



National Centre of Excellence in Intellectual Disability Health

Submission on Draft National Roadmap to Improve the Health and Mental Health of Autistic People

Contact:

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Who we are

The National Centre of Excellence in Intellectual Disability Health ('the Centre') is an important initiative supported by the Australian Government Department of Health and Aged Care. The Centre is a consortium of nine organisations including UNSW Sydney, Centre for Disability Studies (University of Sydney), Council for Intellectual Disability, Down Syndrome Australia, First Peoples Disability Network, Mater Intellectual Disability and Autism Service, Queenslanders with Disability Network, University of Melbourne and Telethon Kids Institute. It also includes another 56 health and disability organisations as partners and collaborators.

The vision of the Centre is to ensure that the 500,000 people with intellectual disability in Australia receive the highest attainable level of healthcare.

The draft Roadmap and Autistic people with intellectual disability

We make the following overarching comments on the application of the draft Roadmap to Autistic people who have co-occurring intellectual disability, and its interaction with the National Roadmap for Improving the Health of People with Intellectual Disability 2021.

Prevalence of co-occurring autism and intellectual disability

Research indicates that approximately 35% of Autistic people also have an intellectual disability (Christensen et al, 2019). We note this is a sizeable proportion.

There are approximately 500,000 people with intellectual disability in Australia. Using the Autism Roadmap's quoted prevalence figures of 205,200 Autistic Australians in 2018, this means that about 15% of Australians with intellectual disability are also on the autism spectrum.

Increased health and support needs

Co-occurring intellectual disability would commonly lead to higher communication and other support needs compared with Autistic people without intellectual disability (McCarthy & Chaplin, 2022). Those Autistic people with co-occurring intellectual disability also have higher health needs than either Autistic people or people with intellectual disability alone, with a higher incidence of neurological conditions (including epilepsy) (Capal et al, 2024), higher rates of self-injurious behaviour and its sequelae (Summers et al, 2017) and higher rates of psychotropic prescribing (McCarthy and Chaplin, 2022).

Terminology

We note that in line with contemporary co-design principles, it is important that each Roadmap reflects the way in which each target group sees itself and the health care needs of its members. For example, in appropriate deference to the most common view in the Autistic community, the draft Autism Roadmap uses the expression “Autistic people”. This reflects a preference for identity first language and the use of a proper noun emphasises that being Autistic is a robust, shared and valued identity.

Equally appropriately, the intellectual disability Roadmap uses the expression “people with intellectual disability”. This emphasises the common desire in the intellectual disability community to emphasise that we are all people first and intellectual disability is but one of the characteristics that some members of society have. The use of lowercase in “intellectual disability” is also a reaction against the previous medical model in which there was emphasis on intellectual disability being a medical diagnosis.

Inclusion in Roadmap Development

Another important area of distinction is in co-design practises and approaches that are necessary to meaningfully involve Autistic people with co-occurring intellectual disability in Roadmap development and implementation. The design and support needed by people with intellectual disability to have a key role in co-design will vary markedly from the needs of Autistic people who do not have co-occurring intellectual disability. Focused means of inclusion of Autistic people with co-occurring intellectual disability in roadmap development are required to facilitate their meaningful engagement, involvement and contribution to this important initiative.

Roadmaps

There is already a 10-year [National Roadmap to Improve the Health of People with Intellectual Disability](#). The Roadmap was released in August 2021 and substantial actions have occurred and continue to occur towards its implementation.

It is very important to maintain separate focuses on the actions needed to improve the health of people with intellectual disability and the health of Autistic people and we support the development of two separate Roadmaps. Otherwise, the particular needs of each group are likely to be sacrificed in a homogenised approach. It is also important that the two Roadmaps complement each other and address the needs of Autistic people with co-occurring intellectual disability.

In view of the prevalence of co-occurring autism and intellectual disability, good practice in intellectual disability health will include a focus on the health care needs of people with co-occurring Autism.

A similar lens will need to be applied in the implementation of the Autism health Roadmap. In some issues, there is scope to consider both separately and together the health reforms needed by Autistic people and people with intellectual disability. An example is in detailing and funding adaptations and supports that are needed by people with disability in primary health and hospital settings (Recommendation 6.3.2 of the Disability Royal Commission). On the other hand, there are other issues where it is very important to separately accommodate the needs of both groups, for example in the development of multidisciplinary health teams and national centres of excellence.

Education and training

In relation to education and training of health students and professionals, there is now a capability framework that has been developed under the Intellectual Disability Health Roadmap through a careful co-design process. The National Centre of Excellence in Intellectual Disability Health is working with the Department of Health and Aged Care and others to pursue prompt implementation of this framework. We would support similar work occurring from the lens of Autistic people, and learnings from the initial implementation of the intellectual disability framework could valuably inform that work. However, the Centre would not support any delay to implementation of the existing Intellectual Disability Health Capability Framework while work is undertaken to develop a similar framework for the health of Autistic people.

Research

We note the dearth of research into the health needs of Autistic people with intellectual disability, especially in adulthood.

Recommendations

In reference to Autistic people with co-occurring intellectual disability, we recommend that:

1. Two separate Roadmaps are needed, one each for people with intellectual disability and Autistic people. However:
2. The population of Autistic people with co-occurring intellectual disability should be given greater consideration in the Autism Roadmap. This includes specific consideration of the increased health and support needs of Autistic people with co-occurring intellectual disability.
3. The ongoing implementation of the National Roadmap for Improving the Health of People with Intellectual Disability should include consideration of the needs of Autistic people with co-occurring intellectual disability.
4. We recommend research into health of Autistic people with co-occurring intellectual disability be identified as a priority.

References

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