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National Roadmap to Improve the Health and Mental Health of Autistic People

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Via email: AutismRoadmapConsultation@health.gov.au

National Roadmap to Improve the Health and Mental Health of Autistic People

Thank you for the opportunity to provide feedback on the draft *National Roadmap to Improve the Health and Mental Health of Autistic People* (the Roadmap).

As the Public Advocate for Queensland, I undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making ability.¹

People with impaired decision-making ability are a broad and diverse group due to the range of conditions that may affect a person's decision-making ability. While not all people with Autism will experience impaired decision-making ability, some will; indeed, a dual diagnosis of Autism and intellectual disability is not uncommon.²

A Roadmap that addresses the issues faced by Autistic people in the health care system and details actions to improve health and mental health outcomes of Autistic people is a welcome initiative. I congratulate the Department on taking this important step towards improving the lives of people with Autism and their families.

I support the focus areas, outcomes and possible actions outlined in the draft Roadmap. I am particularly pleased to see recognition of the need for: improved data collection; building connections between health, mental health and other service sectors, including the NDIS; elimination of harmful restrictive practices; and supporting Autistic People to take part in their health and mental health care as equal partners.

I note that an issue recognised in the draft Roadmap is the intersection of Autism and intellectual disability.³ The unique needs of Autistic people who also have an intellectual disability which impacts on their decision-making ability, necessitates targeted measures to improve their life outcomes. I welcome the recognition of this in the draft Roadmap and look forward to further opportunities to contribute to this component.

In developing the final Roadmap, I would like to put forward the following for consideration.

Sexual and reproductive health

I congratulate the Department of Health and Aged Care (the Department) on recognising, at page 15 of the draft Roadmap, that Autistic people are less likely than others to receive basic reproductive and sexual health care. Unfortunately, there are prevailing misconceptions, prejudices, and

¹ *Guardianship and Administration Act 2000* (Qld) s 209.

² Inclusion Australia, "Engaging with autistic people with an intellectual disability to develop the National Autism Strategy: A report for the Department of Social Services", 2023, p. 3.

³ Department of Health and Aged Care, "National Roadmap to Improve the Health and Mental Health of Autistic People – Draft for consultation", 2024, p. 16.

stereotypes surrounding the sexual and reproductive rights of people with cognitive disability (including people with intellectual disability) that impede the provision of sexual and reproductive health services. There is a common assumption that people with intellectual disability don't or shouldn't have sex, or that they don't have diverse gender or sexual identities.⁴ There is also a prevailing myth that educating people with cognitive disability about sexuality will only make them want to have sex.⁵ These assumptions can lead to a lack of access to sexuality education and reproductive and sexual health care.

Where sexual and reproductive health information is made available to people with an intellectual disability, it is not always offered in flexible and accessible formats. The World Health Organisation (WHO) and the United Nations Population Fund (UNPF) have noted that sexual and reproductive health services are often inaccessible to people with disabilities for many reasons.⁶ Barriers to health services include:

- 'lack of physical access, including transportation and/or proximity to clinics and, within clinics, a lack of ramps, adapted examination tables';
- 'lack of information and communication materials (e.g. lack of materials in Braille, large print, simple language, and pictures; lack of sign language interpreters)';
- 'health-care providers' negative attitudes';
- 'providers' lack of knowledge and skills about persons with disabilities';
- 'lack of coordination among health care providers'; and
- 'lack of funding, including lack of health-care insurance'.⁷

I recommend that the Roadmap consider these barriers and prioritise the design of flexible and accessible sexual and reproductive health education programs that meet the specific needs of Autistic people.

Healthcare during pregnancy

Just as Autistic people are entitled to engage in sexual activity and access sexual and reproductive health information, women with Autism also have the right to have children and to be provided with appropriate healthcare during pregnancy.

However, research has indicated that women with disabilities, should they become pregnant, are less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services.⁸ They can be turned away from such services should they seek help, or chastised because they have decided to have a child.⁹

Studies have also indicated a lack of disability specific knowledge and awareness among healthcare professionals, with midwives reported to have insufficient training or time during appointments to provide adequate support to women with intellectual disability.¹⁰ Often community level midwifery staff will not see women with disabilities, arguing that their birthing process will need the help of a specialist or will require a caesarean section.¹¹

Women with disability have also reported experiencing discrimination in accessing assisted reproductive technologies (such as in-vitro fertilisation and assisted insemination).¹²

⁴ Playsafe NSW, *Fact sheet: Sexual health promotion with young people with disability*, 2023, p.1.

⁵ Family Planning NSW. *Love and Kisses: Taking action on the reproductive and sexual health and rights of people with disability*. Ashfield: Family Planning NSW, 2013.

⁶ World Health Organisation, *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*, 2009, p. 7.

⁷ *Ibid*

⁸ World Health Organisation, *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*, 2009, p.10.

⁹ World Health Organization, World Health Organisation, *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*, 2009, p. 10.

¹⁰ P Pérez-Curiel, E Vicente, M Lucía Morán, and L E Gómez, *The Right to Sexuality, Reproductive Health, and Found a Family for People with Intellectual Disability: A Systematic Review*, 2023, p. 18.

¹¹ World Health Organisation, *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*, 2009, p. 10.

¹² Women With Disabilities Australia, *Position Statement 2 – The Right to Decision-Making*, 2016, p. 10.

In an effort to address these oversights in the provision of care for women with Autism who may choose to have children, I recommend that the Roadmap prioritise the provision of accessible prenatal, labour and delivery and post-natal services to women with Autism.

Supported decision-making

I welcome the recognition throughout the Roadmap, specifically under focus areas A and B, of the importance of Autistic people being supported to make their own health decisions. Supported decision-making is a critical means by which to promote and safeguard the rights, interests and opportunities of Autistic people.

Incorporating supported decision-making throughout the Roadmap aligns with recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), which addressed the ways in which supported decision-making should be further entrenched in legislation, policy and practice to promote and protect the rights of people with a disability. The relevant recommendations range from the provision of information and education on supported decision-making to families of people with a disability,¹³ through to the creation of practice guidance for service providers,¹⁴ systemic advocacy,¹⁵ and several proposed legislative reforms.¹⁶

Including clear supported decision-making policy and practice reforms in the Roadmap would not only be consistent with formal recommendations from the Royal Commission; it would contribute to the 'uniformity and consistency in practice across states and territories' that was proposed by the Royal Commission in its final report.¹⁷

Mental health

I note on page 16 of the draft Roadmap that people with 'co-occurring intellectual, psychological, cognitive, physical or developmental health conditions' have been identified as a priority group for the purposes of the Roadmap. I welcome the recognition that people with Autism who have a dual diagnosis need more support or different adaptations in order to access services.

In 2022, I released a paper, *Better Pathways: Improving Queensland's delivery of acute mental health services*, which proposed several reform options to improve the acute mental health system. In this paper, I made 21 reform recommendations for consideration. I proposed the following at recommendation 12 in relation to people with a dual diagnosis:

'The Queensland Government should fund a specific service to provide assessment, treatment and care of patients with a dual disability (such as a mental illness and an intellectual disability, dementia or acquired brain injury). This service should:

- a. provide expert consultation services for the assessment and treatment of mental health patients with a dual disability;
- b. be accessible to mental health practitioners across all Hospital and Health Services, including in regional and remote areas; and,
- c. operate as a centre of excellence for people with a dual disability.¹⁸

This recommendation is consistent with recommendation 9(a) of the Queensland Parliament Mental Health Select Committee's report on its 'Inquiry into the opportunities to improve mental health outcomes for Queenslanders' (June 2022).

¹³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, "Executive Summary, Our vision for an inclusive Australia and Recommendations", 2023, recommendation 6.13, p. 222.

¹⁴ *Ibid*, recommendation 10.7, p. 288.

¹⁵ *Ibid*, recommendation 6.14, p. 222.

¹⁶ *Ibid*, recommendation 6.6, p. 217, and recommendation 10.6, p. 288.

¹⁷ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, "Executive Summary, Our vision for an inclusive Australia and Recommendations", 2023, p. 71.

¹⁸ Office of the Public Advocate, *Better Pathways: Improving Queensland's delivery of acute mental health services*, 2022, p. 4.

The Queensland government has subsequently committed to 'establishing a Centre for Excellence with state-wide capacity and networked to Hospital and Health Services to respond to the mental health needs of children and adults living with intellectual or developmental disability and their families and carers.'¹⁹

I encourage the Department to consider how the Roadmap might identify service improvements and linkages to improve the wellbeing of patients with a dual disability who require treatment for a mental health condition.

Restrictive practices

I congratulate the Department for including as a desired outcome in the Roadmap, the reduction of restrictive practices and the elimination of harmful restrictive practices.

In the *Better Pathways* paper mentioned above, I brought attention to the Substance Abuse and Mental Health Services Administration (SAMHSA) roadmap to seclusion and restraint free mental health services.²⁰ SAMHSA's roadmap outlines the following six core strategies:²¹

- 1) 'Leadership towards change' – outlining a philosophy of care that targets seclusion and restraint reductions;
- 2) 'Consumer roles in inpatient settings' – having an inclusive approach which involves consumers, carers and other advocates in seclusion and restraint reduction initiatives;
- 3) 'Using data to inform practice' – using data in an empirical, non-punitive way to review, analyse and monitor patterns of seclusion and restraint;
- 4) 'Workforce' – developing procedures, practices and education that promote mental health recovery;
- 5) 'Use of seclusion and restraint reduction tools' – using assessments and other resources to develop individual aggression prevention approaches; and,
- 6) 'Debriefing techniques' – analysing why seclusion and restraint events occurred and evaluating the impacts on individuals with lived experience, families and carers and service providers.

I urge the Department to consider these core strategies in developing the Roadmap as important steps towards the goal of reducing restrictive practices and eliminating harmful restrictive practices.

Discharge from health settings

As has been identified in the draft Roadmap, improved connectivity is required between health, mental health and other services sectors, including the NDIS.

Too often, a lack of co-operation and collaboration between Commonwealth and state services means that people with Autism remain in acute, sub-acute and rehabilitation health care environments (including authorised mental health units) as they are unable to access funding for the supports (eg. NDIS and aged care) they require to maintain their health and wellbeing. This can mean, for instance, that people are unable to access appropriate accommodation in the community, which could include residential aged care and social housing adapted to their needs.

There is a clear need for a collaborative approach to health care to ensure that people with Autism can be sustainably discharged from hospital and other health settings into community settings, without jeopardising their health and wellbeing.

¹⁹ Queensland Health, *Better Care Together: A plan for Queensland's state-funded mental health, alcohol and other drug services to 2027*, 2022 p. 29.

²⁰ Substance Abuse and Mental Health Services Administration, *Roadmap to Seclusion and Restraint Free Mental Health Services*, Rockville, 2005.

²¹ K. Huckshorn, *Reducing seclusion & restraint use in mental health settings: Core strategies for prevention*, *Journal of Psychosocial Nursing and Mental Health Services*, Vol.42, 2004, pp. 22-33.

Additional funding to achieve this goal is always welcome, however, this would need to be accompanied by increased coordination and collaboration between state and Commonwealth agencies, including hospital and health services, state and territory health departments, housing and community services, and state and territory guardianship and administration agencies.

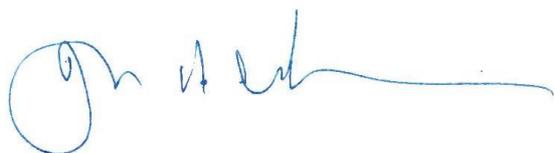
A potential action item for inclusion in the Roadmap may be the development or conversion of existing facilities to provide transitional accommodation for people in health settings who are finalising the details of their NDIS plan or waiting to enter residential aged care. This accommodation could also include rehabilitation and re-ablement services for those people who are not eligible to receive these services in hospital.

The provision of these services may assist people to transition from a hospital or mental health facility back into a residential setting, as well as building the self-confidence and strengths necessary to prevent re-admission to hospital.

In addition, the development or formalisation of discharge teams, consisting, where necessary, of representatives from health, housing, and community services, NDIS support coordinators and aged care finders, and nurse navigators, may also assist in addressing the interface issues and barriers that currently exist.

Thank you again for the opportunity to provide feedback on the draft National Roadmap to Improve the Health and Mental Health of People with Autism. I look forward to the release of the final Roadmap in due course. If you require clarification of any of the issues raised in this correspondence, please contact my office on 07 3738 9513.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'John Chesterman', with a long horizontal flourish extending to the right.

John Chesterman (Dr)
Public Advocate