achieving access to safe and supportive services (Prebble *et al.*, 2013).

## Workforce and training

A key issue in developing specialist services is the availability of a workforce with sufficient expertise to deliver such services. Recent analysis of workforce data for New Zealand and Australia showed that there are up to 18 psychiatrists working in intellectual developmental disability mental health (IDDMH) services on the North Island and seven psychiatrists on the South Island (Cvejic *et al.*, 2018). Those who identified as IDDMH psychiatrists were more likely than the broader psychiatry workforce to be working across public and private health services and treating younger people. The authors highlighted the potential shortage of IDDMH psychiatrists in New Zealand and Australia, and the urgent need to develop a training programme in this specialty. There is no approved specialist training programme in the psychiatry of intellectual disability, although The Royal Australian and New Zealand College of Psychiatrists is currently developing a curriculum for a specialist training programme.

## Conclusion

At a national level, there are key recommendations addressing specifically the mental health needs of people with intellectual disability. A focus on workforce planning and training over the coming years will be important in ensuring a critical mass of expertise across professional groups, which must include psychiatry, psychology, nursing, occupational therapy, and speech and language therapy. Access to a data-set on mortality and morbidity would highlight the ongoing health needs of people with intellectual disability in Aotearoa New Zealand, including the influence of ethnicity. In addition, data on the effects of the IDCCR Act will be informative for Aotearoa New Zealand and other countries regarding how such specific legislation influences health and offender outcomes for people with intellectual disability. In this respect, Aotearoa New Zealand is leading the way, delivering specialist community-based forensic services for offenders with intellectual disability.

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