Queensland Family & Child Commission



Telephone:		
Reference:		

Amber Shuhyta
Assistant Secretary
Allied Health and Service Integration Branch Primary Care Division
Department of Health and Aged Care

Via email:		

Dear Ms Shuhyta

Thank you for the opportunity to review the *National Roadmap to Improve the Health and Mental Health of Autistic People* and to provide feedback on behalf of the Queensland Family and Child Commission (QFCC). The QFCC has provided submissions related to supporting individuals with autism to the *Senate Select Committee on Autism*, the *National Children's Mental Health and Wellbeing Strategy*, and the *Mental Health Select Committee inquiry into the opportunities to improve mental health outcomes for Queenslanders*.

The QFCC's role is to influence systemic change to improve the safety and wellbeing of children and young people by driving accountability, raising awareness, amplifying voices, and advocating for change. Our work is informed by our explicit commitments to Aboriginal and Torres Strait Islander children and their families, and to advancing the rights of all children. The QFCC values the perspectives of children, young people and individuals with lived experience and recognises the learnings these perspectives can provide for meaningful and impactful policy reform.

We commend the Department of Health and Aged Care in the commitment to improving the health and mental health outcomes of people with autism, including outcomes of children, young people and their families. In our submission to the Senate Select Committee on Autism in 2020, the QFCC called for the voices and experiences of autistic children and young people to be incorporated in the development of the National Autism Strategy (the Strategy). We highlighted the importance of including the views and experiences of children and young people throughout the development of the Strategy through appropriate activities, to embed an informed and durable policy reform to best meet the needs of children and young people.

³ QFCC (2022). Inquiry into the opportunities to improve mental health outcomes for Queenslanders: Submission. <u>QFCC – Final Submission</u>



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¹ QFCC (2020). The Senate Select Committee on Autism: Submission. QFCC - Final Submission.

² QFCC (2020). National Children's Mental Health and Wellbeing Strategy: Submission. <u>QFCC-Final Submission</u>

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability highlighted particularly that children with disability (including autism) experience disproportionately high levels of contact at earlier stages of the criminal justice process and are significantly over-represented in youth detention and out-of-home-care settings. ^{4,5} The true number of autistic children and young people in the criminal justice system ⁶ and out-of-home care ⁷ is unknown given the difficulties in accessing diagnostic assessments particularly for young people in detention settings ⁸ or in child protection placements. Additionally, many First Nations children and young people may be undiagnosed or misdiagnosed given the limitation of culturally adequate screening tools in many justice and out-of-home care settings. ⁹

According to our *Community Perceptions Survey 2023*, less than half (48.0%) of young people aged 18–24 years agreed that the views of children and young people are listened to and valued by the disability service system. ¹⁰ QFCC Youth Advocate, Gefion, published a blog on the QFCC website ^{11, 12} detailing their lived experience with autism including their experiences of navigating the diagnostic process, and the need "to include more neurodivergent youth in decision-making processes". The voices and experiences of these young people need to be heard as part of meaningful reform efforts.

As part of the community engagement activities undertaken to inform the National Roadmap, just two participants were aged under 25 years, representing less than two per cent of the total participant cohort. Considering that children and young people represent approximately 31 per cent of the Australian population, the QFCC highlights opportunity for greater meaningful engagement with children and young people with a lived experience of autism to ensure their needs and expectations are reflected in the National Roadmap. The QFCC urges the Department to undertake authentic engagement with children and young people with a lived experience of autism, to ensure their voices and perspectives shape the Roadmap, and further work undertaken by the Department.

In the 2020 submission to the Senate Select Committee the QFCC called for the needs of Australian children and young people living with autism, particularly those experiencing intersectionality, to be recognised as part of the National Autism Strategy (the Strategy). The

¹² Gefion (n.d.) Amplify Blog - The Mental Health Maze. <u>Gefion - Blog Post</u>



⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). Final Report - Volume 8, Criminal justice and people with disability. <u>Disability Royal Commission - Final Report - Volume 8</u>.

⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). Final Report - Volume 8, Criminal justice and people with disability. <u>Disability Royal Commission - Final Report - Volume 8</u>.

⁶ Ringland, C., Boiteux, S. & Poynton, S. (2023). People with disability and offending in NSW: Results from the National Disability Data Asset pilot. Full Report.

⁷ Australian Institute of Health and Welfare (2022). Child protection Australia 2020–21. AIHW – Report and Summary

⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2022). Conditions in detention for people with disability in the criminal justice system. <u>Submissions of Counsel Assisting – Public Hearing 27</u>

⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). Final Report - Volume 8, Criminal justice and people with disability. <u>Disability Royal Commission - Final Report - Volume 8</u>.

¹⁰ QFCC (2023). Community Perceptions Survey 2023: Research Report. <u>Survey Full Report</u>

¹¹ Gefion (n.d.) Amplify Blog - I felt like a ghost. <u>Gefion - Blog Post</u>

QFCC calls on the Department to consider including children and young people as a target group in the Roadmap. Children and young people have unique experiences, and challenges, including life stage transitions between child and youth to adult care and support services, as recognised within the Roadmap. We have heard directly from young people who speak of the challenges they face in transitioning from child-focused to adult services, understanding the roles of clinicians and service providers, and encountering stigma and bias when seeking mental health support. Hearing directly from children and young people about their lived experience of autism is fundamental to developing and delivering effective policy reform and health and mental health services that better meet their intersecting needs.

If you have any queries in relation to this matter, please don't hesitate to contact me directly on the prival email at

Yours sincerely

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Luke Twyford Principal Commissioner Queensland Family and Child Commission

October 2024

