

Queensland Centre of Excellence in Autism and Intellectual Disability Health

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

Who we are

The Queensland Centre of Excellence in Autism and Intellectual Disability Health (QCEAIDH, formerly Mater Intellectual Disability and Autism Service (MIDAS); Queensland Centre for Intellectual and Developmental Disability (QCIDD)) aims to improve the health and wellbeing of people with intellectual and developmental disability across the life span through clinic, research, and education.

QCEAIDH provides a [specialist outpatient service](#), located at Mater Hospital South Brisbane, for patients with diagnosed or suspected intellectual disability and/or autism and complex support needs that are referred by their GP, specialists or Queensland Mental Health Service for additional health assessment and advice. The outpatient clinic is also a teaching clinic, attended by student, trainees and qualified staff who want to improve their knowledge and skills in this area.

QCEAIDH is part of Mater Research Institute-University of Queensland and undertakes research to improve the health and wellbeing of people with intellectual disability and Autistic people. Our research embeds inclusive research principles of co-design in all research activities. We have a strong track record in this area with the research agenda spanning health services and clinical research. Our research includes clinical trials and projects that will require staff to be involved in data collection and analysis.

QCEAIDH delivers tailored education to support the current and emerging (i.e. undergraduate and postgraduate) health workforce to better respond to the health and mental health needs of people with an intellectual or developmental disability across the lifespan.

Feedback on draft Roadmap

The draft Roadmap outlines guiding principles and focus area we broadly support. We acknowledge the commitment to partnership and inclusion of Autistic people in this process. As this process moves forward, the input of Autistic people from priority groups including those with co-occurring intellectual disability and those with high or complex needs must continue to be a priority.

In preparing our feedback, we note the similarities and opportunities to work together with the National Roadmap for Improving the Health of People with Intellectual Disability. Given approximately 35% of Autistic people have a co-occurring intellectual disability,¹ this is an important initiative to learn from. While it is important to have two distinct Roadmaps, many of the initiatives have overlap or opportunities to work together to achieve change for people

¹. Maenner MJ, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ. 2021 Dec 3;70(11):1-16.

who experience overlapping barriers to health care. There are also opportunities to learn from the experience of implementing the National Roadmap for Improving the Health of People with Intellectual Disability, as it is several years ahead of the current draft Roadmap.

We have provided our feedback and recommendations below on the draft Roadmap. In considering our feedback we were conscious of how these actions would be disseminated and implemented in practice. We believe it is important to plan for this and, where possible, tie proposed actions into existing structures to ensure sustainability. It also demonstrates doing this work, and improving health outcomes for Autistic people, is everyone's responsibility.

Health literacy resources for Autistic people

We support the review, collation and development of health literacy resources for Autistic people and their supporters. To ensure Autistic people and their support can access this information, it will need to be in a central location and designed to meet the varied needs of the Autistic community (e.g., plain English, Easy English or video versions). Consideration must be given to resources which may need to be tailored based on different systems access states and territories and across different catchment areas for health and hospital services.

Recommendation: Develop a plan to disseminate and promote accessible health literacy resources to the Autistic people and their supporters.

Resources and training for health professionals

We support the proposed actions in relation to resources and training for health professionals. However, there is a risk only interested and engaged health professionals will seek out these resources and training opportunities. Therefore, the draft Roadmap must plan for how to reach health professionals who are not interested in engaging with these resources. One avenue may be to work with professional bodies, universities and health services to identify minimum mandatory requirements around autism health training. In doing so, it's important to ensure those who have a strong background in working with Autistic people have a place to engage in training applicable to their clinical practice.

Recommendation: Develop a plan to tailor and deliver resources and training to the interest level, experience and skill sets of health professionals.

Models of best practice

We support the recommended areas to develop best practice models. To ensure the success of these models, it is important to also include health professionals in the consultation, design and development of these models to ensure they will be implementable and used in practice. The need for resources or training on how to best use the models should be considered, so health professionals feel confident to follow best practice.

We propose two additional areas to develop best practice models:

Procedural sedation: some Autistic people, particularly those with complex needs, may need extra support or sedation to have investigations. The lack of a clear pathways and process for health services to follow, particularly in adult services, often means Autistic people are not able to have or are delayed in having preventative, routine or diagnostic investigations. This contributes to delayed diagnosis and treatment of health problems and therefore leads to poor health outcomes.

People who are house bound: Autistic people who are not able to leave their home and house bound require consideration in how to best support their health care. Someone might not be able to leave their home for numerous reasons including complex medical problems, unmet mobility needs, unmet support needs, complex behaviours or significant mental illness. Often home visits by a GP are very limited and there are no to limited other health services who can meet the needs of these individuals in this situation.

Recommendation: Involve health professionals in the development of best practice models and include best practice models about procedural sedation and people who are house bound.

Efforts to support GPs and primary care

We broadly support the proposed actions to support GPs and primary care. To ensure these are successful, GPs need to be appropriately remunerated for this work. For example, if a GP was to call the proposed hotline to a specialised health practitioner, remuneration for the GP for this will be needed. This could also include advice to routinely booking longer appointment times and funding for care coordination and case conferencing.

Recommendation: Review Medicare items to identify areas to appropriately remunerate GPs for the extra time to support Autistic patients including care conferencing.

Autism specific services

We fully support autism service navigators/liaison officers. Key to the success of these roles will be learning from other navigator or liaison programs such as those in Queensland and Victoria. Though these may not be specific to autism, the learnings from these other initiatives will be vital to ensuring the success of an autism navigator. For example, the role description and professional group to fill the positions will be need to carefully planned and have flexibility to meet different service needs.

In addition, we argue for the need to have specialised multi-disciplinary health and mental health services in each state and territory. Our service is an example of a service that is able to support people with highly complex health needs and provide assessment and management advice to the individual's health care team. It should be considered if autism could be added to the remit of existing intellectual disability specialised services to leverage existing structures and services. Such services must be co-designed with Autistic people.

Recommendation: Provide state-wide specialised multi-disciplinary health and mental health services in each state and territory.

Research priorities and funding

We support the proposed priority areas identified in the relevant proposed action, noting pain expression and pain assessment as particularly important. Funding for this research must be distributed across the lifespan and centre Autistic experiences and voices.

We propose four additional areas which require more research:

Psychotropic medications: central to the proposed action to co-develop practice guidance and education material on the use of psychotropic medicines, will be research to inform the guidance including around prescribing and prescribing practices.

Complementary and alternative medicines (CAMs): many Autistic people use CAMs but there is limited research on the use of CAMs leading to safety concerns. More research is needed to create health literacy resources so Autistic people can make informed decisions.

Eating disorders: Autistic people experience higher rates of eating disorders but clinical practice guidelines do not consider how the Autistic experience can impact treatment and support. More research is needed to understand how to best support Autistic people with eating disorders.

Prevalence and lived experience of Autistic people with co-occurring intellectual disability: given the major initiatives occurring in both autism and intellectual disability it is important to understand in the Australian context how many people have a diagnosis of both autism and intellectual disability and to understand their lived experience, particularly in relation to accessing health care.

Recommendation: Expand research priorities to include psychotropic medications, CAMs, eating disorders and the prevalence and lived experience of Autistic people with co-occurring intellectual disability.

Avenue for dissemination of resources

Many of the proposed actions relate to the collation and creation of resources. It is imperative these resources and training can be found at a central location.

Recommendation: Develop a central location to provide consistent, up-to-date health information for Autistic people, their supporters and health professionals.

Thank you for the opportunity to provide feedback. We look forward to seeing our feedback incorporated into the National Roadmap to Improve the Health and Mental Health of Autistic People.

Should you require any further information, please contact Katie Brooker at 07 3163 1983 or at k.brooker1@uq.edu.au



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