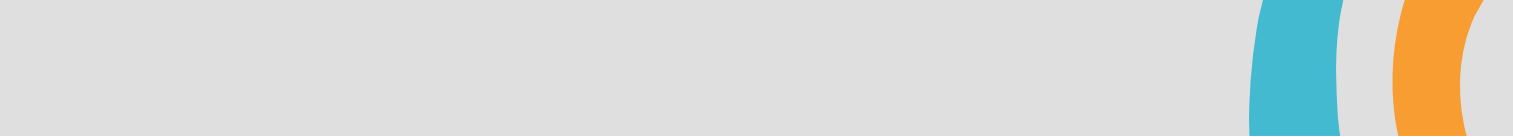


The Senate Select Committee on Autism

Submission

June 2020



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Background

The Queensland Family and Child Commission (QFCC) is pleased to provide a submission to the Senate Select Committee on Autism to inquire into and report on the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy.

Autism is a lifelong neurodevelopmental condition that affects how people perceive the world, how they think and behave, and how they communicate and interact with others.¹ Autism is a spectrum condition, meaning that it can present in different ways and to varying extents in each person. No two people on the autism spectrum are the same - they all have different strengths and abilities.

The number of autistic people in Australia has increased considerably in recent years. There was an estimated 164,000 Australians on the autism spectrum in 2015, representing about 1 in 150 people.²

The QFCC has a statutory responsibility to promote the safety, wellbeing and best interests of children and young people, particularly children in need of protection or in the youth justice system. Reflecting this responsibility, the QFCC's submission will focus on the following four items from the terms of reference of the inquiry:

- (a) current approaches and barriers to consistent, timely and best practice autism diagnosis
- (e) the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages
- (i) the development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy
- (k) the social inclusion and participation of autistic people within the economy and community.

The QFCC aims to promote children's rights and participation and make sure the best interests of children are considered in public policy development and decision making. The QFCC considers an approach to disability services based on human rights is fundamental to addressing systemic issues and community attitudes to improve the lives of people with disability.

This submission is made in support of Article 7 of the United Nations *Convention on the Rights of Persons with Disabilities*, which proclaims all necessary measures must be taken to ensure children with disability enjoy human rights and fundamental freedoms on an equal basis with other children.³

All autistic people deserve to live fulfilling and rewarding lives within a society that accepts and understands them. This submission identifies areas that would help improve the capacity for autistic children and young people to live full lives and experience the fullest possible individual development.

The QFCC advises it has been asked by the Attorney-General of Queensland to undertake separate independent reviews following the death of a four year old girl and the alleged neglect of two teenagers in Queensland. It has been widely reported that the young girl had Down Syndrome and the two teenage boys are both autistic. The death of the young girl and the condition of the boys when found is particularly distressing due to their disabilities. A report on the outcome of the reviews and recommendations on how the system can be improved will be provided to the Queensland Government. This submission is made independently of these reviews.

¹ Autism Spectrum, What is autism?, cited 27 May 2020 <https://www.autismspectrum.org.au/about-autism/what-is-autism>.

² Australian Institute of Health and Welfare 2017. Autism in Australia. Cat. no. WEB 187. Canberra: AIHW, cited 23 April 2020, <https://www.aihw.gov.au/reports/disability/autism-in-australia>.

³ UN General Assembly 2006, *Convention on the Rights of Persons with Disabilities*, Article 7, cited 22 May 2020, https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf

Current approaches and barriers to consistent, timely and best practice autism diagnosis

Recommendation

The QFCC recommends:

- clearer and strengthened diagnostic pathways to achieve a greater level of consistency and early diagnosis of autism for children
- increased community education to improve awareness of autism and encourage families to seek support early so they can benefit from best-practice approaches to early intervention
- developing a culturally specific understanding of autism and the reasons that lead to underdiagnosis in Aboriginal and Torres Strait Islander communities, so education initiatives and interventions are culturally appropriate.

Despite autism being one of the most commonly diagnosed neurodevelopmental conditions in Australia,⁴ there are still deficiencies throughout Australia in obtaining an early diagnosis.

Diagnosis of autism is complex, with no definitive test. Diagnosis is made based on developmental assessments and behavioural observations, with one result being a lack of consistency in diagnostic practice.⁵

Autism can be reliably diagnosed between the age of two to three years. On average most autistic children are diagnosed well after this age, with a possible average delay of two years and common delays of up to four years.⁶

Further, there are significant system issues that prevent gaining a timely diagnosis, including lengthy wait times in the public health system and reduced access to diagnostic services in rural and remote areas. For parents not willing to wait up to and more than 12 months for a diagnosis in the public health system, the cost of diagnosis through the private health system is expensive.⁷

The QFCC stresses the importance of diagnosis at the earliest opportunity. Early diagnosis is a critical first step in accessing early support and intervention. The age at which intervention begins has been associated with improved outcomes, with younger children showing greater gains from intensive early intervention.⁸ Early intervention has been shown to improve learning, communication and social skills, as well as underlying brain development.

Aboriginal and Torres Strait Islander children

There is an overall lack of research on Aboriginal and Torres Strait Islander autistic children or research on how Aboriginal and Torres Strait Islander communities perceive and experience autism. The little research that is

⁴ May, T., Sciberras, E., Brignell, A., & Williams, K. (2017). Autism spectrum disorder: Updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample. *BMJ Open*, 7.

⁵ Taylor, L., Brown, P., Eapen, V., Midford, S., Paynter, J., Quarmby, L., Smith, T., Maybery, M., Williams, K. and Whitehouse, A. (2016). *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane, p. 5.

⁶ Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *The Medical Journal of Australia*, 202, 317–320.

⁷ Lilley, R., Sedgwick, M., & Pellicano, E. (2019). “We Look After Our Own Mob”: Aboriginal and Torres Strait Islander Experiences of Autism. Sydney, Australia: Macquarie University, p 16; Australian Autism Alliance, 2019, Submission 77 to the Joint Standing Committee on the National Disability Insurance Scheme, p. 3.

⁸ Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *The Medical Journal of Australia*, 202, 317–320.



available suggests that Aboriginal and Torres Strait Islander children on the autism spectrum are less likely to be diagnosed and if diagnosed are more likely to have this occur later in life.⁹

Several factors contribute to the underdiagnosis of autism in Aboriginal and Torres Strait Islander communities, including an absence of knowledge about autism, shame and stigmatisation around disability, inequities in access to diagnostic services (particularly in regional and remote communities) and cultural and language barriers.¹⁰

More education in Aboriginal and Torres Strait Islander communities about autism and available support services is vital to enable Aboriginal and Torres Strait Islander autistic children to be diagnosed and supported. Education initiatives need to be culturally appropriate, tailored to each community and translated into local languages.

The demand for and adequacy of government services to meet the needs of autistic people at all life stage

Recommendation

The QFCC recommends:

- clearer identification and coordination of post-diagnostic service supports and therapeutic interventions to help families better navigate all available options
- enhanced service supports and therapeutic interventions for autistic young people, particularly as they transition to adulthood
- the inclusion of cultural content in autism services and therapies
- increased education and training about autism for workers in the child protection and youth justice systems to make sure positive behaviour support and intervention strategies meet the needs of autistic children.

Accessing timely post-diagnostic support is important for autistic children, as they need a range of supports and these can alter over time. In addition, autism is often linked with other physical, developmental or mental health conditions such as intellectual disability, epilepsy, gastro-intestinal issues, attention deficit hyperactivity disorder, dyspraxia, anxiety or depression.¹¹ These co-occurring conditions can further complicate an autism diagnosis, including exacerbating features of autism. It can be challenging to provide supports and holistic therapeutic interventions to meet all the needs of an autistic child where comorbidities exist.

Families can often feel isolated and overwhelmed upon hearing their child is autistic, and families have reported being unsure of what to do next.¹² Post-diagnosis support is a difficult journey to navigate and parents can feel they do not have enough information on the different options for therapeutic interventions, with the expectation that it is up to families to contact therapists to determine appropriate courses of action.

While it be hard to identify what therapeutic interventions families should access, in many cases they are simply unavailable, with this a particular concern in regional and remote Australia. Those therapies that are available can

⁹ Benjamin Bailey and Joanne Arciuli (2020) Indigenous Australians with autism: A scoping review, Autism 1-16.

¹⁰ Roy & Balaratnasingam, 2010: In Australia culture and language barriers are considered a possible factor in the underdiagnosis of autism within the Aboriginal population.

¹¹ Hannah Furfaro, 2018, *Conditions that accompany autism, explained*, Autism Spectrum, cited 27 May 2020 <https://www.spectrumnews.org/news/conditions-accompany-autism-explained/>.

¹² Valentine, K., Rajkovic, M., Dinning, B., & Thompson, D. (2011). Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers. *Australian Department of Families, Housing, Community Services and Indigenous Affairs, Occasional Paper*, 35.



be costly, and the National Disability Insurance Scheme (NDIS) funding often does not fully meet those support needs.¹³

The QFCC stresses the importance of mapping the post-diagnostic support system to families in a way that is easy to navigate. Parents should be able to find this information through various access points including online, community health centres and general practitioners.

It is also important that consistent, targeted support is provided across an autistic person's lifetime. A multiagency response can be required to make sure families are allocated sufficient resources to continue to care for and meet all the needs of their autistic child. The provision of case management support can assist families in navigating the pathway from diagnosis into therapy. This level of direct support can also help to coordinate a child's involvement with several therapies and provide ongoing advice for families as the needs of their child changes, particularly as a child transitions to adulthood.¹⁴

Connection to culture for Aboriginal and Torres Strait Islander children

Once and if an Aboriginal or Torres Strait Islander child receives a diagnosis of autism, they are less likely to access support services. Aboriginal and Torres Strait Islander families have reported that post-diagnostic support is sometimes difficult to access. They have also emphasised a lack of cultural content in autism therapies, specialised schooling curricula and NDIS planning.¹⁵

It is important mainstream and specialised support services recognise the unique cultural needs of Aboriginal and Torres Strait Islander children, emphasising that where possible, services should be helping to promote and maintain a child's connection to their Aboriginal or Torres Strait Islander culture during interventions.

Aboriginal and Torres Strait Islander children have a right to express and maintain their culture as expressed under Article 30 of the UNCR.¹⁶ In Queensland, Aboriginal and Torres Strait Islander peoples' distinct rights to enjoy, maintain and control their cultural heritage are protected under the *Human Rights Act 2019* (Qld).¹⁷

For Aboriginal and Torres Strait Islander children their identity is centred around their culture. Connection to family, community, culture and country helps Aboriginal and Torres Strait Islander people make sense of the world around them and their place in it.

Children in contact with the child protection system

Autistic children can be particularly vulnerable to abuse and neglect due to their reliance on others for care. Research has found that children with disabilities can be disproportionately represented in child abuse and neglect allegations and substantiated allegations.¹⁸

It is not possible to determine exact numbers of autistic children in out-of-home care in Australia. In 2018, the Australian Institute of Health and Welfare estimated the number of children with disability in out-of-home care to be approximately 14 per cent.¹⁹

¹³ Lilley, R., Sedgwick, M., & Pellicano, E. (2019). "We Look After Our Own Mob": Aboriginal and Torres Strait Islander Experiences of Autism. Sydney, Australia: Macquarie University, p 19.

¹⁴ Valentine, K., Rajkovic, M., Dinning, B., & Thompson, D. (2011). Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers. *Australian Department of Families, Housing, Community Services and Indigenous Affairs, Occasional Paper*, 35.

¹⁵ Lilley, R., Sedgwick, M., & Pellicano, E. (2019). "We Look After Our Own Mob": Aboriginal and Torres Strait Islander Experiences of Autism. Sydney, Australia: Macquarie University, p 49.

¹⁶ *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 30.

¹⁷ Human Rights Act (Qld) 2019, s 28.

¹⁸ Maclean MJ, Sims S, Bower C, et al. Maltreatment Risk Among Children With Disabilities. *Pediatrics*. 2017; 139(4):e20161817.

¹⁹ Australian Institute of Health and Welfare (2018). *Child protection Australia 2017–18*, p. 51.



The real number of autistic children in out-of-home care may be higher than anticipated as many children's disabilities can go undiagnosed. Underdiagnosis puts children in out-of-home care at risk of having their needs neglected, and of their rights to access appropriate care and support not being realised.

The needs of autistic children can be misunderstood as they move through the out-of-home care system. This can result in a child's behaviours being inappropriately managed and may contribute to them coming into contact with the youth justice system.²⁰

Staff and service providers need to be informed of the signs that indicate a child may have autism so they can provide an early, coordinated response to help a child access appropriate assessment and holistic therapeutic interventions. The QFCC advocates for a review of the education and training provided to workers in the child protection system to make sure positive behaviour support and therapeutic intervention strategies meet all the needs of autistic children over the short and long term.

Youth justice

While the specific numbers of autistic children in the youth justice system are hard to determine, the QFCC recognises the general overrepresentation of children with cognitive disabilities in the youth justice system throughout Australia.²¹

Cognitive vulnerabilities and impaired emotional processing associated with autism and other developmental disorders serve to exacerbate poor emotional and behavioural control which in turn, often results in a punitive youth justice response.

Inadequate police responses to disability-related behaviours have the effect of propelling children and young people further into the youth justice system.²² Police often do not have a full understanding of autism, which can result in misinterpreting the behaviour of autistic individuals, leading to an increased likelihood of being arrested.²³

Research also suggests that once in custody, the communication and sensory difficulties associated with autism may prevent autistic people from effectively participating in the custody process, ultimately resulting in a negative experience.²⁴

Earlier diagnosis and appropriate intervention for neurological and neurodevelopmental disorders may mitigate contact with the law and prevent or reduce time spent in detention for many children, allowing them to experience their fullest possible individual development.²⁵

The QFCC advocates for fair treatment of autistic children in the youth justice system. This includes access to specialised supports and services to address specific needs, and early intervention strategies that can diagnose autism and provide holistic therapeutic support.

In June 2018, Bob Atkinson, appointed as a Special Advisor to the Minister for Child Safety, Youth and Women and Minister for the Prevention of Domestic and Family Violence in Queensland, released the *Report on Youth Justice*. This report made a series of recommendations to improve the operation of the youth justice system in

²⁰ Prison Reform Trust (2016); Shaw (2016); Taylor (2016); Victoria Legal Aid (2016); Staines (2017).

²¹ Eileen Baldry, Damon B. Briggs, Barry Goldson & Sophie Russell (2018). 'Cruel and unusual punishment': an inter-jurisdictional study of the criminalisation of young people with complex support needs, *Journal of Youth Studies*, 21:5, 636-652.

²² Eileen Baldry, Damon B. Briggs, Barry Goldson & Sophie Russell (2018). 'Cruel and unusual punishment': an inter-jurisdictional study of the criminalisation of young people with complex support needs, *Journal of Youth Studies*, 21:5, 636-652.

²³ Chloe Alice Holloway, Nell Munro, John Jackson, Sophie Phillips, Danielle Ropar (2020). Exploring the autistic and police perspectives of the custody process through a participative walkthrough, *Research in Developmental Disabilities*, Vol 97, p. 2.

²⁴ Chloe Alice Holloway, Nell Munro, John Jackson, Sophie Phillips, Danielle Ropar (2020). Exploring the autistic and police perspectives of the custody process through a participative walkthrough, *Research in Developmental Disabilities*, Vol 97, p. 2.

²⁵ UN General Assembly 1989, *Convention on the Rights of the Child*, Article 23, cited 22 May 2020, <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>.



Queensland. It noted the increased prevalence of neurodevelopmental disorders among the cohort of children in contact with the youth justice system, and made two relevant recommendations:

- recommendation 12: that the capacity to conduct full physical health, mental health, disability and educational assessments of children at all levels of the youth justice system, together with referral to related treatment and programs, be progressed to the greatest extent possible
- recommendation 13: that training in the impact of trauma on neurological development and the risk of impairment be adopted for key staff working in the youth justice system, notably frontline police, teachers, judiciary and legal practitioners, as well as Youth Justice staff and non-government service providers.²⁶

Following the release of the *Report on Youth Justice*, the Queensland Government developed the *Youth Justice Strategy 2019-2023*, which commits to undertaking specialist mental health, fitness for trial and soundness of mind assessments of children and adolescents through Child and Youth Mental Health Court Liaison Services.²⁷

There is an opportunity to implement nationally consistent standards in assessment and training to make sure autistic children who come into contact with youth justice are given appropriate support. This could potentially be supported through the National Autism Strategy proposed by the Australian Government.

The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy

Recommendation

The QFCC recommends:

- the national autism strategy recognises the needs of autistic children and young people in Australia
- development of a national autism strategy includes the voices and experiences of autistic children and young people.

The QFCC welcomes the development of a national autism strategy to advocate and drive change for autistic people across Australia. A national autism strategy will complement the NDIS, providing a targeted approach to support the needs of autistic Australians.

A national autism strategy should focus on increasing awareness of autism and should assist in providing clear pathways for diagnosis and holistic therapeutic interventions. The proposed strategy should be aimed at improving the life outcomes and opportunities of autistic people, including in the areas of diagnosis, education, employment, health, mental health and social inclusion.

Several overseas countries have national autism strategies that are working to improve the lives of autistic people. The United Kingdom introduced autism specific legislation in 2009, followed by a national autism strategy in 2010. It aims to increase awareness of autism, establish clear pathways for diagnosis and needs assessment, promote independent living and access to work, and help the development of local services.²⁸

The QFCC advocates a proposed national autism strategy that would recognise the needs of children and young people in Australia, particularly those more vulnerable such as children in contact with the child protection and

²⁶ Atkinson B. (2018). *Report on Youth Justice*, Brisbane: Youth Justice Taskforce, <https://www.youthjustice.qld.gov.au/resources/youthjustice/reform/youth-justice-report.pdf>, cited 22 May 2020, p. 8.

²⁷ Queensland Government (2019). *Working Together Changing the Story: Youth Justice Strategy 2019-2023*, <https://www.youthjustice.qld.gov.au/resources/youthjustice/reform/strategy.pdf>, cited 22 May 2020, p. 19.

²⁸ Walsh, N. and Hall, I. (2012). "The Autism Strategy: implications for people with autism and for service development", *Advances in Mental Health and Intellectual Disabilities*, Vol. 6 No. 3, p. 113-120.



youth justice systems, children from culturally and linguistically diverse communities, and Aboriginal and Torres Strait Islander children.

The QFCC also stresses the importance of including the views and experiences of children and young people throughout the development of a national autism strategy, doing so through a child-focused, child-friendly and disability-friendly consultation process. Hearing the experiences of autistic children and young people is fundamental to the development and delivery of durable policy reform and of services that better meet the needs of children and young people.

Article 12 of the United Nations *Convention on the Rights of the Child* (UNCRC) says children and young people have a right to have a say on all issues that affect them and for their views to be taken seriously.²⁹ Children and young people continue to tell the QFCC they care about their right to be heard.³⁰ The right to be heard is an avenue through which rights for children and young people are realised. Children and young people who have a voice can speak up about the infringement of other rights and identify barriers to the full enjoyment of their rights.

The social inclusion and participation of autistic people within the economy and community

Recommendation

The QFCC recommends:

- autistic children and young people be afforded the same life chances and opportunities for social inclusion and participation within the economy and community as their peers.

Under article 23 of the UNCRC, children who have any kind of disability should receive special care and support so that they can experience the fullest possible individual development.³¹ Similarly, article 7 of the United Nations *Convention on the Rights of Persons with Disabilities* holds children with disability must be afforded the same rights as other children, their best interests should be the primary consideration, and they have the right to express their views freely on all matters affecting them.³²

In Australia, many autistic people are not afforded the same opportunities and life-chances as non-autistic people. Autistic children are more likely to be bullied, underachieve at school, and be excluded from school. Once they leave school, autistic people are far less likely to gain employment and many have ongoing issues with their mental health.³³

It is important to recognise that autistic people have skills which are incredibly valuable to the wider community. Public spaces and services need to be autism friendly to better support access, participation and inclusion of autistic children and young people in the community. Acknowledging and accommodating the sensory and social difficulties associated with autism can help to improve access, participation and inclusion of autistic children and young people in the community.³⁴

²⁹ UN General Assembly 1989, *Convention on the Rights of the Child*, Article 12, cited 22 May 2020, <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

³⁰ The State of Queensland, Queensland Family and Child Commission (2018). *This place I call home: The views of children and young people on growing up in Queensland*, <https://www.qfcc.qld.gov.au/>.

³¹ United Nations 1990, *Convention on the Rights of the Child*, resolution 44/25, article 23.

³² United Nations 2008, *Convention on the Rights of Persons with Disability*, resolution 61/106, article 7.

³³ Australian Autism Alliance (2019). Submission 77 to the Joint Standing Committee on the National Disability Insurance Scheme, p. 2.

³⁴ Rachel Roberts, Julie Beadle-Brown, Darran Youell (2011). Promoting social inclusion for children and adults on the autism spectrum – reflections on policy and practice, *Tizard Learning Disability Review*, Vol 16 No. 4 p. 45-52.