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

September 2024

## About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 22,500 physicians and 9,600 trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties across 33 specialty areas including paediatrics and child health, adolescent and young adult medicine, rehabilitation medicine, occupation and environmental medicine, and public health medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients, the medical profession and the community.

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*We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.*

The Royal Australasian College of Physicians (RACP) appreciates the opportunity to provide feedback on the draft *National Roadmap to Improve the Health and Mental Health of Autistic People* (the Autism Roadmap).

Please note that as per the Autism Roadmap, use of identity-first language has been used throughout this submission. The RACP acknowledges that there is no single term to appropriately refer to individuals on the autism spectrum and that agency should be given to individuals to choose how they identify themselves. The RACP strongly suggests that community groups and organisations are consulted on, and given agency to determine, use of language within the Autism Roadmap.

## Key comments

The RACP welcomes the development of the Autism Roadmap to help advance the health and wellbeing outcomes of Autistic people and initiate a more coordinated, national approach to supporting the Autistic community across Australia. The RACP commends the commitment of the Australian Government to complete this work, as recommended by the Senate Select Committee on Autism.<sup>1</sup>

The RACP emphasises and celebrates diversity and inclusiveness in relation to support for individuals living with an autism diagnosis, and their families/carers. The RACP applauds the engagement with the Autistic community to co-design this work.

The RACP is committed to advocating for enhanced services, supports and life outcomes for Autistic children, adolescents and adults. As an organisation that draws on the professional experience of our physicians in a range of specialities, the RACP has concerns regarding existing levels of support and health care for Autistic people across all ages and social groups in Australia.

In 2022, it is estimated that 1 in 100 people in Australia were living with autism.<sup>2</sup> Autism is the collective term for a group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction, and by repetitive patterns of behaviour and restricted interests.<sup>3</sup> The behavioural features that characterise autism are often present before three years of age but may not become apparent until the school years or later in life.<sup>4</sup> The developmental challenges, signs and/or symptoms can vary widely in nature and severity between individuals, and in the same individual over time, and may be accompanied by mental and physical health problems.<sup>5</sup> Some individuals will go through life with very little support, while others will need a lifetime of care and support.<sup>6</sup>

Autistic people are more likely to experience a range of both physical and mental health conditions.<sup>7</sup> In Australia, Autistic people face significant challenges in accessing adequate health care and mental health services.<sup>8</sup> Barriers include a shortage of

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<sup>1</sup> Senate Select Committee on Autism Final Report: Services, support and life outcomes for autistic Australians (2022) [Services, support and life outcomes for autistic Australians – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Services-support-and-life-outcomes-for-autistic-Australians-Parliament-of-Australia)

<sup>2</sup> ABS. (2024). *Disability, Ageing and Carers, Australia: Summary of Findings, 2022*

<sup>3</sup> WHO. (2023). Autism. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

<sup>4</sup> AIHW. (2017). Autism in Australia. <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism>

<sup>5</sup> Hodges, H et al. (2020). Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. *Translational Pediatrics*. 9(Suppl 1):S55-S65. doi: [10.21037/tp.2019.09.09](https://doi.org/10.21037/tp.2019.09.09)

<sup>6</sup> WHO. (2023). Autism. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

<sup>7</sup> Mason, D et al. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord*. 49(8):3387-3400. doi: [10.1007/s10803-019-04049-2](https://doi.org/10.1007/s10803-019-04049-2).

<sup>8</sup> Adama, D., Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *J of Aut and Dev Disord*. 8(10). DOI:[10.1007/s40489-020-00226-7](https://doi.org/10.1007/s40489-020-00226-7)

specialised providers, long wait times, and fragmented services.<sup>9</sup> Despite growing awareness, current systems often fail to meet the unique needs of Autistic people.<sup>10</sup>

Improving health care and mental health services for autistic people is not only a necessity but an urgent priority. Autistic people often face unique challenges in accessing appropriate health care, including misdiagnosis, lack of autism-informed care, and inadequate mental health support.<sup>11</sup> By prioritising autism-affirming health care and mental health services, Autistic people will receive the tailored interventions they need, fostering long-term physical health, mental health and wellbeing, while promoting greater inclusion and equity in society.

## Specific RACP feedback on the draft National Roadmap to Improve the Health and Mental Health of Autistic People

The *National Roadmap to Improve the Health and Mental Health of Autistic People* is a significant initiative to guide the systemic change required to address the health disparities Autistic people face. While the Autism Roadmap is a promising start, RACP members have identified the following areas for improvement.

### Access to paediatric health care

Our RACP members have raised concern that the Autism Roadmap does not address access issues to paediatric health care, especially developmental diagnosis and assessment. Many children and young people are unable to access timely assessments, particularly in regional, rural and remote locations. Children and adolescents are often placed on long public waitlists, with some turned away when health care services lack capacity.<sup>12</sup>

There is a significant workforce shortage in Developmental Paediatrics. The reasons are many and complex, including the need to accommodate part-time work of physicians, inadequate Medicare items for complex assessments and follow-ups, and an insufficient number of training positions in this paediatric specialty area of Community Child Health. The RACP has been actively engaged in advocating for improvements in the overall training capacity and access within the healthcare system, particularly in relation to the current paediatrician shortages and long waiting lists for paediatric assessments. The RACP has provided submissions to jurisdiction inquiries around this issue, calling for investment in integrated models of care to address workforce issues.<sup>13</sup> <sup>14</sup> Given the impact delayed intervention can have on a child's life trajectory,<sup>15</sup> it is essential that barriers to timely assessment, appropriate health care and ongoing support and are acknowledged in the Autism Roadmap as crucial elements requiring action to address the serious health inequities faced by Autistic people.

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<sup>9</sup> Rasheed, Z. (2023). Autism in Australia: Understanding, challenges, and support. *Int J Health Sci.* 17(5):1-4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10484064/>

<sup>10</sup> [A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults - PubMed \(nih.gov\)](#)

<sup>11</sup> Camm-Crosbie, L. et al (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism.* 23(6):1431-1441. doi: [10.1177/1362361318816053](https://doi.org/10.1177/1362361318816053)

<sup>12</sup> Rymill, L. (2024, May 18). Families forced to wait up to three years to see paediatric specialists, or pay hefty costs for city appointments. *ABC News.* <https://www.abc.net.au/news/2024-05-18/paediatric-wait-lists-parents-pay-thousands-in-travel-regional/103830314>

<sup>13</sup> [RACP submission to the Western Australia Inquiry into the Child Development Services. \(May 2022\).](#)

<sup>14</sup> [RACP Submission to the NSW Inquiry into improving access to early childhood health and development checks. \(Mar 2024\)](#)

<sup>15</sup> Whitehouse, A. et al. (2021). Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis. *JAMA Paediatrics.* 175(11):e213298. doi:[10.1001/jamapediatrics.2021.3298](https://doi.org/10.1001/jamapediatrics.2021.3298)

## **Affirming health care**

Our RACP members note the need to embed autism-affirming and neurodiverse approaches in health care services, as well as trauma-informed care and culturally safe health care services. The wide range of co-occurring conditions that may present with autism pose a challenge for healthcare professionals to identify and manage underlying or emerging conditions, particularly mental health conditions in Autistic adults.<sup>16</sup> In the healthcare system, and particularly in hospital settings, there is a particular need for specialty teams with expertise in autism and neurodiversity more broadly, to ensure appropriate, comprehensive and timely care and access to support services.

In comparison, our RACP paediatricians report that while behavioural and emotional difficulties, often seen in neurodiverse children and are part of the broader aspect of mental health, these are frequently viewed as behavioural concerns. As a result, these children may be excluded from receiving appropriate mental health supports, since their behaviour is misinterpreted as something separate from their mental health needs.

Our RACP paediatricians report that this is especially the case for Autistic children and young people who are in crisis due to severe complex behavioural challenges, and whose acute health care needs are not met due to a lack of co-ordinated, specialist multidisciplinary healthcare services. This highlights the need for a more nuanced understanding of mental health in children with neurodiverse conditions like autism, as well as the need for specialist teams for acute presentation of complex co-occurring health conditions, to ensure children can access the appropriate services that address both behavioural and mental health challenges in an integrated manner.

While the Autism Roadmap aims to capture the health care and mental health needs of both children and adults, our RACP members have raised concerns that the broad approach fails to recognise the unique needs of the paediatric and adolescent population and in turn, fails to reflect the guiding principle of understanding and promoting the individualised and intersecting needs of Autistic people.

The synergy of health services tailored for people with autism fosters more inclusive, personalised care, ultimately benefiting the broader population by promoting accessibility, understanding, and comprehensive wellbeing for diverse needs.

It is essential that the Autism Roadmap addresses the nuances of affirming care and provides evidence-based solutions that address the unique needs of Autistic people, leading to more effective diagnosis, treatment, and support. Addressing this gap will ensure that healthcare services are inclusive, responsive, and tailored to the needs of Autistic people.

## **Systems-approach to integrated support**

The Senate Select Committee on Autism final report<sup>17</sup> highlighted the difficulty faced by Autistic people: that they and their families/carers are forced to navigate fragmented systems. Autistic people often require multiple supports across various sectors in an integrated manner. For instance, mental health issues can significantly impact their education and employment opportunities and outcomes. Without proper supports, Autistic people may face challenges in academic achievement, workplace integration, and social participation. An integrated approach that involves collaboration between health care, mental health services, education systems, and employment agencies is crucial.

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<sup>16</sup> Camm-Crosbie, L et al. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. 23(6): 1431-1441. doi: [10.1177/1362361318816053](https://doi.org/10.1177/1362361318816053)

<sup>17</sup> Senate Select Committee on Autism Final Report: Services, support and life outcomes for autistic Australian (2022) [Services, support and life outcomes for autistic Australians – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Services-support-and-life-outcomes-for-autistic-Australians)

Service integration is a systemic and organisational activity and a consequence of a well-designed system.<sup>18</sup> The development of the National Autism Strategy and the Autism Roadmap, by both the Department of Social Services and the Department of Health and Aged Care, presents respectively, opportunities and challenges. While the distinct focus areas of broader social inclusion and supports, and health and mental health care for Autistic people may allow for more specialised approaches, the separation of these efforts may reinforce existing gaps in coordination and holistic care for Autistic people.

The RACP welcomes the development of the Autism Roadmap and the National Autism Strategy, however a unified and coordinated approach is needed to address the fragmented systems that act in silo, resulting in delayed supports, gaps in care and poorer health outcomes.<sup>19</sup>

### **Inclusive education**

Our RACP members have raised concerns that the importance of inclusive education settings is notably absent within the Autism Roadmap. Early childhood education and care (ECEC) settings provide a critical foundation for children's development, offering opportunities to build social, emotional, and cognitive skills in a child's formative years. These early years of life are the time when investment into prevention and early intervention is most effective and cost-effective.<sup>20</sup> For Autistic children, inclusive quality early childhood environments are essential for ensuring equitable access to learning, development and support.

An estimated 4% of children in schools aged 7-14 years have a primary diagnosis of autism.<sup>21</sup> Without a strong commitment to funding and making ECEC and primary school more inclusive, Autistic children may be denied the same opportunities to thrive as their peers. It is vital that there are dedicated funding and policy commitments to ensure ECEC and the education system is accessible, inclusive, and tailored to the needs of all children, so that no child is left behind.

### **Involvement with child protection and youth justice settings**

RACP members note that while the Autism Roadmap includes children in out-of-home care as a priority population under *People in residential settings* (p16), it fails to capture children and young people who may interact with care and protection services. This includes those receiving services at home, or in the care of family or guardians, or those in kinship or foster care. As highlighted in the RACP *Health Care of Children in Care and Protection Services* position statement,<sup>22</sup> children in, or involved with, care and protection services are more likely to have chronic health problems, poorer physical, mental and developmental health outcomes, and increased health needs compared with the general population.<sup>23</sup> This is in large part due to the adverse effect of neglect, alcohol and substance abuse, family violence and other forms of abuse on neurodevelopment.<sup>24</sup>

The Autism Roadmap must acknowledge both children in out-of-home care, as well as those involved with care and protection services, as priority populations. Additionally, one of our RACP members has suggested that under *Autistic people in correctional*

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<sup>18</sup> Trankle, S et al. (2019). Integrating health care in Australia: a qualitative evaluation. *BMC Health Services Research*. 19(954). <https://doi.org/10.1186/s12913-019-4780-z>

<sup>19</sup> Trankle, S et al. (2019). Integrating health care in Australia: a qualitative evaluation. *BMC Health Services Research*. 19(954). <https://doi.org/10.1186/s12913-019-4780-z>

<sup>20</sup> Heckman, J. (2023). Invest in Early Childhood Development: Reduce Deficits, Strengthen the Economy. <https://www.heckmanequation.org>

<sup>21</sup> ACARA. (2023). School student with Disability. <https://www.acara.edu.au/reporting/national-report-on-schooling-in-australia/school-students-with-disability>

<sup>22</sup> RACP Health Care of Children in Care and Protection Services position statement. (2023).

<sup>23</sup> RACP Health Care of Children in Care and Protection Services position statement. (2023).

<sup>24</sup> Teicher MH, Samson JA, Anderson CM, Ohashi K. The effects of childhood maltreatment on brain structure, function and connectivity. *Nature Reviews Neuroscience*. 2016; 17:652- 666

*settings* (p16), the Autism Roadmap must address the issue that children and young people in the youth/juvenile justice system are often unable to access wraparound developmental care to meet their functional needs and lose their NDIS funding while incarcerated.

## **Implementation**

Although the Autism Roadmap lays out the issues and goals well, there is a need for more specific detail about how these goals will be operationalised. As suggested in our RACP submissions to the draft National Autism Strategy<sup>25</sup> and the preceding discussion paper,<sup>26</sup> measurable targets and outcomes that focus on improving life outcomes for Autistic people must be developed.

The Autism Roadmap and any subsequent implementation plan must clearly define the roles and responsibilities of stakeholders involved in activities. The RACP acknowledges that while the Autism Roadmap is an initiative of the Federal Government, many of the goals and actions outlined would fall under the responsibility of State and Territory Governments. To ensure a nationally consistent approach to achieving improved health outcomes for all Autistic people in Australia, collaboration and engagement among all levels of government, ideally at a national cabinet level, would be required for the successful implementation of the Autism Roadmap.

## **Closing remarks**

The RACP supports the range of possible actions within the Autism Roadmap and acknowledges significant work will be required to achieve them. The RACP would welcome the opportunity to work with the Department of Health and Aged Care and other stakeholders to ensure successful delivery of this important work.

The RACP eagerly awaits the publication of the *National Roadmap to Improve the Health and Mental Health of Autistic People* later this year.

Should you require further information or wish to engage with the RACP and our experts, please contact Priscilla Rodriguez, Policy and Advocacy Officer, via [policy@racp.edu.au](mailto:policy@racp.edu.au).

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<sup>25</sup> [RACP Submission to the draft National Autism Strategy \(2024\)](#)

<sup>26</sup> Department of Social Services. What we have heard: moving towards development of a National Autism Strategy – Discussion paper. <https://engage.dss.gov.au/wp-content/uploads/2023/09/national-autism-strategydiscussionpaper2.pdf>