



**Australian
Human Rights
Commission**

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

Australian Human Rights Commission submission to the Senate Standing
Committees on Community Affairs

28 November 2019

ABN 47 996 232 602

Level 3, 175 Pitt Street, Sydney NSW 2000

GPO Box 5218, Sydney NSW 2001

General enquiries 1300 369 711

Complaints info line 1300 656 419

TTY 1800 620 241

Australian Human Rights Commission
www.humanrights.gov.au

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 28 November 2019

1	Introduction	1
2	Previous Commission submissions and reports.....	1
3	The national response to FASD	2
4	A human rights-based approach	2
4.1	<i>PANEL Principles.....</i>	3
4.2	<i>Declaration on the Rights of Indigenous Peoples</i>	4
(a)	<i>Declaration Principles.....</i>	4
(b)	<i>Protection from alcohol-related harm</i>	5
4.3	<i>The Racial Discrimination Act.....</i>	5
(a)	<i>Special measures in domestic law</i>	6
(b)	<i>Special measures in international law</i>	7
4.4	<i>Convention on the Rights of the Child.....</i>	7
4.5	<i>The Convention on the Rights of Persons with Disability.....</i>	8
5	Paucity of data on FASD	9
6	Recognition of FASD as a Disability in Australia	10
7	FASD and Aboriginal and Torres Strait Islander communities	12
7.1	<i>FASD and the Justice System.....</i>	13
8	Effective Prevention Strategies.....	15
8.1	<i>Placing FASD and other alcohol-related harms in context.....</i>	15
8.2	<i>Community-led best practice approaches to reducing alcohol-related harms.....</i>	16
(a)	<i>Holistic Approaches.....</i>	17
(b)	<i>Implementation</i>	19
8.3	<i>Interventions and targeted approaches</i>	19
(a)	<i>Awareness-raising and education</i>	20
(b)	<i>Alcohol restrictions</i>	21
(c)	<i>The Cashless Debit Card.....</i>	21
8.4	<i>A multipronged strategic approach.....</i>	23
9	Effective Diagnosis and Support Strategies	26
9.1	<i>Parenting programs.....</i>	26
9.2	<i>Remote locations.....</i>	27
10	Recommendations.....	28

1 Introduction

1. The Commission welcomes the opportunity to make comments to the Senate Standing Committee on Community Affairs in relation to its inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. This submission touches on a number of matters listed in the inquiry's terms of reference but focuses primarily on the prevalence of, and approaches to, Fetal Alcohol Spectrum Disorder (FASD) in Indigenous communities, a topic contained within item (h) of the terms of reference.

2 Previous Commission submissions and reports

2. The Commission has provided recent comment and guidance on effective human rights-based strategies to prevent and mitigate alcohol-related harms (including FASD) in Indigenous communities, and on how best to support those communities to lead and implement their own solutions. For example:
 - the 2010 Social Justice Report contains a case study on a Community Response to Fetal Alcohol Spectrum Disorders
 - in February 2012, the Commission provided a submission to the Standing Committee on Social Policy and Legal Affairs inquiry into Foetal Alcohol Spectrum Disorders
 - the 2013 Social Justice and Native Title Report includes a section on 'Human rights in practice—alcohol policy'
 - in April 2014, the Commission provided a submission to the House of Representatives Standing Committee on Indigenous Affairs on the harmful use of alcohol in Aboriginal and Torres Strait Islander Communities, and
 - in February 2018, the Commission provided a submission on the Draft National Alcohol Strategy.
3. The Commission has also provided recent guidance relating to FASD in respect of the rights of children and persons with a disability:
 - in November 2018, the Commission provided a submission to the UN Committee on the Rights of the Child for the Committee's consideration of

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

the Australia's progress on implementing the Convention on the Rights of the Child (CRC), and

- in July 2019, the Commission provided a submission to the United Nations Committee on the Rights of Persons with Disabilities, for the Committee's consideration of Australia's progress on implementing the Convention on the Rights of Persons with Disabilities (CRPD).

3 The national response to FASD

4. FASD is a set of disorders that may occur when a mother consumes harmful quantities of alcohol at crucial points during pregnancy, potentially resulting in a range of impairments including brain injury, birth defects, and behavioural and mental health issues.
5. Long-term outcomes for children with FASD are poor. Overseas research suggests that 90% will have mental health problems, 80% will remain unemployed, 60% will come into aggravated contact with the law and less than 10% will be able to work independently by the age of 21.¹
6. The Commission notes that in 2012, the House of Representatives Standing Committee on Social Policy and Legal Affairs released its inquiry report, *FASD: The Hidden Harm*, leading to the development of an online FASD hub and national Australian FASD diagnostic tool and guide.²
7. In November 2018, the Australian Government released the National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018–2028. The priority areas in the action plan are prevention, screening and diagnosis, support and management, and priority groups and populations at increased risk. The FASD Action Plan also recognises the difficulty of measuring FASD prevalence in Australia and commits to improving national prevalence data.³
8. The Commission is supportive of the National Fetal Alcohol Spectrum Disorder Strategic Action Plan and notes that its effective implementation could reduce the prevalence of FASD and its impact on individuals, families, carers and communities.

4 A human rights-based approach

9. The Commission recommends a human rights-based approach to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder.

10. Rather than dictating what policy should involve, a human rights-based approach sets out a clear process to policy development. For example, with respect to FASD prevention, a human rights-based approach would require neither the free flow of alcohol into every community, nor the blanket application of alcohol bans, and requires that communities are empowered to make decisions about the policies adopted to manage alcohol within their community. It also ensures that measures are reasonable, proportionate and necessary.
11. Evidence tells us⁴ that taking a human rights-based approach to reduce substance-related harms increases the effectiveness, efficiency and legitimacy of measures taken and assists in delivering sustainable alcohol and other drug services which are respectful of the inherent dignity of individuals.⁵

4.1 **PANEL Principles**

12. Common principles to implementing a human rights-based approach have been identified. These principles can be referred to by the acronym 'PANEL':
 - **Participation:** everyone has the right to participate in decisions which affect their lives. Participation must be active, free and meaningful, and give attention to issues of accessibility, including access to information in a form and a language which can be understood.
 - **Accountability:** accountability requires effective monitoring of compliance with human rights standards and achievement of human rights goals, as well as effective remedies for human rights breaches. For accountability to be effective there must be appropriate laws, policies, institutions, administrative procedures and mechanisms of redress in order to secure human rights. This also requires the development and use of appropriate human rights indicators.
 - **Non-discrimination and equality:** a human rights-based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated. It also means that priority should be given to people in the most marginalised or vulnerable situations who face the biggest barriers to realising their rights.
 - **Empowerment:** everyone is entitled to claim and exercise their rights and freedoms. Individuals and communities need to be able to understand their rights, and to participate fully in the development of policy and practices which affect their lives.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

- **Legality:** a human rights-based approach requires that the law recognises human rights and freedoms as legally enforceable entitlements, and the law itself is consistent with human rights principles.⁶

13. In order to ensure consistency with Australia's obligations under international human rights law, all measures should be consistent with these PANEL principles.

4.2 ***Declaration on the Rights of Indigenous Peoples***

(a) *Declaration Principles*

14. In addition to the PANEL principles, any measures affecting Aboriginal and Torres Strait Islander communities should be consistent with the four guiding principles of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) which are:

- **Self-determination:** If communities organise and respond to alcohol misuse, which may require varying levels of facilitation and enablement by government, then responses to alcohol misuse can be seen as an exercise in self-determination.
- **Participation in decision making underpinned by free, prior and informed consent:** Free, prior and informed consent is key to developing responses to alcohol misuse in line with human rights. The best way to prove that the measures are reasonable and proportionate with a legitimate objective is to develop and implement them in close consultation with the community. Without the consent of communities, any response should not be legitimately considered a special measure, nor is it likely to be effective.
- **Respect for and protection of culture:** Respect for and protection of culture is paramount through all stages of any alcohol management planning process and the implementation of any measures. It is key to ensuring that interventions have the greatest chance of being effective. Culturally appropriate rehabilitation services, demand reduction strategies and strong communities are all important to address alcohol misuse.
- **Non-discrimination and equality:**⁷ Australia has obligations under both domestic and international law relating to non-discrimination on the basis of race.⁸ This principle is acutely relevant to FASD prevention measures because many alcohol policies, particularly geographic bans, involve treating

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

Aboriginal and Torres Strait Islander people differently from other Australians. Any policy response to alcohol misuse must not be discriminatory, therefore when targeting discrete Aboriginal and/or Torres Strait Islander communities, it must be implemented as a special measure (see below).

15. As has been stated in previous Social Justice Reports produced by the Commission, strategies developed in line with the principles of the UNDRIP are also likely to be effective in addressing alcohol harms.⁹

(b) *Protection from alcohol-related harm*

16. Protection from alcohol-related harm is a legitimate goal consistent with the human rights contained in the Declaration, and one which mandates action to address and protect those most vulnerable to this harm. As well as the principles underpinning the Declaration, specific articles contain rights which are pertinent to alcohol policy. In particular, article 7(1) includes the rights to life, physical and mental integrity, liberty and security of person.¹⁰ Article 22 of the Declaration is also important in any approach to this issue. It states:

- Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration.
- States shall take measures, in conjunction with Indigenous peoples, to ensure that Indigenous women and children enjoy the full protection and guarantees against all forms of violence and discrimination.

4.3 The Racial Discrimination Act

17. The *Racial Discrimination Act 1975* (Cth) (RDA) is based on Australia's international legal obligations under the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). There are three key questions to assess whether measures are consistent with the RDA:¹¹

- Where the measure is established by legislation, does it guarantee equality before the law?¹²
- Is the measure implemented in such a way that avoids both direct and indirect discrimination?¹³
- Is the measure exempt as a special measure?¹⁴

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

18. Measures that have a disproportionate impact on the ability of particular racial groups to enjoy their rights can be considered racial discrimination. The Commission considers that all responses to reducing alcohol-related harms (including FASD) should be non-discriminatory and consistent with the RDA and Australia's international human rights obligations.

(a) *Special measures in domestic law*

19. 'Special measures' are positive actions taken to rectify disadvantage and ensure the 'full and equal enjoyment of human rights and fundamental freedoms' of a particular racial group. The RDA permits special measures that foster greater racial equality and the elimination of racial discrimination in the Australian community.¹⁵ The following characteristics must be satisfied in order for any measure, including those aimed at reducing alcohol-related harms, to be considered a special measure:

- The measure must have the sole purpose of securing adequate advancement of those experiencing disadvantage so they can equally enjoy their human rights and fundamental freedoms.
- The protection given by the special measure must be necessary for the target group to enjoy and exercise their human rights equally with others.
- The measure must be temporary in achieving its objective.
- The measure must be designed and implemented on the basis of need and be implemented through prior consultation and active participation of the target group.
- The measures should not maintain unequal or separate rights for different racial groups after the objectives have been achieved.¹⁶

20. The Commission has previously expressed concern that the Government has sought to justify measures that are on their face discriminatory as constituting special measures under the RDA. Special measures are actions taken to promote equality not to restrict human rights.¹⁷ Furthermore, the test for what is required as a special measure under the RDA does not fully accord with the requirements set out in international instruments.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

(b) *Special measures in international law*

21. The Commission is of the view that if governments are to act in good faith, and in compliance with their obligations under the Declaration, ICERD and other international instruments,¹⁸ they must satisfy more than the narrower requirements of the RDA. They must seek the free, prior and informed consent of the communities concerned, or as a bare minimum, undertake effective consultation.

22. Special measures are a complex area of law where international law sets a higher benchmark than domestic Australian law. The Declaration's principle of non-discrimination and equality, informed by ICERD and the guidance from the CERD Committee, provides authority as to what can be considered a special measure at international law. The CERD Committee states that:

Special measures should be appropriate to the situation to be remedied, be legitimate, necessary in a democratic society, respect the principles of fairness and proportionality, and be temporary. ... States should ensure that special measures are designed and implemented on the basis of prior consultation with affected communities and the active participation of such communities.¹⁹

23. A way to apply this guidance, and ensure that special measures are legitimately characterised, is to ensure they:

- have a legitimate objective
- be a reasonable and proportionate measure to achieve that objective²⁰
- have a rational connection between the objective and the measures.²¹

24. The legitimacy and proportionality of an objective will be harder to establish if the measures involve impeding the rights of or criminalises the purported beneficiaries. More restrictive measures are more likely to be considered reasonable if accompanied by a suite of measures which treat the problem in a holistic manner.

4.4 *Convention on the Rights of the Child*

25. The *Convention on the Rights of the Child* (CRC) provides the international human rights framework for the protection, promotion and fulfilment of rights of children and young people. The guiding principles of the CRC are non-discrimination, the best interests of the child, participation of the child, and

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

ensuring the child's survival and development, which are applicable to all of the rights contained in the CRC.

26. Under article 24 of the CRC, Australia has obligations to:

'Recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.'²²

27. Australia must also take appropriate measures to implement this right, including measures relevant to the prevention of FASD, and diagnosis and health care support for children and families. These include measures to:

- ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care
- ensure appropriate pre-natal and post-natal health care for mothers
- ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the basic knowledge of child health, and
- develop preventive health care, guidance for parents and family planning education and services.

28. Article 23 of the CRC is also relevant for many children with FASD. It recognises that children with mental or physical disabilities should enjoy 'a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community'. They have a right to special care and assistance, which should be provided free of charge wherever possible, taking into account the financial resources of the parents or others caring for the child.

29. In accordance with article 12 of the CRC, Australia must ensure that children have the right to express their views, will and preferences freely in respect of all health-related matters affecting them, and for these views to be given due weight in accordance with their age and maturity.²³

4.5 *The Convention on the Rights of Persons with Disability*

30. The CRPD requires Australia 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.²⁴

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

31. The CRPD reflects a broad understanding of disability and recognises that disability is an 'evolving concept' resulting from interaction with 'attitudinal and environmental barriers'.²⁵ Article 1 provides that persons with disabilities include 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. Individuals with FASD would qualify as people with disability according to the CRPD.
32. As the CRPD is the most recent international human rights convention and the first international convention to address exclusively the rights of people with disability, it offers important guidance for realising the human rights of people with FASD in Australia. Many provisions of the CRPD require States to take positive action, including significant law reform, to implement the principles underlying the CRPD and protect the rights contained within it.
33. Following Australia's ratification of the CRPD in 2008, the Commonwealth, State and Territory governments developed the National Disability Strategy. This sets out a ten-year national strategic plan (2010–2020) to implement the CRPD and aims to 'ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability, their families and carers'.²⁶

5 Paucity of data on FASD

34. The lack of accurate information about the incidence and prevalence of FASD is a serious impediment to developing effective health and policy responses.
35. The National Children's Commissioner has raised concerns about the lack of available data on children in Australia, especially data disaggregated by age, location, socioeconomic status, cultural background, disability, lesbian, gay, bisexual, trans and intersex (LGBTI) status.²⁷ This includes lack of national information across a range of health and wellbeing domains, such as: children with disability, including FASD.
36. In July 2018, the Australian Government created the Office of the National Data Commissioner. This office will oversee and monitor the integrity of Australia's data system and will be responsible for implementing a simpler data sharing and release framework. It is hoped the new framework will break down barriers preventing efficient use and re-use of public data, while maintaining strong security and privacy protections. The Commission supports this initiative. In the submission to the UN Committee on the Rights of the

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

Child in 2018, the Commission recommended that this national children's data framework address key data concerns and data gaps, such as on children with FASD, and enable disaggregation by developmental phases and age groupings, and priority population groups such as Aboriginal and Torres Strait Islander children.²⁸

37. The Commission notes that the National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018–2028 also recognises the difficulty of measuring FASD prevalence in Australia and commits to improving national prevalence data.²⁹

6 Recognition of FASD as a Disability in Australia

38. The Commission notes that FASD would fall within the definition of 'disability' in section 4 of the *Disability Discrimination Act 1993* (Cth), as well as the definition of disability used by the Australian Bureau of Statistics ('any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months').³⁰ FASD would also come within the definition of 'developmental delay' contained within section 9 of the *National Disability Insurance Act 2013* (Cth).
39. Nonetheless, FASD is not included on the Australian Government's List of Recognised Disabilities.³¹ As a result, comprehensive clinical diagnosis is often difficult, and many individuals remain undiagnosed.³² The failure to recognise FASD as a disability also reduces the availability of other disability support services in the community. For those already experiencing multiple forms of discrimination and limited access to services, such as remote Aboriginal and Torres Strait Islander communities, this compounds harm and further entrenches inequalities in accessing essential services and supports.
40. For example, to gain access to additional supports such as the Disability Support Pension, those with FASD often need a diagnosis of an intellectual disability, which means they must have an IQ below 70. This is not the case for many people with FASD, who can have behavioural and neurodevelopment problems, but an IQ greater than 70. The lack of disability recognition of FASD also poses a significant barrier in accessing the Carer Allowance (for children) and Carer Payment (for adults), as applicants must establish their eligibility using disability assessment tests which are often difficult and time consuming and which generally encompass only severe cases of FASD.
41. People with FASD also face major challenges in accessing the National Disability Insurance Scheme (NDIS). The NDIS is available for individuals with

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

functional disability related to FASD. While the NDIS does not require a specific diagnosis of FASD to qualify for funding, documented evidence of functional impairment is required. Obtaining such evidence is often difficult for individuals with FASD, particularly Aboriginal and Torres Strait Islander peoples who face additional social, cultural, educational or literacy barriers, as well as intersectional discrimination, when trying to navigate the NDIS.

42. The Committee on the Rights of Persons with Disabilities (CRPD Committee) recently recognised the importance of the NDIS for people with disability in Australia. However, the Committee noted a number of challenges associated with implementation of the NDIS, including overly complex procedures, limited publicly available and accessible information, a lack of services in remote areas.³³ The CRPD Committee also noted that the disability assessment that individuals must undergo to receive services through the NDIS 'still relies heavily on the medical model of disability' and does not provide Aboriginal and Torres Strait Islander persons with disabilities and persons with intellectual or psychosocial disabilities with equal opportunities.³⁴
43. The CRPD Committee recommended that the Australian Government review the disability assessment criteria under the NDIS and align them with the human rights model of disability, ensuring adequate support for Aboriginal and Torres Strait Islander persons with disabilities and persons with intellectual or psychosocial disabilities. The CRPD Committee further recommended that NDIS procedures be simplified, clarified and made more transparent, to ensure that the Scheme 'meets the diverse and intersecting requirements' of people with disability in all areas.³⁵
44. The Commission considers that inclusion of FASD on the List of Recognised Disabilities would enhance access to disability support services for people with FASD, while also encouraging greater awareness of FASD in disability policy development and reform. The Commission emphasises the particular need for awareness of FASD among staff at the National Disability Insurance Agency (NDIA). Training and guidance for NDIA staff should be closely tailored to local contexts, building on localised knowledge and leveraging existing networks in Aboriginal and Torres Strait Islander communities. This should be coupled with improved diagnostic capacity and greater culturally appropriate support for individuals with FASD, particularly those living in rural or remote areas, to foster their awareness of, and effective participation in, the NDIS.
45. In parallel with the recognition of FASD as a disability, there is a need of measures to de-stigmatise FASD. People with FAS can progress in life very successfully with the right supports and contribute to their communities in

many positive ways. The 'Language Guide' by the Looking After Each Other outlines respectful ways to discuss FASD and empower individuals with FASD.³⁶

7 FASD and Aboriginal and Torres Strait Islander communities

46. Harmful alcohol use is one of the most challenging issues confronting communities over every demographic in Australia. Compared to the broader population, a greater percentage of Aboriginal and Torres Strait Islander people do not drink alcohol at all.³⁷ However, Aboriginal and Torres Strait Islander people who do drink are more likely to do so at levels that are risky.³⁸
47. Misuse of alcohol in Indigenous communities is inextricably linked to the ongoing effects of colonisation, and inter-generational trauma, and this has translated to high incidence of FASD in Indigenous communities such as the Fitzroy Valley in Western Australia where the rate of one in five children was shown to be amongst some of the highest rates in the world.
48. Like other alcohol-related harms, FASD is not just an 'Aboriginal and Torres Strait Islander problem' and we need to be sensitive to ensure that it does not place another stigma on Aboriginal and Torres Strait Islander communities. Nonetheless, awareness of the very high incidence of FASD in Indigenous communities has promoted the prioritisation of FASD as a key issue for their peoples.
49. Of particular concern to Indigenous communities is the effect of FASD on memory which can result in:
 - a reduced ability to learn and retain information, which may limit educational gains and also impact on future employment and opportunities for economic participation
 - a reduced ability to avoid or correct behaviours that are likely to result in contact with the criminal justice system
 - a reduced ability to learn and retain information critical to the preservation of Aboriginal and Torres Strait Islander Peoples' cultures, given their oral traditions of passing down cultural knowledge through stories and ceremony.
50. The pioneering Lililwan Study carried out in the Fitzroy Valley from 2009–14 to investigate FASD prevalence and to design effective support and prevention strategies is the only population-based data on FASD in Australia. This has

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

meant that much of the evidence and expertise that exists in Australia regarding FASD is developed by and in partnership with Indigenous communities and organisations. Following the Lililwan Study, Marninwarntikura Women's Resource Centre has launched the Marulu Strategy—a holistic FASD care and support strategy.

7.1 FASD and the Justice System

51. The Commission notes that Aboriginal and Torres Strait Islander people with mental and cognitive disabilities are at high risk of coming into contact with the criminal justice system in early life due to the lack of appropriate health, support and diversion pathways available.³⁹
52. Research indicates a high prevalence of children and young people in juvenile detention with FASD.⁴⁰ For example, recent research from Banksia Hill youth detention facility in Perth shows that 89% of children within that facility had at least one form of severe brain impairment, and preliminary results show that 36% have FASD.⁴¹ Most of these children had not been previously identified as having the disorder.⁴² There is a clear need for improved screening and diagnosis in communities, pre-trial screening for children who have come into contact with the justice system, and cognitive testing for children before they enter detention.
53. The CRPD Committee recently expressed concern about the over-representation of young Aboriginal and Torres Strait Islander people with disability in the juvenile justice system.⁴³ The most recent available data indicates that despite making up just under 6% of the youth population, Aboriginal and Torres Strait Islander children account for 56% of children in custodial detention, and 17 times more likely to be under youth justice supervision than their non-Indigenous counterparts⁴⁴
54. The Commission has previously noted in 'Equal before the law: towards disability justice strategies' that necessary procedural accommodation for people with disability is frequently not provided in the justice system. People with disability often have limited access to appropriate legal representation, are not always fully aware of their legal rights and therefore do not ask for appropriate adjustments and supports.⁴⁵ In a similar vein, the CRPD Committee recently expressed concern about the lack of adequate legal protections and redress for people with disability in the justice system in Australia.⁴⁶
55. As a result, Aboriginal and Torres Strait Islander people with disability experience issues which affect sentencing decisions: on the level of

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

competency to stand trial, validity of expert testimony, potentially diminished capacity to understand right and wrong, ability to testify and recidivism.⁴⁷ A recent Australian study of FASD in Australia's juvenile detention population reports that:

'There is increasing concern regarding the forensic implications of FASD in Australia, as the neuropsychological sequelae can affect all aspects of the legal proceedings, including the person understanding the expectations and providing credible evidence in forensic interviews, fitness to plead, capacity to stand trial and the process of sentencing.'⁴⁸

56. To address these concerns, among others, the CRPD Committee recommended that the Australian government develop nationally consistent disability justice plans across jurisdictions to ensure that people with disability are supported in accessing the same legal protections and redress as the rest of the community. The CRPD Committee also recommended that the government address the overrepresentation of young Aboriginal and Torres Strait Islander persons in the juvenile justice system, eliminate substitute decision-making, provide gender and culture-specific individualized support, including psychosocial support, for people with disability in the justice system, make information accessible and provide community-based sentencing options.⁴⁹

57. The Commission also remains concerned that in some jurisdictions declarations of unfitness to stand trial may lead to the indefinite detention of unconvicted people with disability, including children with disability. Children with FASD are at particular risk of being held in indefinite detention and are overrepresented in the juvenile justice system.⁵⁰

58. As stated by Disability Discrimination Commissioner Ben Gauntlett in his opening statement before the 22nd Session of the United Nations Committee on the Rights of Persons with Disabilities:

'The Commission continues to be concerned by the Government's lack of action in repealing legislation and withdrawing policies and practices that can lead to the indefinite detention of unconvicted people with disability. Although the Commission welcomes the endorsement in August 2019 of the *National Statement of Principles Relating to Persons Unfit to Plead or Found Not Guilty By Reason of Cognitive or Mental Health Impairment* (National Statement) by Australian states and territories, with the exception of South Australia, the Commission is concerned that the National Statement has not been implemented in state and territory legislation, policy and procedures.'⁵¹

59. The CRPD Committee expressed its 'serious' concern about legislative frameworks, policies and practices that result in the arbitrary and indefinite

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

detention and forced treatment of persons with disabilities, and that such frameworks, policies and practices disproportionately affect Aboriginal and Torres Strait Islander persons with disabilities and persons with intellectual or psychosocial disabilities. The CRPD Committee also expressed its serious concern about the commitment people with intellectual or psychosocial disability to custody, often indefinitely or for terms longer than those imposed in criminal convictions.⁵²

60. The Commission supports a requirement in all jurisdictions that at the time a detention order is made, a plan is put in place with review mechanisms every six months. It should also include timeframes to ensure support, treatment and rehabilitation services are provided with the aim of transition into progressively less restrictive environments, and eventually being reintegrated back into the community, where possible.⁵³ All state and territory governments should also establish, as a matter of urgency, an appropriate range of appropriate facilities to accommodate people who are found unfit to stand trial and/or not guilty by reason of mental impairment.⁵⁴

8 Effective Prevention Strategies

8.1 *Placing FASD and other alcohol-related harms in context*

61. A primary consideration in designing and implementing effective responses and interventions to reducing FASD and other alcohol-related harms should be an understanding that the consumption of alcohol does not occur in historical and social isolation, and any associated harms are a health, social and economic issue.⁵⁵
62. A 'determinants framework' is increasingly the favoured approach to understanding the underpinning historical and contemporary factors driving alcohol consumption and harms.⁵⁶ Determinants of Indigenous health inequality exist within a historical context of practices of dispossession, assimilation and colonisation of Aboriginal and Torres Strait Islander peoples, leading to cycles of intergenerational trauma. In this context, the harmful use of alcohol is a contemporary reflection of Aboriginal and Torres Strait Islander peoples' historical treatment.⁵⁷
63. For strategies and policies to effectively use the determinants framework, consideration must be given to the social and emotional wellbeing (SEWB) of Aboriginal and Torres Strait Islander peoples.⁵⁸ It is well documented that for Indigenous peoples SEWB encompasses a range of cultural and spiritual components such as: familial and kinship relationships, connection to country

and ongoing practice of ceremony, traditional law and language.⁵⁹ In general, SEWB is intrinsically interconnected with community cohesiveness, financial security and the standard of the built environment and infrastructure including housing, sanitation, access to transport and clean and safe public spaces.⁶⁰

8.2 *Community-led best practice approaches to reducing alcohol-related harms*

64. There is a history of Aboriginal and Torres strait islander communities taking leadership in this space, especially women. For example, the 1986 Women's Business report noted women's concerns of increasing alcohol access in vulnerable communities and its direct relationship with a variety of harms including the consumption of alcohol while pregnant.⁶¹

65. In the Commission's view, one of the major barriers to implementing successful programs to reduce alcohol-related harms such as FASD in Aboriginal and Torres Strait Islander communities is a lack of meaningful community engagement and participation in the governance, design and delivery of programs and services. The effectiveness of any response is highly influenced by the level of buy-in from the community and interventions imposed without community control or culturally appropriate adaption can be counterproductive.⁶²

66. There is significant evidence to show that a commitment to strategies led by Aboriginal and Torres Strait Islander peoples ensures cultural appropriateness, safety and sensitivity and the use of local knowledge in service design and delivery leading to better outcomes.⁶³ Community-led services, which utilise local initiatives and solutions, can improve access to care and treatment, and the provision of more holistic approaches in responding to people from diverse linguistic and cultural backgrounds and with complex needs.⁶⁴

67. In summary, research indicates that successful community-led approaches incorporate the following principles, that they are:

- supported, owned and controlled by affected communities
- designed and tailored to the specific needs of particular communities and subgroups within them
- culturally sensitive and appropriate

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

- adequately resourced and supported, including to cater to those with complex needs
- provide a mix of broad-based and substance specific services
- planned and integrated as a suite of interventions.⁶⁵

(a) *Holistic Approaches*

68. As alcohol misuse is a multi-causal phenomenon, any response must take a holistic approach. Long-term holistic approaches taken within the community-controlled sector are successful because they acknowledge and address the reasons people turn to alcohol and other drugs.⁶⁶ Holistic approaches incorporate the social and cultural determinants of health framework, as explored above, to address both driving factors and root causes of substance use problems, as well as responding to the symptoms.⁶⁷

69. In this holistic approach, trauma-informed and healing practices are increasingly being used to improve social and emotional wellbeing in responding to a range of interrelated harms.⁶⁸ Trauma-informed and healing practices are inherently community-led as they draw on cultural and community strengths as protective factors to enhance dignity, self-esteem, and respect for Aboriginal and Torres Strait Islander peoples in confronting and recovering from the impacts of trauma, consequently addressing a myriad of social issues, including a reduction in alcohol use and harm.⁶⁹ The figure below outlines the key principles of trauma-informed practice.⁷⁰

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

Table 1: Core values of trauma-informed services

Principle	Explanation
Understand trauma and its impact on individuals, families and communal groups	<p>This expertise is critical to avoid misunderstandings between staff and clients that can re-traumatise individuals and cause them to disengage from a program.</p> <p>Two strategies promote understanding of trauma and its impacts: trauma-informed policies and training.</p> <p>Trauma-informed policies formally acknowledge that clients have experienced trauma, commit to understanding trauma and its impacts, and detail trauma-informed care practices.</p> <p>Ongoing trauma-related workforce training and support is also essential. For example, staff members need to learn about how trauma impacts child development and attachment to caregivers. Appropriate support activities might include regular supervision, team meetings and staff self-care opportunities.</p>
Promote safety	<p>Individuals and families who have experienced trauma require spaces in which they feel physically and emotionally safe.</p> <p>Children need to advise what measures make them feel safe. Their identified measures need to be consistently, predictably and respectfully provided.</p> <p>Service providers have reported that creating a safe physical space for children includes having child-friendly areas and engaging play materials. Creating a safe emotional environment involves making children feel welcome (e.g. through tours and staff introductions), providing full information about service processes (in their preferred language) and being responsive and respectful of their needs.</p>
Ensure cultural competence	<p>Culture plays an important role in how victims/survivors of trauma manage and express their traumatic life experience/s and identify the supports and interventions that are most effective.</p> <p>Culturally competent services are respectful of, and specific to, cultural backgrounds. Such services may offer opportunities for clients to engage in cultural rituals, speak in their first language and offer specific foods.</p> <p>Culturally competent staff are aware of their own cultural attitudes and beliefs, as well as those of the individuals, families and communities they support. They are alert to the legitimacy of inter-cultural difference and able to interact effectively with different cultural groups.</p>
Support client's control	<p>Client control consists of two important aspects. First, victims/survivors of trauma are supported to regain a sense of control over their daily lives and build competencies that will strengthen their sense of autonomy. Second, service systems are set up to keep individuals (and their caregivers) well informed about all aspects of their treatment, with the individual having ample opportunities to make daily decisions and actively participate in the healing process.</p>
Share power and governance	<p>Power and decision making is shared across all levels of the organisation, whether related to day-to-decisions or the review and creation of policies and procedures.</p> <p>Practical means of sharing power and governance include recruiting clients to the board and involving them in the design and evaluation of programs and practices.</p>
Integrate care	<p>Integrating care involves bringing together all the services and supports needed to assist individuals, families and communities to enhance their physical, emotional, social, spiritual and cultural wellbeing.</p>
Support relationship building	<p>Safe, authentic and positive relationships assist healing and recovery. Trauma-informed services facilitate such relationships; for example, by facilitating peer-to-peer support.</p>
Enable recovery	<p>Trauma-informed services empower individuals, families and communities to take control of their own healing and recovery. They adopt a strengths-based approach, which focuses on the capabilities that individuals bring to a problem or issue.</p>

Source: Adapted from Guarino et al. (2009).

(b) *Implementation*

70. To develop successful community-led strategies, it is vital to consider the components of implementation necessary to ensuring initiatives adequately reach their objectives, in this case a reduction in alcohol harms. A summary of evidence highlights the following best-practice phases of implementation:

- **Root cause and needs analysis** — mapping the historical and contemporary context, and current needs of the community.
- **Co-design process** — community members and stakeholders work with funders and partners to design the project, strategy and implementation plan.
- **Adequate resourcing** — secure essential resources including financial for the operations and staffing of the initiatives.
- **Monitoring and evaluation frameworks** — develop local performance indicators to meet benchmarks targets and guide overall program evaluation.
- **Capacity building** — deliver relevant training in supporting the community to continue successful delivery and ownership of initiatives.⁷¹

71. Ongoing support for these initiatives and increased participation and involvement in the design and implementation of programs addressing alcohol harms will improve the likelihood of success and will protect the human rights of Aboriginal and Torres Strait Islander people as outlined in the Declaration.⁷²

8.3 *Interventions and targeted approaches*

72. In general, the Commission supports the evidence that population-based measures to restrict the supply of alcohol, through limiting accessibility, increasing taxation and pricing of alcohol and bans on advertising⁷³ are most effective in reducing alcohol harms across the entire population as well as at-risk populations, including Aboriginal and Torres Strait Islander peoples.⁷⁴

73. Where appropriate, whole of population approaches can be supplemented by targeted responses which recognise disproportionate risks and harms experienced across different populations.⁷⁵ Targeted responses are effective when they are designed to enhance the equal enjoyment of human rights and fundamental freedoms for Aboriginal and Torres Strait Islander communities.

74. There is a broad range of evidence highlighting successful interventions designed to significantly reduce alcohol harms in situations where the supply

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

and consumption of alcohol in vulnerable communities poses a serious immediate and ongoing threat to life.⁷⁶ These interventions are characterised as circuit breakers to a crisis, to create a breathing space in which need can be assessed to ensure culturally appropriate and place-based responses to alcohol treatment and recovery are implemented successfully.

(a) *Awareness-raising and education*

75. The Commission reiterates the views expressed in its submission to the 2012 Standing Committee FASD Inquiry, which stated that:

- Education and community awareness about FASD should be accessible to all people, without discrimination, including people with disability, people from culturally and linguistically diverse backgrounds, people living in rural and remote areas, Indigenous communities, and people with low socio-economic status.
- Health education measures should highlight the risks alcohol poses for pregnant women. Given the escalation of alcohol consumption during pregnancy a population-based approach is advised.
- It is also important that young people have access to information and education about sexual and reproductive health, and alcohol consumption and its dangers.⁷⁷

76. Considering that teenage pregnancy is generally higher in Aboriginal communities (ABS data from 2015, which reported that approximately 25.7% of young mothers aged 15–19 identify as Aboriginal or Torres Strait Islander⁷⁸), educating children and young parents on the dangers of FASD should be a priority.

77. As has been demonstrated by the work in Fitzroy Crossing through the Lililwan Project and the Marulu Strategy, awareness-raising and education programs should be co-designed with communities and, to be effective, must be culturally appropriate and trauma-informed. In particular, it is critical that these programs take care to avoid stigmatising communities, families and individuals with FASD. For example, it is important that women are not made to feel blame or shame about having consumed alcohol while pregnant as this can lead to disengagement and is counterproductive to the aim of prevention.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

(b) *Alcohol restrictions*

78. A common response to alcohol misuse is the imposition of restrictions, often in the form of complete bans, over specific geographic areas. This approach has been implemented predominantly in discrete and remote communities with varying results.
79. There are several examples of communities deciding to be 'dry' and implementing successful policies. For example, the Groote Eylandt community of Umbakumba, which was featured in the *Social Justice Report 2007*, developed a plan to manage alcohol through an extended and in-depth process. The alcohol bans in Umbakumba and restrictions on the sale of takeaway alcohol in other parts of the island saw reduced consumption of alcohol along with a reduction in instances of violence and crime.⁷⁹
80. There are also places where the community has chosen to restrict the availability of alcohol, as opposed to a complete ban. This approach has had success in areas such as Fitzroy Crossing, where restrictions have provided a circuit breaker to address dysfunction.⁸⁰
81. On the other hand, bans imposed on communities, without consultation or consent, have been less effective and resulted in feelings of disempowerment and marginalisation in communities.⁸¹ The Northern Territory Intervention is an example of this. The Commission has consistently highlighted evidence which indicates that blanket alcohol bans, such as those imposed in the Northern Territory Intervention, are less effective than those driven by communities.⁸²
82. Negative consequences of blanket alcohol bans include increased drinking in unsafe environments and displacement of people from communities into larger towns where alcohol is more readily available.⁸³ Blanket bans also have the effect of criminalising behaviour that is not subject to criminalisation anywhere else. This is highly problematic given the disproportionate rate at which Aboriginal and Torres Strait Islander people are imprisoned in comparison to the non-Indigenous population.⁸⁴

(c) *The Cashless Debit Card*

83. Any targeted measures to enable Aboriginal and Torres Strait Islander people to address the challenge of FASD in their communities should not impede the full and equal enjoyment of their human rights. As has been articulated in our recent submissions, the Commission holds concerns about the Cashless Debit

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

Card (CDC) trials, and the compatibility with human rights standards, including the CDC's impact on equality and non-discrimination, social security and privacy.⁸⁵

84. The Commission also noted the limitations of the two evaluations that have been carried out to assess the efficacy of the Cashless Debit Card, and continues to hold the view that there is a lack of robust evidence to suggest that punitive or discriminatory interventions put in place to address alcohol-related harms in Indigenous communities have been effective.⁸⁶
85. Ultimately, interventions alone seldom develop the skills for an individual to manage finances, regulate their own alcohol consumption, and manage a range of other social and economic factors in their life. As outlined in this submission, investment in community-led solutions aimed at targeting root causes and enhancing cultural protective factors and social and emotional wellbeing have more efficacy and evidenced success in reducing alcohol harms, as well as addressing a range of social and economic issues.
86. The Commission considers that if intervention measures are applied, the approach must be underpinned by participation in decision making, based on free, prior and informed consent and good faith. Should a community choose to introduce income management measures, the Commission confirms, in line with previous statements, that its preferred features of an income management measure with an objective to reduce alcohol harms are an approach that:
- enables participants to voluntarily opt-in
 - utilises income management as a 'last resort' for targeted risk areas such as child protection (that is supported by case management and support services)
 - is applied for a defined period and in a manner proportionate to the context,⁸⁷ and
 - is supported by a range of other services and treatment options to support participants.⁸⁸
87. A human rights approach requires that any measures be non-discriminatory, effective, subject to monitoring and review and genuinely tailored to the needs and wishes of the local community and must be justifiable in accordance with Australia's international human rights obligations.

8.4 *A multipronged strategic approach*

88. In its 2014 submission to the House of Representatives Standing Committee on Indigenous Affairs on the harmful use of alcohol in Aboriginal and Torres Strait Islander Communities, the Commission included Appendix B: A Community Response to Fetal Alcohol Spectrum Disorders, an extract from Section 3.3, Chapter 3 of the Social Justice Report 2010.
89. The content of this appendix focused on best practice approaches to diagnosis and support in Indigenous communities based on the Fitzroy Valley experience. The Commission maintains that the work being carried out under these programs provides an excellent example of a collaborative community-led approach. See figure below:⁸⁹

Overview of the Marulu Strategy 2017–22

Vision			
Healthy children, families and communities are thriving in the Fitzroy Valley, free from harm. All children and families have access to community-designed models of therapeutic supports, and healing-aware and trauma-informed care (the Marulu model) that meet changing needs throughout their lives.			
Purpose			
Make FASD History and strengthen community capacity, resilience and wellbeing			
Key stakeholders			
The Marulu Strategy Leadership Group along with Essential Partners and an expanding Circle of Friends.			
Our core values and principles			
We are community led. We work from and build the evidence. We strengthen strategic partnerships. We build capacity. We respond to the lived experiences and knowledge of the Fitzroy Valley community. We have a healing-informed and trauma-aware approach to all we do.			
Goals and priorities			
1	2	3	4
Prevent children in the Fitzroy Valley from being born with FASD and experiencing ELT	Support children and families living with FASD and ELT throughout their lives	Build capacity and enhance services for children, adults and families affected by FASD and ELT	Develop a sustainable community-driven response to FASD and ELT
Champion Nindilingarri	Champion Marninwarntikura	Champion Marninwarntikura	Champion Marninwarntikura with Nindilingarri
1.1 Provide drug and alcohol support for pregnant women 1.2 Build on community awareness 1.3 Increase education and prevention initiatives 1.4 Provide services that support and empower families to heal from trauma(s)	2.1 Identify intergenerational and early life trauma and promote healing 2.2 Connect families with targeted therapeutic supports 2.3 Identify gaps and create solutions that incorporate trauma-informed practice with comprehensive wraparound supports 2.4 Ensure all families continue to have their needs met through the changing circumstances of their lives	3.1 Advocate for multidisciplinary diagnostic clinics 3.2 Collect data to build on the Lililwan findings 3.2 Support therapeutic programs 3.3 Ensure Make FASD History is the responsibility of all 3.4 Build understandings and the capacity of all services interacting with Fitzroy Valley families 3.5 Strengthen the capacity of families and carers	4.1 Develop a whole-of-community harm reduction strategy 4.2 Set priorities and coordinate community-driven research opportunities 4.3 Build and share information through the Marulu Knowledge Hub 4.4 Use our experience and expanding knowledge base to influence the national agenda
Build the evidence, share knowledge and extend impact			

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

90. As was stated by the previous Social Justice Commissioner, Mick Gooda:

‘This work shows what is possible when control of an issue is taken at the community level by strong Aboriginal women . . . It shows what is possible when Aboriginal leaders engage as equals with researchers . . . This work is an example of those researchers reciprocating both the spirit and intent of the community by working to address the challenges of FASD in a genuine partnership – one where research is done with the community, not just about the community’.⁹⁰

91. The Fitzroy Valley experience highlights that strategies and associated actions to address alcohol harms should be understood within a holistic framework. Alcohol harms are not an isolated issue but are part of a complex range of factors.⁹¹ For Aboriginal and Torres Strait Islander peoples and communities there is no ‘one size fits all’ approach, or a single intervention that can act as a panacea in addressing alcohol harms.⁹²

92. Interventions should be considered as part of a multipronged approach incorporating a clearly articulated and agreed implementation strategy which enhances the capacity of community-controlled organisations, through the provision of adequate financial resourcing and support, to improve service delivery at the local level to be able to effectively and appropriately address and prevent alcohol harms in both the short and long-term.⁹³

93. Importantly, addressing alcohol harms cuts across sectors and includes a focus on welfare reforms. In designing interventions and reforms, coordination across sectors is essential to implement successful strategies which respond to the evidence of how approaches may have a positive or negative impact on the use of alcohol and other drugs.

94. The Commission suggests that governments consider increased investments into holistic, trauma-informed and healing evidence-based initiatives for Aboriginal and Torres Strait Islander communities experiencing a disproportionate impact of alcohol-related harms. Investment in these approaches should be commensurate with need and the health, social and economic concerns and issues of the community in question.⁹⁴ Resource allocation to developing community-led approaches in addressing alcohol harms must be needs-based and appreciate the changing circumstances and priorities of Aboriginal and Torres Strait Islander communities.⁹⁵

9 Effective Diagnosis and Support Strategies

95. Effective FASD diagnosis and support should be embedded within community-driven multi-pronged approaches as discussed in the previous section of this submission.

96. Within this framework, studies by researchers the Lililwan Study and Marulu Strategy have said that early intervention is vital,⁹⁶ and have called for an enhanced capacity to diagnose, manage and prevent FASD is a priority throughout Australia⁹⁷ including:

- antenatal screening for risk factors
- widely accessible FASD diagnostic services
- supportive case management
- multidisciplinary health services, and
- psychoeducation and support of caregivers.⁹⁸

97. The Commission notes that while ad hoc funding provided for studies into particular communities has provided some important benefits, effective early intervention in these communities and beyond will require the design and implementation of sustainable funding models. There is also a clear need for assistance to enable children and their families to apply for NDIS funding.

9.1 *Parenting programs*

98. Professor Elizabeth Elliot AM and other researchers who were involved in the Lililwan Study and Marulu Strategy in Fitzroy Crossing are currently carrying out the 'Bigiswun Study' to assess health and well-being in the Lililwan cohort 10 years on in adolescence and to identify their needs.

99. The researchers have noted that behavioural issues are highly prevalent in children with FASD and that this has impacted children's lives at home and school. The 'Bigiswun Study' will identify to what extent children and their families were able to access ongoing services (including youth,

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

vocational and parenting programs) and assess their interactions with education, justice and child protection systems, and how these could be improved through more effective support systems.

100. One way in which the Fitzroy Valley community and their partners have approached improving support for parents of children with FASD is through adaptation and implementation of the 'Triple P' (positive parenting program), which has resulted in an increase in parent knowledge, skills and confidence, improved parental mental health and empowerment, and decreased challenging behaviours in children.
101. This has been done by training parent coaches to deliver Triple P to local carers in a tailored way that is sensitive and culturally appropriate and increase their capacity of parent coaches to assist families and support the sustainability of the program.⁹⁹
102. Another resource that has been developed in the Fitzroy Valley is a guide for educators working with children and young people with FASD.¹⁰⁰

9.2 Remote locations

103. Researchers¹⁰¹ involved in the Lililwan Study and Marulu Strategy have noted that there are additional complexities to the provision of effective diagnosis and support in remote locations:
- 'Limited accommodation is an invisible barrier to health care delivery and often means that health staff must fly or drive in/out. This is expensive, time consuming and may result in inconsistent health care from a workforce not well known to or culturally informed about the community.'¹⁰²
 - 'High staff turnover results in a lack of continuity of local and cultural knowledge—especially of children and their extended families. This results in a constant need for Aboriginal people to build new relationships, which might impact on their willingness to engage with the health system at all. It leads to confusion amongst service providers as to who to contact or where to refer patients and is expensive.'¹⁰³

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

- 'Poor co-ordination and poor communication and linkages between health services as barriers to accessing health care, especially for people with chronic, complex disorders.'¹⁰⁴
- 'Some practitioners observed that an opportunistic approach to assessment and treatment can work when parents bring children to the clinic for other matters—but in these instances ... online database containing medical records and histories for patients may not be available, making treatment uncoordinated and possibly ineffective or even risky.'¹⁰⁵

104. The researchers noted that:

- 'Models of best practice for remote settings are client-focused services delivered by a multi-disciplinary team that can demonstrate consistency and commitment over time.'¹⁰⁶
- 'The role of child health nurses, Aboriginal liaison officers and others in assisting families to navigate the health system is crucial.'¹⁰⁷
- 'It is not uncommon to find clinic appointment letters written in English scattered unread in communities. Technology including access to mobile phones and messenger applications may assist in the future.'¹⁰⁸
- 'Resources are needed for provision of quality, ongoing primary health care that is quarantined from acute demands.'¹⁰⁹
- 'There is a need for a formal, prospective audit of child health services ... with development of services to fill gaps in consultation with community and integration of services to maximise efficiency and minimise duplicity.'¹¹⁰

105. The Commission supports calls for the implementation of best-practice service design, better integration of services, adequate resourcing, and the effective application of technologic solutions (including telehealth where appropriate).

10 Recommendations

106. The Commission makes the following recommendations:

Recommendation 1: that the Australian Government support implementation of the National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018–

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

2028 and address the recommendations made by the Senate Inquiry into Effective Approaches to Prevention, Diagnosis and Support for Fetal Alcohol Spectrum Disorder.

Recommendation 2: that Australian governments take a human rights-based approach to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder, consistent with ICERD, UNDRIP, CRC and CRPD.

Recommendation 3: that Australian governments take measures to improve the availability of data relating to the prevalence and impact of FASD, and the availability and effectiveness of services to people with FASD.

Recommendation 4: that FASD be included in the Australian Government's List of Recognised Disabilities.

Recommendation 5: that Australian governments take measures to improve pre-trial screening for those children who are facing charges, and cognitive testing for children before they enter juvenile detention.

Recommendation 6: that Australian governments should ensure that laws that allow for children to be detained following a finding of unfitness to stand trial, or a verdict of not guilty by reason of mental impairment:

- impose effective limits on the total period of detention
- require regular reviews of the need for detention
- require a plan to be put in place, including actions to be taken for the child's rehabilitation to facilitate their transition into progressively less restrictive environments, and eventually out of detention.

Recommendation 7: that all state and territory governments establish, as a matter of urgency, a range of appropriate facilities to accommodate people who are found unfit to stand trial and/or not guilty by reason of mental impairment.

Recommendation 8: that Australian governments support measures to raise awareness and educate about FASD throughout Australia and, as a priority, to ensure that groups at higher risk are provided with relevant, trauma-informed and culturally appropriate information on FASD (ideally developed in partnership with local community organisations).

Recommendation 9: that Australian governments support, and adequately resource, holistic, trauma-informed community-led approaches to prevention,

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

diagnosis and support of FASD in Aboriginal and Torres Strait Islander communities.

Recommendation 10: that participation in the Cashless Debit Card trials be made voluntary.

Recommendation 11: that Australian governments' approaches to the prevention, diagnosis and support for FASD include: supporting best-practice service design; taking measures to better integrate systems and services; providing adequate and sustainable resourcing; and investing in the effective application of technology.

Recommendation 12: The Commission recommends that Australian governments invest in core infrastructure in remote communities including roads, staff housing and clinics, and in recruiting, training and retaining staff on the ground who can play a key liaison and coordination role with health professionals and community members.

Endnotes

¹ Jane Latimer, Elizabeth Elliot, James Fitzpatrick, Manuela Ferreira, Maureen Carter, June Oscar, Meredith Kefford (eds), *Marulu: The Lillilwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: a community consultation*, The George Institute for Global Health (April 2010) 5.

² Carol Bower, Elizabeth J Elliott, on behalf of the Steering Group, *Australian Guide to the diagnosis of FASD, Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*, Department of Health (2016).

³ Department of Health, *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018 – 2028*, (2018) 23 <www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>.

⁴ Dennis Gray and Edward Wilkes, Australian Institute of Health and Welfare, *Reducing alcohol and other drug related harm*, Closing the Gap Clearinghouse Resource Sheet no. 3 (2010) <www.aihw.gov.au/getmedia/2bf0bc1c-40fc-45e9-93fd-99c05ab609f2/ctgc-rs03.pdf.aspx?inline=true>.

⁵ Victorian Equal Opportunity and Human Rights Commission, *From Principle to Practice: Implementing the Human Rights Based Approach In Community Organisations* (September 2008) <www.humanrightscommission.vic.gov.au/our-resources-and-publications/toolkits/item/303-from-principle-to-practice-implementing-the-human-rights-based-approach-in-community-organisations-sept-2008>.

⁶ Australian Human Rights Commission, *Social Justice and Native Title Report 2015*, (2015) 51 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and-1>.

⁷ United Nations General Assembly, *United Nations Declaration on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly (2 October 2007) A/RES/61/295* <www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf>.

⁸ *Racial Discrimination Act 1975* (Cth) and *United Nations International Convention on the Elimination of All Forms of Racial Discrimination*, 1969.

⁹ Australian Human Rights Commission, *Social Justice Report 2013*, (2013) 17 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and>.

¹⁰ These Declaration rights are strongly supported by *United Nations International Convention on the Elimination of All Forms of Racial Discrimination*, 1969, art 5(b); *International Covenant on Civil and Political Rights*, 1966, art 9; *Convention on the Rights of the Child*, 1990.

¹¹ Australian Human Rights Commission, *Social Justice and Native Title Report 2015* (2015) 51 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and-nati-1>.

¹² *Racial Discrimination Act 1975* (Cth) s 10.

¹³ *Racial Discrimination Act 1975* (Cth) s 9.

¹⁴ *Racial Discrimination Act 1975* (Cth) s 8.

¹⁵ Australian Human Rights Commission, *Social Justice and Native Title Report 2015*, (2015) 53 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and-1>.

¹⁶ Australian Human Rights Commission, *Social Justice and Native Title Report 2013*, (2013) 127 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and>.

For a more detailed understanding of what constitutes a special measure and the relationship between special measures and the *Racial Discrimination Act* please refer to United Nations Committee on the Elimination of Racial Discrimination (CERD), *General Recommendation no. 32, The*

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

meaning and scope of special measures in the International Convention on the Elimination of All Forms [of] Racial Discrimination (24 September 2009) <www.refworld.org/docid/4adc30382.html>.

¹⁶ United Nations Committee on the Elimination of Racial Discrimination, *General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of Racial Discrimination* (24 September 2009) paras 16, 18 <www2.ohchr.org/english/bodies/cerd/docs/GC32_English.pdf>.

¹⁷ UN Committee on the Elimination of Racial Discrimination, *General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of Racial Discrimination* (2009) paras 16, 18.

¹⁸ Such as the *United Nations International Convention on Civil and Political Rights*, 1966 and the *United Nations International Covenant on Economic, Social and Cultural Rights*, 1966.

¹⁹ Committee on the Elimination of Racial Discrimination, *General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of Racial Discrimination* (2009) paras 16, 18 <https://www2.ohchr.org/english/bodies/cerd/docs/GC32_English.pdf>.

²⁰ Committee on the Elimination of Racial Discrimination, *General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of Racial Discrimination* (2009) <https://www2.ohchr.org/english/bodies/cerd/docs/GC32_English.pdf>.

²¹ Committee on the Elimination of Racial Discrimination, *General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of Racial Discrimination* (2009) <https://www2.ohchr.org/english/bodies/cerd/docs/GC32_English.pdf>.

²² United Nations, *Convention on the Rights of the Child* (1989) <<https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>>.

²³ Above n 22, art 12.1; *Convention on the Rights of Persons with Disabilities* (2007) art 7.3.

²⁴ UN General Assembly *Convention on the Rights of Persons with Disabilities*, (2007) 2515 UNTS 3, art 1 <www.refworld.org/docid/45f973632.html>.

²⁵ UN General Assembly, *Convention on the Rights of Persons with Disabilities* (2007) 2515 UNTS 3 Preamble (5) <www.refworld.org/docid/45f973632.html>.

²⁶ Department of Social Services, *National Disability Strategy 2010-2020* (2012) <www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>.

²⁷ Australian Human Rights Commission, *Report to the UN Committee on the Rights of the Child* (2018) (1 November 2018) Recommendation 10 <www.humanrights.gov.au/our-work/childrens-rights/publications/report-un-committee-rights-child-2018>.

²⁸ Australian Human Rights Commission, *Report to the UN Committee on the Rights of the Child* (2018) (1 November 2018) <www.humanrights.gov.au/our-work/childrens-rights/publications/report-un-committee-rights-child-2018>.

²⁹ Department of Health, *National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-2028* (2018) 23 <www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>.

³⁰ Australian Bureau of Statistics, *Disability. Ageing and Carers, Australia Summary of Findings 2018* (2019) <<https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features52018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>>>.

³¹ Department of Social Services, *Guide to the List of Recognised Disabilities*, (2014) <<https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carers-allowance/guide-to-the-list-of-recognised-disabilities>>. See also House of Representatives Standing Committee on Social Policy and Legal Affairs, Parliament of Australia, *FASD: The Hidden Harm Inquiry into the Prevention, Diagnosis and Management of Fetal Alcohol Spectrum Disorders* (November 2012) <www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=spla/fasd/report.htm>.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

³² Australian Institute of Health and Welfare, Closing the gap clearinghouse: *Fetal alcohol spectrum disorders: a review of interventions for prevention and management in Indigenous communities*, resource sheet no. 36 (February 2015) <www.aihw.gov.au/getmedia/778f54f3-5618-428f-a094-40c347ed3c7f/ctgc-rs36.pdf.aspx?inline=true>.

³³ UN Convention on the Rights of Persons with Disabilities Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, CRPD/C/AUS/CO/2-3 (15 October 2019)1-3.

³⁴ UN Convention on the Rights of Persons with Disabilities Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, CRPD/C/AUS/CO/2-3 (15 October 2019)1-3.

³⁵ UN Convention on the Rights of Persons with Disabilities Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, CRPD/C/AUS/CO/2-3 (15 October 2019)1-3.

³⁶ Manitoba FASD Coalition, *FASD Language Guide: Promoting dignity for those impacted by FASD* (October 2017) <www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/>.

³⁷ Australian Institute of Health and Welfare, *2010 National Drug Strategy Household Survey report* (2011) <<http://www.aihw.gov.au/publication-detail/?id=32212254712>>. Note that some reservations were held over the accuracy of this data given the small sample size.

³⁸ Australian Institute of Health and Welfare, *2010 National Drug Strategy Household Survey report* (2011) 60 <www.aihw.gov.au/publication-detail/?id=32212254712>.

³⁹ Australian Human Rights Commission, *Equal before the law: towards disability justice strategies* (2014)

<www.humanrights.gov.au/sites/default/files/document/publication/2014_Equal_Before_the_Law.pdf>

⁴⁰ Australian Law Reform Commission, *Pathways to Justice—Inquiry into the Incarceration Rate of Aboriginal and Torres Strait Islander Peoples* ALRC Report 133 (28 March 2018) 66

<www.alrc.gov.au/publications/indigenous-incarceration-report133>. and Carol Bower et al, 'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia' (April 2018) 8(2) <bmjopen.bmj.com/content/8/2/e019605>.

⁴¹ Nicolas Perpetch, *Nine out of 10 Banksia Hill youth detainees have severe brain impairment* (15 Feb 2018) ABC News Online <www.abc.net.au/news/2018-02-14/majority-banksia-hill-detainees-have-mental-impairment/9435364>.

⁴² Carol Bower, Rochelle Watkins and Raewyn Mutch, 'Fetal Alcohol Spectrum Disorder and Youth Justice: A Prevalence Study Among Young People Sentenced to Detention in Western Australia' (2018) 8 BMJ Open <<https://bmjopen.bmj.com/content/8/2/e019605>>.

⁴³ UN Convention on the Rights of Persons with Disabilities Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, CRPD/C/AUS/CO/2-3 (15 October 2019) 6.

⁴⁴ Australian Institute of Health and Welfare, *Youth Justice in Australia 2017–18*. Cat. no. JUV 129. Canberra: AIHW (2019)

⁴⁵ Australian Human Rights Commission, *Equal before the law: towards disability justice strategies* (2014) 19

<www.humanrights.gov.au/sites/default/files/document/publication/2014_Equal_Before_the_Law.pdf> and Australian Human Rights Commission, *Submission to the UN Committee on the Rights of Persons with Disabilities* (25 July 2019) 18 – 19 <www.humanrights.gov.au/our-work/legal/submission/information-concerning-australias-compliance-convention-rights-persons>.

⁴⁶ UN Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third periodic reports of Australia*, CRPD/C/AUS/CO/2-3 (15 October 2019) 6-8.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

⁴⁷ Australian Human Rights Commission Submission to the Australian Law Reform Commission, *Inquiry into Incarceration Rates of Aboriginal and Torres Strait Islander Peoples* (4 September 2017) <www.alrc.gov.au/wp-content/uploads/2019/08/43._ahrc.pdf>.

⁴⁸ Australian Human Rights Commission Submission to the Australian Law Reform Commission, *Inquiry into Incarceration Rates of Aboriginal and Torres Strait Islander Peoples* (4 September 2017) <www.alrc.gov.au/wp-content/uploads/2019/08/43._ahrc.pdf>.

⁴⁹ UN Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, CRPD/C/AUS/CO/2-3 (15 October 2019) 7.

⁵⁰ Parliament of Australia, Standing Committee on Indigenous Affairs, *Inquiry into the harmful use of alcohol, hurting people and harming communities* (June 2015) <www.aph.gov.au/Parliamentary_Business/Committees/House/Indigenous_Affairs/Alcohol/Report>.

⁵¹ Commissioner Ben Gauntlett, Disability Discrimination Commissioner on behalf of the Australian Human Rights Commission, Opening Statement at 22nd Session of the Committee on the Rights of Persons with Disabilities, Geneva (September 2019) <www.humanrights.gov.au/about/news/speeches/convention-rights-persons-disabilities-briefing-civil-society-2019>

⁵² UN Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, CRPD/C/AUS/CO/2-3 (15 October 2019) 7.

⁵³ Australian Human Rights Commission, Submission 6 to the Senate Community Affairs References Committee, Parliament of Australia, *Inquiry into Indefinite Detention of People with Cognitive and Psychiatric impairment in Australia* (March 2016) <www.humanrights.gov.au/our-work/legal/submission/indefinite-detention-people-cognitive-and-psychiatric-impairment> and First Peoples Disability Justice Consortium, Submission 39 to the Senate Community Affairs References Committee, Parliament of Australia, *Inquiry into Indefinite Detention of People with Cognitive and Psychiatric impairment in Australia* (April 2016)

⁵⁴ Australian Human Rights Commission, Submission 6 to the Senate Community Affairs References Committee, Parliament of Australia, *Inquiry into Indefinite Detention of People with Cognitive and Psychiatric impairment in Australia* (March 2016) <www.humanrights.gov.au/our-work/legal/submission/indefinite-detention-people-cognitive-and-psychiatric-impairment> and First Peoples Disability Justice Consortium, Submission 39 to the Senate Community Affairs References Committee, Parliament of Australia, *Inquiry into Indefinite Detention of People with Cognitive and Psychiatric impairment in Australia* (April 2016)

⁵⁵ Gray D, Cartwright K, Stearne A, Saggars S, Wilkes E, Wilson M, *Review of the harmful use of alcohol among Aboriginal and Torres Strait Islander people*, Australian Indigenous HealthInfoNet, (2017) 15 <www.aodknowledgecentre.net.au/aodkc/alcohol/reviews/alcohol-review>.

⁵⁶ Intergovernmental Committee on Drugs, The National Aboriginal and Torres Strait Islander Peoples' Drug Strategy 2014 – 2019, (2014) 24 <www.nationaldrugstrategy.gov.au/internet/drugstrategy/Publishing.nsf/content/natsipds2014-19>.

⁵⁷ Darren Dick on behalf of Mr Tom Calma, *Social Determinants and the health of Indigenous people in Australia – a human rights based approach* (Presentation delivered at the International Symposium on the Social Determinants of Indigenous Health (29 – 30 April 2007) <www.humanrights.gov.au/news/speeches/social-determinants-and-health-indigenous-peoples-australia-human-rights-based>.

⁵⁸ Department of the Prime Minister and Cabinet, Australian Government, *Aboriginal and Torres Strait Islander Health Performance Framework Report* (2014) 2.16 Risky Alcohol Consumption 112 <www.pmc.gov.au/sites/default/files/publications/Aboriginal_and_Torres_Strait_Islander_HPF_2014%20-%20edited%2016%20June2015.pdf>.

⁵⁹ See Lowitja Institute of Health, Social and Emotional Wellbeing <www.lowitja.org.au/research-topics/social-and-emotional-wellbeing>.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

⁶⁰ Department of the Prime Minister and Cabinet, *National strategic framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing 2017-2023* (2017) 201

<healthinfonet.ecu.edu.au/keyresources/publications/33834/?title=National%20strategic%20framework%20for%20Aboriginal%20and%20Torres%20Strait%20Islander%20peoples%27%20mental%20health%20and%20social%20and%20emotional%20wellbeing%202017-2023>.

⁶¹ Phyllis daylight, Mary Johnstone, *Women's Business: Report of the Aboriginal Women's Taskforce* (1986) Commonwealth of Australia.

⁶² D Gray and E Wilkes, *Reducing alcohol and other drug related harm*, Closing the gap clearinghouse Resource sheet no. 3 (2010) 2

<www.aihw.gov.au/closingthegap/documents/resource_sheets/ctgc-rs03.rtf>.

⁶³ Commonwealth of Australia, *Report of the Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities* (25 June 2015) 62

<www.aph.gov.au/Parliamentary_Business/Committees/House/Indigenous_Affairs/Alcohol/Report>.

⁶⁴ Gray D, Cartwright K, Stearne A, Saggars S, Wilkes E, Wilson M (2017), *Review of the harmful use of alcohol among Aboriginal and Torres Strait Islander people*, Australian Indigenous Health InfoNet, (2017) 22 <www.aodknowledgecentre.net.au/aodkc/alcohol/reviews/alcohol-review>.

⁶⁵ Australian Human Rights Commission, Submission no 31 to The House Of Representatives Standing Committee On Indigenous Affairs, Parliament of Australia, *Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities 2015* (April 2014) 8-9.

⁶⁶ Vanessa Lee and Jessica Stewart, the Public Health Association of Australia: Policy-at-a-glance – Aboriginal and Torres Strait Islander Peoples Substance Use Policy, (September 2013) 7-8

<www.phaa.net.au/documents/item/1668>.

⁶⁷ Vanessa Lee and Jessica Stewart, the Public Health Association of Australia: *Policy-at-a-glance – Aboriginal and Torres Strait Islander Peoples Substance Use Policy*, (September 2013) 7-8

<www.phaa.net.au/documents/item/1668>.

⁶⁸ Department of the Prime Minister and Cabinet, Commonwealth of Australia, *National Strategic Framework For Aboriginal and Torres strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023* (2017) 14 <pmc.gov.au/resource-centre/indigenous-affairs/national-strategic-framework-mental-health-social-emotional-wellbeing-2017-23>.

⁶⁹ For more information on recovering from trauma by enhancing cultural protective factors, increasing SEWB and reducing interrelated issues of harm as a consequence of trauma see the Healing Foundation resource portal <healingfoundation.org.au/resources/introducing-the-healing-portal/>.

⁷⁰ Judy Atkinson, Australian Government, Australian Institute of Health and Welfare, Australian Institute of Family Studies, *Trauma-informed services and trauma-specific care for Indigenous Australian children* Resource sheet no. 21 produced for the Closing the Gap Clearinghouse (July 2013) <aihw.gov.au/getmedia/e322914f-ac63-44f1-8c2f-4d84938fcd41/ctg-rs21.pdf.aspx?inline=true>.

⁷¹ For examples of best-practice implementation see: The Healing Foundation, *Our Men Our Healing: Creating Hope Respect and Reconnection: evaluation report* (2015) 9-13

<healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=2650>; Vanessa Lee and Jessica Stewart, the Public Health Association of Australia: Policy-at-a-glance – Aboriginal and Torres Strait Islander Peoples Substance Use Policy (September 2013) 1-11 <phaa.net.au/documents/item/1668> and Gray D, Cartwright K, Stearne A, Saggars S, Wilkes E, Wilson M, Review of the harmful use of alcohol among Aboriginal and Torres Strait Islander people Australian Indigenous HealthInfoNet (2018) 1-37 <healthbulletin.org.au/wp-content/uploads/2018/02/Alcohol-Review-Bulletin-2018.pdf>.

⁷² Judy Atkinson, *Trauma-informed services and trauma-specific care for Indigenous Australian children*, *Closing the gap clearinghouse Resources sheet no. 21* (2013) <fwtdp.org.au/rap-resources/practice-resources/trauma-informed-care> and Australian Human Rights Commission, *Social Justice Report 2011* (2011) 149 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-3> 9

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

⁷³ The World Health Organization, *Global strategy to reduce the harmful use of alcohol* (2010)10 – 19. <www.who.int/substance_abuse/activities/gsrhua/en/>.

⁷⁴ Foundation of Alcohol Research and Education (FARE), Submission to the Northern Territory Government, *Alcohol Policies and Legislation Review 2017* (August 2017) <<http://fare.org.au/archives/83167>>.

⁷⁵ Intergovernmental Committee on Drugs, *The National Aboriginal and Torres Strait Islander Peoples' Drug Strategy 2014 – 2019*. (2019)11 <www.nationaldrugstrategy.gov.au/internet/drugstrategy/Publishing.nsf/content/natsipds2014-19>.

⁷⁶ Selden S & Lyle D, *A framework for supporting the implementation of community-based alcohol prevention and early intervention programs*, Centre for Remote Health Research, University of Sydney, (2009) 16-17.

⁷⁷ Australian Human Rights Commission Submission to the Standing Committee on Social Policy and Legal Affairs inquiry into Foetal Alcohol Spectrum Disorders (February 2012). <www.humanrights.gov.au/our-work/legal/inquiry-foetal-alcohol-spectrum-disorders-2012>.

⁷⁸ Australian Human Rights Commission, *Children's Rights Report 2017*, (2017) 117 <www.humanrights.gov.au/our-work/childrens-rights/publications/childrens-rights-report-2017>.

⁷⁹ Human Rights and Equal Opportunity Commission, *Social Justice Report 2007* (2008) <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-3>.

⁸⁰ Australian Human Rights Commission, *Social Justice Report 2010* (2011) 28 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-0>.

⁸¹ Central Land Council, *The Central Land Council Community Development Framework* (2009) p 8 <www.clc.org.au/files/pdf/The_CLCs_Community_Development_framework.pdf>.

⁸² Human Rights and Equal Opportunity Commission, *Social Justice Report 2007* (2008) 285-289 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-3>.

⁸³ Aboriginal and Torres Strait Islander Legal Services and Aboriginal Peak Organisations Northern Territory, *The Future of the Northern Territory 'Intervention: Issues Paper* (2010) 7 <www.clc.org.au/files/pdf/NTER_Issues_Paper_ATSILS_APO_NT_.pdf>.

⁸⁴ The rate of imprisonment for Indigenous persons is 2 268 per 100,000 compared the general population rate of 169 per 100 000 (based on average daily imprisonment rate): Australian Bureau of Statistics (ABS), 'Corrective Services Australia June Quarter 2012', 4512.0 (September 2012) <www.abs.gov.au/ausstats/abs@.nsf/mf/4512.0?OpenDocument>.

⁸⁵ See Australian Human Rights Commission, Submission to Senate inquiry into Social Services Legislation Amendment (Cashless Debit Card) Bill 2017, (29 September 2017); Australian Human Rights Commission, Submission to Senate inquiry into Social Services Legislation Amendment (Cashless Debit Card Trial Expansion) Bill 2018, (20 July 2018); and Australian Human Rights Commission, Submission to Senate inquiry into Social Security (Administration) Amendment (Income Management to Cashless Debit Card Transition) Bill 2019, (2 October 2019).

⁸⁶ See Australian Human Rights Commission, Submission to Senate inquiry into Social Services Legislation Amendment (Cashless Debit Card) Bill 2017, (29 September 2017); Australian Human Rights Commission, Submission to Senate inquiry into Social Services Legislation Amendment (Cashless Debit Card Trial Expansion) Bill 2018, (20 July 2018); and Australian Human Rights Commission, Submission to Senate inquiry into Social Security (Administration) Amendment (Income Management to Cashless Debit Card Transition) Bill 2019, (2 October 2019).

⁸⁷ Australian Human Rights Commission, Submission No 76 to Senate Standing Committees on Community Affairs, *Inquiry into the Welfare Reform and Reinstatement of Racial Discrimination Act Bill 2009 and other Bills* (10 February 2010) 26 <www.humanrights.gov.au/our-work/legal/inquiry-welfare-reform-and-reinstatement-racial-discrimination-act-bill-2009-and>.

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

-
- ⁸⁸ Australian Human Rights Commission, *Social Justice Report 2015*, (2015) 57 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-and-1>.
- ⁸⁹ Marulu Strategy, Making FASD History (2019) <www.marulustrategy.com.au/>.
- ⁹⁰ Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, Lucas BR, Doney R, Salter C, Try J, Hawkes G, Fitzpatrick E, Hand M, Watkins RE, Martiniuk AL, Bower C, Boulton J, Elliott EJ.J Paediatric Child Health, *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project* (April 2015) 51(4):450-7. doi: 10.1111/jpc.12814. Epub 2015 Jan 15.
- ⁹¹ Department of Health, *My Life My Lead: Opportunities for strengthening approaches to the social determinants and cultural determinants of Indigenous health: Report on the national consultations*, (December 2017) 7
- ⁹² Australian Human Rights Commission, *Social Justice and Native Title Report 2010* (2010) 109 – 111 <www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-0>.
- ⁹³ Department of Health, *My Life My Lead: Opportunities for strengthening approaches to the social determinants and cultural determinants of Indigenous health: Report on the national consultations*, (December 2017) 7 <[www1.health.gov.au/internet/main/publishing.nsf/Content/D2F6B905F3F667DACA2580D400014BF1/\\$File/My%20Life%20My%20Lead%20Consultation%20Report.pdf](http://www1.health.gov.au/internet/main/publishing.nsf/Content/D2F6B905F3F667DACA2580D400014BF1/$File/My%20Life%20My%20Lead%20Consultation%20Report.pdf)>.
- ⁹⁴ Gray D, Cartwright K, Stearne A, Siggers S, Wilkes E, Wilson M, *Review of the harmful use of alcohol among Aboriginal and Torres Strait Islander people*, Australian Indigenous HealthInfoNet, (2017) 21 <www.aodknowledgecentre.net.au/aodkc/alcohol/reviews/alcohol-review>.
- ⁹⁵ Gray D, Cartwright K, Stearne A, Siggers S, Wilkes E, Wilson M, *Review of the harmful use of alcohol among Aboriginal and Torres Strait Islander people*. Australian Indigenous HealthInfoNet (2017) 21-27 <www.aodknowledgecentre.net.au/aodkc/alcohol/reviews/alcohol-review>.
- ⁹⁶ Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, Lucas BR, Doney R, Salter C, Try J, Hawkes G, Fitzpatrick E, Hand M, Watkins RE, Martiniuk AL, Bower C, Boulton J, Elliott EJ.J Paediatric Child Health, *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project* (April 2015) 51(4):450-7. doi: 10.1111/jpc.12814. Epub 2015 Jan 15.
- ⁹⁷ Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, Lucas BR, Doney R, Salter C, Try J, Hawkes G, Fitzpatrick E, Hand M, Watkins RE, Martiniuk AL, Bower C, Boulton J, Elliott EJ.J Paediatric Child Health, *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project* (April 2015) 51(4):450-7. doi: 10.1111/jpc.12814. Epub 2015 Jan 15.
- ⁹⁸ Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, Lucas BR, Doney R, Salter C, Try J, Hawkes G, Fitzpatrick E, Hand M, Watkins RE, Martiniuk AL, Bower C, Boulton J, Elliott EJ.J Paediatric Child Health, *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project* (April 2015) 51(4):450-7. doi: 10.1111/jpc.12814. Epub 2015 Jan 15.
- ⁹⁹ Andersson E1,2, McIllduff C3,4, Turner K3, Thomas S4, Davies J4, Elliott EJ2,5, Einfeld S, Jandu Yani U 'For All Families' Triple P-positive parenting program in remote Australian Aboriginal communities: a study protocol for a community intervention trial BMJ Open (October 2019) 9;9(10):e032559. doi: 10.1136/bmjopen-2019-032559.
- ¹⁰⁰ Jane Weston and Sue Thomas, *Fetal alcohol spectrum disorder (FASD) and complex trauma: A resource for educators*, Marninwarntikura Women's Resource Centre (2018) <mwrc.com.au/pages/mwrc-blog>.
- ¹⁰¹ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western*

Australian Human Rights Commission
Effective approaches to prevention, diagnosis and support for FASD, 29 November 2019

Australia identifies challenges and informs solutions (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰² Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰³ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁴ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁵ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁶ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁷ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁸ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹⁰⁹ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.

¹¹⁰ Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, Boulton J, Fitzpatrick E, Latimer J, Elliott EJ, Martiniuk AL, *Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions* (2019) BMC Health Serv Res. 2019 Oct 26;19(1):758. doi: 10.1186/s12913-019-4605-0.