Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Submission 14

Queensland
Family & Child
Commission

# Senate inquiry into effective approaches to prevention, diagnosis and support for fetal alcohol spectrum disorder Submission

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**Queensland Family and Child Commission** 

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The Queensland Family and Child Commission (QFCC) is pleased to provide a submission to the Senate Standing Committees on Community Affairs regarding effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD).

On 9 May 2017, the QFCC held a FASD learning forum in Cairns, inviting frontline practitioners working directly with children and young people. The forum heard from a range of professionals, including legal, health and medical professionals and child protection practice leaders.

The forum revealed three key themes:

- FASD is prevalent across all areas of society and is often misdiagnosed
- FASD is preventable and therefore it is important to increase community awareness
- it is important that mandatory training is available for all professionals working in the human services so they have fundamental knowledge of the common features of FASD relevant to their area of practice.

Following the learning forum, the QFCC developed short videos to raise awareness and understanding of FASD, which are available on the QFCC website.<sup>1</sup>

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 three of the inquiry's terms of reference:

- (a) the level of community awareness of risks of alcohol consumption during pregnancy
- (h) the prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities
- (i) the recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses.

## Community awareness

### Recommendation

The QFCC recommends:

- community awareness specifically target young people with youth-friendly and youth-focused information
- · community education strategies consider ways to reduce stigma and encourage families to seek support.

Raising community awareness of the risks of alcohol consumption during pregnancy is an important step in preventing, diagnosing and supporting those living with FASD.

The QFCC stresses the importance of educating children and young people about the risks of consuming alcohol while pregnant, ensuring education initiatives are child-friendly and child-focused. Early education is important to reach those who will become parents at a young age.

Community awareness strategies need to incorporate the views of children and young people. The QFCC has sought advice from young people about the types of educational materials that may successfully promote behaviour change. These young people recommended strategies include:

<sup>&</sup>lt;sup>1</sup> Queensland Family and Child Commission 2017, *Fetal Alcohol Spectrum Disorder (FASD) Learning Forum, Cairns*, <a href="https://www.qfcc.qld.gov.au/news/fetal-alcohol-spectrum-disorder-fasd-learning-forum-cairns">https://www.qfcc.qld.gov.au/news/fetal-alcohol-spectrum-disorder-fasd-learning-forum-cairns</a>, accessed 19 November 2019.

- serious and believable stories presented in short videos
- colourful and brief written materials
- peer-to-peer support between children and young people.

It is important to engage and hear directly from children and young people in order to deliver targeted communications strategies that effectively create awareness.

### **Talking Families**

Families dealing with the risks of alcohol consumption during pregnancy may be reluctant to seek help for several reasons. There may be high levels of stigma or shame associated with asking for help, or parents may be fearful of potential involvement from child protection services.<sup>2</sup>

Community education initiatives aiming to raise awareness of FASD should take into consideration this stigma and help families to seek support where required. As an example, the QFCC has developed the Talking Families initiative to support parents, carers and families to find information. The QFCC has created a website and Facebook community to give parents, carers and families tips on who to talk to and how to start conversations. Similar approaches may help to combat stigma and encourage help-seeking behaviour when raising awareness of FASD and providing support to families.

# Approaches to FASD in vulnerable populations

### Recommendation

The QFCC recommends:

responses to FASD be trauma-informed and culturally safe.

Under article 23 of the United Nations *Convention on the Rights of the Child*, children who have any kind of disability should receive special care and support so that they can experience the fullest possible individual development.<sup>4</sup> 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.<sup>5</sup>

Although it can be hard to determine exact numbers, some particularly vulnerable cohorts in Australia, including children in care, children in correctional facilities and Aboriginal and Torres Strait Islander children, have a significantly higher prevalence of FASD compared with the general population.<sup>6</sup>

To combat and reduce the prevalence of FASD within these cohorts, a targeted holistic response is required. Specific strategies need to be implemented for prevention and support. Responses should be culturally safe and trauma-informed.

<sup>&</sup>lt;sup>2</sup> McLean S, and McDougall S 2014, Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention, Child Family Community Australia Paper No. 29, p. 8, <a href="https://aifs.gov.au/cfca/publications/fetal-alcohol-spectrum-disorders-current-issues-awareness-prevention-and">https://aifs.gov.au/cfca/publications/fetal-alcohol-spectrum-disorders-current-issues-awareness-prevention-and</a>, accessed 19 November 2019.

<sup>&</sup>lt;sup>3</sup> Queensland Family and Child Commission, *Talking Families*, <a href="https://www.qfcc.qld.gov.au/families-communities/talking-families">https://www.qfcc.qld.gov.au/families-communities/talking-families</a>, accessed 19 November 2019.

<sup>&</sup>lt;sup>4</sup> United Nations 1990, Convention on the Rights of the Child, resolution 44/25, article 23.

<sup>&</sup>lt;sup>5</sup> United Nations 2008, Convention on the Rights of Persons with Disability, resolution 61/106, article 7.

<sup>&</sup>lt;sup>6</sup> Popova S, Lange S, Shield K, Burd L, and Rehm J 2019, 'Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis', *Addiction*, Vol. 114, Iss. 7, pp. 1150-1172.

Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Submission 14

A 2002 US study estimated children in care are 10-15 times more likely to have FASD than other children.<sup>7</sup> The child protection system needs to cater to the special needs of children and young people with FASD, with professionals and services engaging in a trauma-informed way. These children and young people need a therapeutic environment that is structured, predictable, calm and nurturing in order to thrive.<sup>8</sup>

Culturally safe responses to FASD are particularly important given the higher prevalence of FASD within Aboriginal and Torres Strait Islander communities. Responses need to consider the specific needs of an Aboriginal or Torres Strait Islander child with FASD, including their cultural needs.

While community education strategies should be culturally sensitive, they should take care not to directly and exclusively target Aboriginal and Torres Strait Islander women and families, to avoid any misconception that FASD only affects Aboriginal and Torres Strait Islander communities.<sup>9</sup>

# Criminal justice and rehabilitation

### Recommendation

The QFCC recommends:

- children and young people be assessed for FASD and other developmental impairments upon entry to the youth justice system
- staff and service providers in the youth justice system be provided comprehensive therapeutic training in FASD.

It has been well established that children with FASD are more likely to come into contact with the youth justice system. Cognitive vulnerabilities associated with FASD, including impaired self-regulation and poor decision-making, mean children with FASD are more open to negative peer pressure and antisocial behaviour.<sup>10</sup>

The 2018 Telethon Kids Institute study into children held in the Banksia Hill Detention Centre in Western Australia found 36 per cent lived with FASD. Of this group, only two had been diagnosed prior to the study. A major recommendation coming out of the study was the need for young offenders to be fully assessed upon entry into the youth justice system. This will enable children living with FASD and other developmental impairments to have their specific needs recognised and allow appropriate care and support to be provided. <sup>11</sup>

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 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:

<sup>&</sup>lt;sup>7</sup> Astley, S., Stachowiak, J., Clarren, S., Clausen, C 2002 'Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population', *The Journal of Pediatrics*, Vol. 141, No. 5, pp. 712-717.

<sup>&</sup>lt;sup>8</sup> Royal Commission into the Protection and Detention of Children in the Northern Territory, 2017, *Final Report*, Chapter 3, p. 140.

<sup>&</sup>lt;sup>9</sup> McLean S, and McDougall S, 2014, *Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention*, Child Family Community Australia Paper No. 29, p. 9-10.

<sup>&</sup>lt;sup>10</sup> McLean S, and McDougall S, 2014, *Fetal alcohol spectrum disorders: Current issues in awareness, prevention and intervention*, Child Family Community Australia Paper No. 29, p. 11.

<sup>&</sup>lt;sup>11</sup> Bower C, Watkins RE, Mutch RC, et al., 2018, Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia, BMJ Open.

Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Submission 14

- 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.<sup>12</sup>

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.<sup>13</sup>

There is an opportunity to implement nationally consistent standards in assessment and training to make sure all children who come into contact with youth justice are given appropriate support. Staff and service providers within the youth justice system should undertake comprehensive training in FASD, underpinned by a therapeutic approach. Staff and service providers should provide a coordinated response to young people with neurodevelopmental impairments, creating rehabilitation plans and actions that build on each child's strengths.

<sup>&</sup>lt;sup>12</sup> Atkinson B 2018, *Report on Youth Justice*, Brisbane: Youth Justice Taskforce, <a href="https://www.youthjustice.qld.gov.au/resources/youthjustice/reform/youth-justice-report.pdf">https://www.youthjustice.qld.gov.au/resources/youthjustice/reform/youth-justice-report.pdf</a>, accessed 20 November 2019, p. 8.

<sup>&</sup>lt;sup>13</sup> Queensland Government 2019, Working Together Changing the Story: Youth Justice Strategy 2019-2023, https://www.youthjustice.qld.gov.au/resources/youthjustice/reform/strategy.pdf, accessed 20 November 2019, p. 19.