Preventing the Criminalisation of People with Fetal Alcohol Spectrum Disorder (FASD)

A Submission to the ACT 2022-23 Budget Consultation

May 2022

Foundation for Alcohol Research & Education

About FARE

The Foundation for Alcohol Research and Education (FARE) is the leading not-for-profit organisation working towards an Australia free from alcohol harms.

We approach this through developing evidence-informed policy, enabling people-powered advocacy and delivering health promotion programs.

Working with local communities, values-aligned organisations, health professionals and researchers across the country, we strive to improve the health and wellbeing of everyone in Australia.

To learn more about us and our work visit www.fare.org.au.

You can get in touch via email at info@fare.org.au

FARE is a registered charity, and every dollar you give helps fund projects keeping our communities healthy and safe. You can make a tax-deductible donation at: www.fare.org.au/donate.

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Executive summary

> "*Children with FASD should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility*." (U.N. Convention on the Rights of the Child)[1]

Fetal Alcohol Spectrum Disorder (FASD) is an incurable brain injury and the leading preventable developmental disability in Australia. The disorder describes impacts on the brain and body of people prenatally exposed to alcohol. People with FASD experience challenges in their daily living and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.

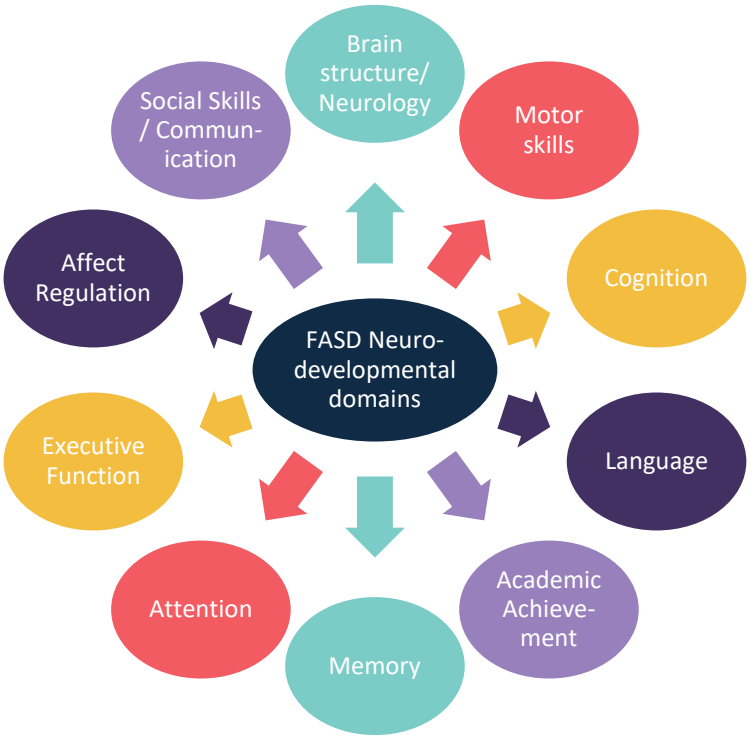
Without adequate support, these life challenges can mean people with FASD are more likely to have interactions with the criminal justice system, such as contact with police, courts and prisons.[2] For example, in the Banksia Hill Youth Detention Centre in Western Australia, representative research indicated more than a third of young people screened in detention had FASD.[3] A compounding factor is that Aboriginal and Torres Strait Islander communities – often over-policed and disproportionately incarcerated – can also significantly be impacted by FASD.[4]

This criminalisation of people with FASD is a harmful experience that further traumatises and can lead to a revolving door of incarceration and recidivism. Preventing this criminalisation is possible with the right investment in services in the community and in the justice system itself.

FARE's submission outlines a plan for how the ACT Government can achieve this. Preventing criminalisation will mean people with FASD can live their lives to the fullest, realising their human rights, and better engaging and contributing to Canberra society. This can lead to improvements in over half of the 56 indicators in all 12 of the domains of the ACT Wellbeing Framework.[5]

FARE thanks the ACT Government for the opportunity to make this submission to the 2022-23 ACT Budget consultation and looks forward to working together in future.

Ten brain domains affected by FASD[6]



Summary of recommendations

FARE makes the following recommendations to the ACT Government:

Decolonising justice and preventing criminalisation

Recommendation 1. Implement a decolonising and self-determination approach to preventing criminalisation of people with FASD, by ensuring that any interventions (including assessment, diagnostic and support services), build local community capacity in Aboriginal community-controlled services and all training for relevant professionals is culturally secure.

Recommendation 2. Reduce the stigmatisation of people with FASD and other disabilities, people with alcohol and/or other drug (AOD) issues and people engaging with the justice system. This includes implementing anti-stigma training, positive portrayals of people with FASD and other disabilities, and by using non-stigmatising language that acknowledges the social determinants of health.

Recommendation 3. Adopt the Social Model of Disability within the ACT Disability Strategy and the ACT Disability Justice Strategy Action Plan, recognising that attitudes, practices and structures are disabling and can prevent people from enjoying participation, inclusion and equality.

Recommendation 4. Establish a lived experience advisory group to centre the voices of people with lived experience of FASD and other disabilities, of AOD dependence and of incarceration. Ensure co-production of policies and programs targeting the prevention of criminalisation of people with FASD.

Recommendation 5. Implement a human rights approach to preventing criminalisation of people with FASD, that responds to health and disability issues, (such as FASD and AOD dependence), as health and disability issues, not as criminal justice issues. This includes implementing Recommendation 4 of the 2019 ACT Auditor-General's Report '*Obligations under the Human Rights Act 2004*': *"The Justice and Community Safety Directorate and Community Services Directorate should include, in key decision-making documents, a section for the explicit consideration and documentation of human rights in the decision."*

ACT justice system

Recommendation 6. Fully fund the reforms to service system identified in the '*Review of the service system and implementation requirements for raising the minimum age of criminal responsibility in the ACT*'. These include: *early identification and help, strengthening universal settings, improved integration of responses, building workforce capacity, building more trauma-informed services, a self-determined Aboriginal and Torres Strait Islander response, an independent authority, and a children's wellbeing and safety framework*.

Recommendation 7. Fully fund the implementation of the ACT Disability Justice Strategy Action Plans, including actions to improve education, screening, referral and assessment, service delivery and data.

Recommendation 8. Take an integrated, whole-of-Government approach to preventing the criminalisation of people with FASD, that facilitates information sharing and decision-making about all disability programs and funding. This could be through the Disability Justice Reference Group, and would involve the Health, Education, Justice and Community Safety, and Community Services Directorates.

Community support

Recommendation 9. Implement mandatory FASD professional development for all health, education, child protection and community services professionals, within the broader disability context, to improve awareness, understanding and capacity. This must be culturally secure and ideally be delivered face-to-face. This includes implementing recommendation 23 of the Australian Government Senate FASD Inquiry: *"Provide all educators with professional development training in the awareness, understanding and management of FASD."*

Recommendation 10. Implement adequately funded, neuro-developmental (including FASD) assessment and diagnosis, within the broader disability context, in health, education and child protection contexts, by building capacity in community owned and managed organisations. This includes implementing recommendation 24, 26 and 27 of the Senate FASD Inquiry: *"Ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level. All children and young people entering the child protection systems are screened for FASD."*

Recommendation 11. Implement effective referral pathways to appropriate and adequately funded community services for people with FASD, their families and carers, including housing, healthcare, education, disability, employment, and other social services.

Recommendation 12. Work with the Commonwealth Government to address barriers to access and eligibility with both the National Disability Insurance Scheme (NDIS) and Disability Support Pension (DSP). This includes advocating for full implementation of recommendations 21 and 22 of the Senate FASD Inquiry i.e. "*to include FASD in the List of Recognised Disabilities and that the eligibility requirements for the Disability Support Pension be reviewed to include individuals with FASD with an IQ above the low range".*

Justice reform

Recommendation 13. Advocate to the Commonwealth Government to restore eligibility of people in the ACT justice system to universal services, i.e. National Disability Insurance Scheme (NDIS), Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare.

Recommendation 14. Develop an ACT Bench Book for ACT Judicial Officers as a resource to guide them in providing accommodations, decision-making, and making appropriate referrals, for people with disabilities (including FASD). Such a resource would need to be culturally secure.

Recommendation 15. Implement mandatory FASD professional development for all justice professionals, within the broader disability context, to improve awareness, understanding and capacity. This must be culturally secure and ideally be delivered face-to-face. This includes implementing recommendation 28 of the Senate FASD Inquiry: *"Provide further funding to train custodial officers in FASD-specific strategies for dealing with youth with FASD or suspected FASD in correctional facilities."*

Recommendation 16. Implement adequately funded, neuro-developmental (including FASD) assessment, diagnosis, and support, within the broader disability context, in youth and adult justice systems by building capacity in community owned and managed organisations. This includes implementing recommendations 26 and 27 of the Senate FASD Inquiry: *"All children and young people entering youth justice are screened for FASD."*

Recommendation 17. Design and implement a disability specialist court, modelled on the FASD Court in Manitoba, Canada. This specialist court would be culturally secure, disability-accommodating (including FASD), and provide diversionary alternatives. This includes supporting recommendation 29 of the Senate FASD Inquiry: *"Fund an independent study into best-practice diversionary programs and alternative therapeutic facilities for individuals with FASD or suspected FASD within the justice system."*

Evaluation

Recommendation 18. Improve data collection to better inform FASD policy and program responses, by ensuring information about prenatal alcohol exposure is collected in an informed, supportive and confidential manner, and prenatal alcohol exposure and diagnostic records are made accessible to all relevant health and justice staff. This includes fully implementing recommendation 3 of the Senate FASD Inquiry: *"Implement mandatory reporting on standardised data for maternal alcohol consumption in the Perinatal National Minimum Data Set."*

Glossary of terms

ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ALS	Aboriginal Legal Service
AMC	Alexander Maconochie Centre
Apgar	A quick test performed on a baby at 1 and 5 minutes after birth.
CICADA	Care and intervention for children and adolescents affected by drugs and alcohol
CJS	Criminal Justice System
CLE	Continuing Legal Education
Confabulate	Fabricate imaginary experiences as compensation for loss of memory.
CYPS	Child and Youth Protection Service
Decolonise	Reverse and remedy the inter-generational physical, cultural and psychological impacts of European colonisation of Aboriginal and Torres Strait Islander peoples.
DSP	Disability Support Pension
FARE	Foundation for Alcohol Research and Education
FASD	Fetal Alcohol Spectrum Disorder
FSANZ	Food Standards Australia New Zealand
GPs	General Practitioners
JACS	Justice and Community Safety Directorate
MACR	Minimum Age of Criminal Responsibility
NACCHO	National Aboriginal Community Controlled Health Organisation
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NOFASD	National Organisation for Fetal Alcohol Spectrum Disorder
NPDC	National Perinatal Data Collection
OOHC	Out Of Home Care
PAE	Prenatal Alcohol Exposure
PBS	Pharmaceutical Benefits Scheme
RJU	Restorative Justice Unit
SAFER initiative (WHO)	Strengthen restrictions on alcohol **availability** Advance and enforce **drink driving** counter measures Facilitate access to screening, brief interventions and **treatment** Enforce bans on alcohol advertising, sponsorship, and **promotion** Raise **prices** on alcohol through excise taxes and pricing policies
Senate FASD Inquiry	Senate Inquiry into *effective approaches to prevention, diagnosis and support for FASD* that reported in March 2021.
Sentinel facial features	Facial anomalies which, when seen in combination, are indicative of, and highly specific to prenatal alcohol exposure.
UN	United Nations
VicFAS	Victorian Fetal Alcohol Service
WHO	World Health Organisation

1. Introduction

FARE has recently been engaging with the ACT Government across a number of inquiries and reviews. These have included lodging submissions to the '*Review of ACT health programs for children and young people'*, the '*Raising the Minimum Age of Criminal Responsibility Inquiry'* and the '*ACT Community Corrections Inquiry'*.

FARE has also been working closely with ACT Health to deliver health promotion programs in the ACT, including '*Ripple'*, '*TOM'* (Third of Men), '*Reduce Your Risk'* and '*Pregnant Pause'*. The ACT Government's support for these successful campaigns, set the foundation for FARE to successfully seek federal funding for a national campaign on alcohol, pregnancy and breastfeeding. This national awareness program focusses on the primary prevention of Fetal Alcohol Spectrum Disorder (FASD).

However, prevention of FASD does not help the many people who already live with FASD (diagnosed or undiagnosed) in Australia.

Our submission outlines recommendations so the ACT Government can ensure people with FASD are appropriately supported, both in the community, to prevent engaging with the criminal justice system, and within the criminal justice system, to prevent further criminalisation.

This submission was developed through consultation with a range of government and non-government organisation stakeholders, with legal, clinical, academic, social service, disability and lived experience expertise of FASD and the criminal justice system. Experts across Australia were consulted, as well as targeted engagement with ACT stakeholders.

Health prevention framework

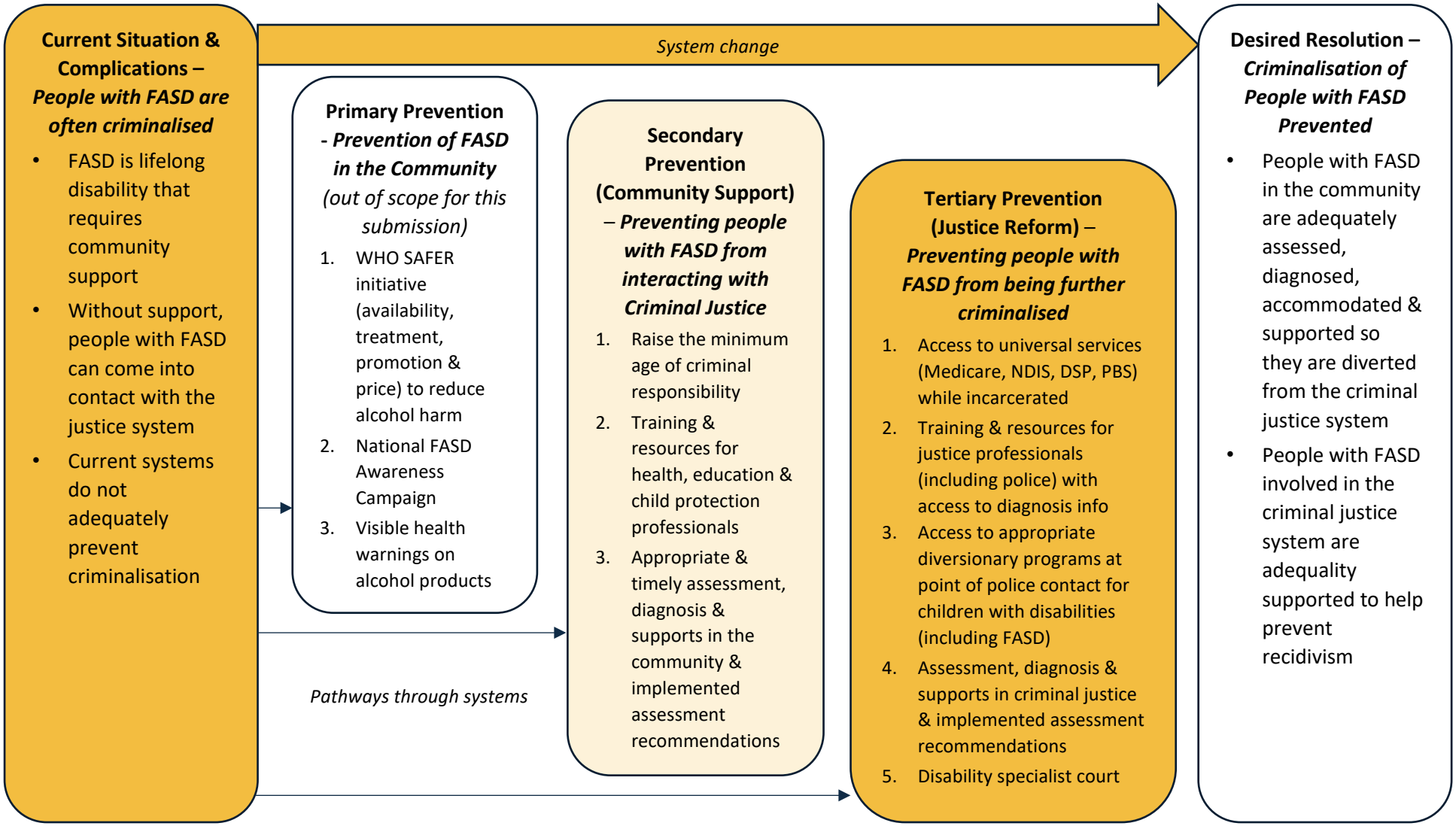
On the next page, we show how using a health prevention framework can help prevent the criminalisation of people with FASD. It shows the current situation where there is a high prevalence of people with FASD in the criminal justice system, and a desired resolution of preventing criminalisation of people with FASD.

Primary prevention (out of scope for this submission), aims to prevent FASD in the community. This Budget Submission targets secondary and tertiary prevention of people with FASD interacting with the criminal justice system. Secondary prevention (see the '*Community support'* section) aims to prevent the criminalisation of people with FASD in the community, by preventing interacting with the criminal justice system due to FASD. Tertiary prevention (see the '*Justice reform'* section), aims to prevent further criminalisation of people with FASD by providing adequate supports in the criminal justice system.

The three-tier health prevention model parallels the public health services pyramid model of primary (universal), secondary (specialised) and tertiary (crisis) services. The higher the level of service is, the more complex the need and the individual service delivery response. When universal and secondary services are adequately funded and accessible, it provides a structural health prevention, reducing the need for tertiary (crisis) services. For example, research into the cost-effectiveness of early intervention programs has shown that $1 spent early in life, can save $17 by the time a child reaches mid-life.[7]

However, the *Review of the service system and implementation requirements for raising the Minimum Age of Criminal Responsibility (MACR) in the ACT*[8] identified a bottleneck in the ACT service system at the secondary level. The report said that it was very difficult for children and their families to access secondary services from universal services, and once problems escalate tertiary services, (child protection and youth justice), inevitably become involved. This submission addresses those gaps in the ACT service system which can help prepare for raising minimum age of criminal responsibility, and help prevent the criminalisation of people with FASD.

Theory of change to prevent the criminalisation of people with FASD



2. Background about FASD

FASD definition, causes, consequences and prevalence

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term describing a range of neuro-developmental impairments[9]. FASD is a lifelong disability, that describes impacts on the brain and body of individuals prenatally exposed to alcohol. People with FASD experience challenges in their daily living and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.[10]

Causes

There is no known safe level of prenatal alcohol exposure.[11] Alcohol passes the placenta during pregnancy and the embryo/fetus has minimal ability to metabolise alcohol. This is why the National Health and Medical Research Council (NHMRC) recommends *'women who are pregnant or planning a pregnancy should not drink alcohol'*[12]. Other risks of alcohol consumption in pregnancy include miscarriage, stillbirth, low birth weight and pre-term birth.

Australia has comparatively high rates of prenatal alcohol exposure.[13] There are a range of factors contributing to this, such as wider socio-cultural factors and the social environment around women who are pregnant, including their own attitudes and beliefs.[14] Research has also shown that levels of alcohol use prior to the pregnancy, and experience of intimate partner violence, increase the likelihood of prenatal alcohol exposure.[15] Other factors include:

- lack of awareness (or disbelief) of risk and of the national alcohol guidelines,
- about 40 per cent of all pregnancies are unplanned,[16]
- relatively high levels of alcohol use across the population,[17]
- inadequate support and services for people with problematic alcohol use, and
- limited use of screening and brief interventions in antenatal care.

The underlying causes of FASD are complex and primary prevention initiatives require a range of efforts to inform and support women who are pregnant to avoid alcohol intake.

Consequences

The immediate consequences of having FASD are the physical, emotional, social and learning challenges outlined above. These challenges can also present as behaviours and attitudes that can be misinterpreted as intentional criminal behaviour or as defiance towards justice professionals. This results in a significant over-representation of people with FASD in the criminal justice system. Yet these behaviours and attitudes are a result of people's brain-based disability and functional capacity, not wilful criminal acts.

Without diagnosis and appropriate intervention, people with FASD have a higher likelihood of secondary issues such as requiring greater support with education, health and mental health, problems with parenting and employment, homelessness, and problematic alcohol and other drug use. With the many co-morbid conditions people with FASD experience, the medical and social costs are great. In Australia, the annual cost of FASD in 2018 was estimated at $1.18 billion.[18]

Receiving a diagnosis of FASD can lead to appropriate services and support, as well as understanding of the individual's strengths and difficulties. It allows for future planning and can also assist in prevention of future alcohol-exposed pregnancies. All these differences can improve life outcomes for the individual receiving the diagnosis.

Prevalence of FASD in Australia

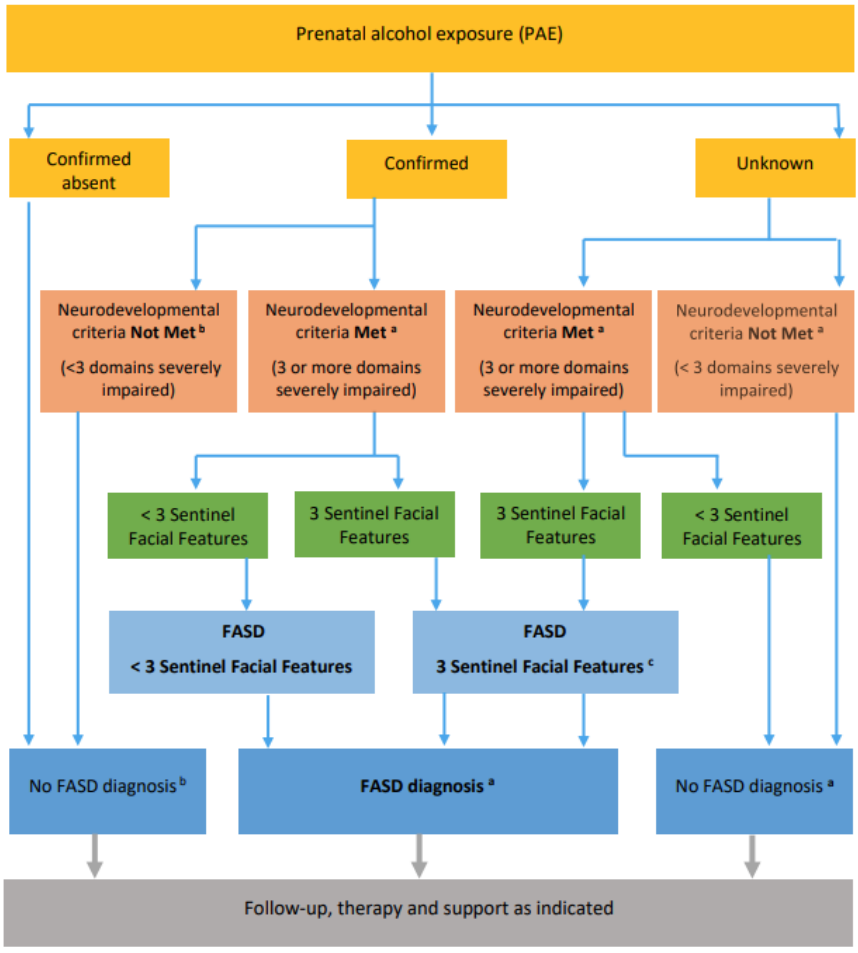
FASD is the leading preventable developmental disability in Australia. However, data collection relating to FASD is inadequate, and so the actual prevalence of FASD is not accurately known. There are concerns that current figures are likely to underestimate the rates of FASD.[19] As of 2012 estimates suggested that 2 per cent of all Australian babies were born with some form of FASD.[20] Modelling for the Food Regulation Standing Committee in 2018 concluded there is a plausible FASD prevalence rate of five per cent of the Australian population, drawing on a range of international data and research.[21] Literature on FASD generally reports that the 5 per cent figure is an underestimate due to the lack of diagnostic services for children and adults.[22]

ACT prevalence

The ACT has an opportunity to implement effective data collection and provide health practitioners and researchers with more information to inform treatments. Maternal perinatal data collection of births in ACT hospitals and home births, covers such topics as mother's demographics, type of induction, method of birth, malformations, and apgar scores (baby's condition) at birth.[23]

GPs, midwives and gynaecologists should be trained and supported to collect accurate information about prenatal alcohol exposure, in an informed, supportive and confidential manner. This should then be matched with data about children who are found to have impairments at early health screening. FASD diagnosis relies on confirming prenatal alcohol exposure.

Diagnostic algorithm for FASD[24]



Recent FASD-related inquiries, action plans and campaigns

FASD has received attention in recent years, both nationally and in the ACT. Following is an overview of recent FASD-related inquiries, reviews, action plans, advocacy and awareness campaigns. These initiatives build on expert FASD work done over previous decades.

FASD-related Australian inquiries

Senate FASD Inquiry (2019-2021): The inquiry into *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder* (Senate FASD Inquiry) by the Senate Community Affairs References Committee, reported in March 2021.[25] The inquiry made recommendations for State and Territory Governments to improve awareness, prevention and support for people with FASD. These included prevalence research, awareness and prevention, diagnosis, disability and parent / carer support, screening young people in child protection and youth justice systems.

FARE lodged a submission to the Inquiry[26] and appeared at two public hearings. The submission made recommendations about a National Awareness Campaign, progress on previous inquiries and the national action plan, health professionals, media and industry, pregnancy warning labelling, data collection and prevalence studies and the World Health Organisation (WHO) Global Alcohol Strategy.

Disability Royal Commission (2019-2023): The *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* was established in April 2019 and is due to table its final report in September 2023. Its October 2020 Interim Report references FASD and various public hearings heard about experiences of people with FASD.[27]

Coroner's Court of Western Australia Inquest (2017-2019): *The Inquest into the 13 Deaths of Children and Young Persons in the Kimberley Region*, between 2012 and 2016, found similar circumstances, life events, developmental experiences and behaviours appear to have contributed to making the deceased vulnerable to suicide. The coroner reported that FASD was likely to have played a part in some of these youth suicides, and made recommendations about FASD screening, National Disability Insurance Scheme (NDIS), Medicare, local FASD projects, diagnostic capacity and education campaigns.[28]

FASD-related ACT inquiries and reviews

Review of ACT health programs for children and young people (March – June 2021): The ACT Standing Committee on Health and Community Wellbeing inquired into programs in place in the ACT providing for children and young people. This included assessing the adequacy, availability, and implementation of current preventative programs and associated programs for screening, diagnosis, and treatment for FASD.[29] The inquiry report has just been published in May 2022. FARE lodged a submission[30] to the inquiry welcoming efforts by the ACT Government in raising awareness of FASD, supporting mums-to-be in going alcohol free, and efforts to implement mandatory pregnancy health warnings on all alcohol products. The submission made recommendations about the above Senate FASD Inquiry, data collection gaps left by NDIS and improved FASD screening, diagnosis and support.

ACT Raising Minimum Age of Criminal Responsibility Inquiry (June – August 2021): The ACT Government has committed to raising the minimum age of criminal responsibility and is considering how that could be implemented. As part of this planning, it established an independent review led by Emeritus Professor Morag McArthur[31], and published a Discussion Paper for community comment. FARE lodged a submission to the inquiry[32], which made recommendations about alternative ways to achieve community safety, FASD in alternate pathway model design, professional workforce development and trauma-informed care. The review published its final report in October 2021,[33] which identified gaps in the ACT service system that require reform. This included lack of

service system coordination and integration, demand outstripping availability, children commonly not eligible for a range of services, workforce capability issues, need for safe accommodation, and limited prevention, early intervention and individualised support services availability.

ACT Disability Justice Strategy Review (August – September 2021): The Disability Justice Strategy 2019-2029 launched in August 2019, and is supported by the First Action Plan 2019-2023. Over the next ten years the Strategy will guide a shift in how the justice system interacts with people with disability. The strategy reflects the ACT Governments ongoing commitment to supporting the inclusion of people with disability in all spheres of life. From August to September 2021 the government asked for community and stakeholder feedback through surveys, face-to-face meetings, community events, and written submissions. The results of this feedback process have not yet been published.[34]

ACT Community Corrections Inquiry (June – November 2021): The ACT Justice and Community Safety Committee is inquiring into Community Corrections[35], seeking input from offenders and their families, victim survivors, and professionals working in the justice system and community sector. The inquiry reporting date is yet to be announced. FARE lodged a submission to the inquiry[36], which made recommendations about evidence-based, public health and human rights approach to reducing alcohol harm, both in the criminal justice system and in wider community, trauma-informed mental health and alcohol and other drug (AOD) treatment, the above Senate FASD Inquiry, FASD screening, diagnosis and support, gaps of the NDIS, Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare and FASD professional understanding and capacity.

The ACT Disability Strategy 2022-32 Review (March – July 2022): The ACT government is developing a ten-year Strategy to create a more welcoming and accessible community and improve the lives of the more than 80,000 Canberrans who identify as people with disability. The Strategy will centre the voices of people with disability. The ACT government is seeking ideas and experiences about how the ACT should implement inclusive actions and activities that create positive change in the community.[37]

FASD action plans

National FASD Strategic Action Plan 2018-2028: Following on from the *Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016,*[38] the *National FASD Strategic Action Plan 2018-2028* was developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia.[39] It aims to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities.

The national priority areas and objectives are:

- **Prevention (primary):** Reduce access and consumption of alcohol in the Australian community. Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy.
- **Screening and diagnosis:** Increase screening, diagnostic skills and knowledge in frontline professionals. Improve capacity for screening, diagnosis and surveillance.
- **Support and management:** Implement and evaluate better models of management, support and care. Support for parents, carers and families and in education and employment.
- **Priority groups:** Continue to support and evaluate targeted strategies and models of care for groups who are at higher risk than the general population. Work with the criminal justice system to implement therapeutic justice interventions.

Campaigns and developments

Diagnostic tool: In 2010, the Commonwealth Department of Health and Ageing commissioned FASD experts to develop a national diagnostic tool for FASD and a related guide. The tool aimed to assist clinicians in the diagnosis, management and referral of FASD, and contribute to the prevention of FASD through raising awareness of the potential harms of alcohol use during pregnancy. In 2015, a draft diagnostic tool and a guide were trialled, reviewed and revised.

The *Australian Guide to the diagnosis of FASD* was released in May 2016, and an updated version published in early 2020.[40] The Senate FASD Inquiry recommended that the Government undertake a national audit of current FASD diagnostic services and provide funding to identify priority areas and inform a longer-term and sustainable funding model. It also noted that this audit should include consideration of new diagnostic models and trials in order to evaluate their efficacy and cost-effectiveness if they were to be implemented more broadly in Australia.[41]

The University of Queensland (UQ) in collaboration with 12 organisations around Australia are currently undertaking a comprehensive review of the *Australian Guide for Assessment and Diagnosis of FASD*. As part of the process of revising the guideline, UQ is gathering experiences, input, and feedback from a wide range of Australian clinicians.[42]

Visible health warnings on alcohol (labelling): For more than 20 years, health groups, community organisations and people with FASD and their families advocated for visible health warnings about alcohol and pregnancy. In 2020, a visible health warning about the harm alcohol can cause to an unborn baby was made mandatory on alcohol products by Food Standards Australia New Zealand (FSANZ).[43]

National Alcohol Guidelines: In December 2020 the National Health and Medical Research Council (NHMRC) released updated guidelines on alcohol which include "*Guideline 3: To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol*".[44]

Awareness: FARE has received government support to run various health promotion programs:

- *Women Want to Know* provided practical resources to support health professionals to have conversations with pregnant women who weren't receiving much information.
- *Pregnant Pause* supported Canberra mums-to-be to go alcohol free during their pregnancy.
- The Senate FASD Inquiry recommended that the Australian Government develop a national public education campaign about alcohol and pregnancy. In December 2019, the Australian Government announced funding for FARE to undertake the '***National awareness campaign for pregnancy and breastfeeding'*** which will run from July 2020 to September 2024.[45] The National Program has four streams: targeting the general public, health professionals, women who are most at risk and Aboriginal and Torres Strait Islander peoples.

3. Decolonising justice and preventing criminalisation

Decolonising justice

Impact of colonisation, dispossession and systemic racial discrimination

The current social and economic circumstances of Aboriginal and Torres Strait Islander people are inextricably linked to the current and previous generations' experiences of European colonisation and dispossession. The consequences of colonisation are far-reaching and inter-generational. Violence, exercise of power and control by European settlers resulted in dispossession of land, disruption of culture and kinship systems, removal of children, racism, social exclusion, institutionalisation and entrenched poverty for Aboriginal and Torres Strait Islander people.[46]

The Royal Commission into Aboriginal Deaths in Custody (1987-1991) found that:

> "*The high rates of Aboriginal deaths in custody were directly related to the underlying factors of poor health and housing, low employment and education levels, dysfunctional families and communities, dispossession and past government policies… the most significant contributing factor bringing Aboriginal people into conflict with the criminal justice system was their disadvantaged and unequal position in the wider society*"[47]

Over-representation of Aboriginal and Torres Strait Islander people

The impact of colonisation also applies to the over-representation of Aboriginal and Torres Strait Islander people in criminal justice systems. Aboriginal and Torres Strait Islander people make up 30 per cent of all prisoners, but only 3.3 per cent of the Australian population.[48] Increasing over-representation in criminal justice institutions has the potential, in the absence of more appropriate responses, to further perpetuate social and economic exclusion, and compound losses of culture, family and purpose, for a growing number of Aboriginal and Torres Strait people.

Aboriginal and Torres Strait Islander children are significantly over-represented in detention, accounting for almost two thirds (65 per cent) of younger children in prisons. Aboriginal and Torres Strait Islander young people (75 per cent) were more likely than non-Indigenous young people (63 per cent) to have been under supervision. Nearly 2 in 5 (38 per cent) Aboriginal and Torres Strait Islander young people under supervision in 2019–20 were first supervised when aged 10–13, compared with about 1 in 7 (14 per cent) non-Indigenous young people.[49]

As the Uluru Statement from the Heart says:

> *"Proportionally, we are the most incarcerated people on the planet. We are not an innately criminal people. Our children are aliened from their families at unprecedented rates. This cannot be because we have no love for them. And our youth languish in detention in obscene numbers. They should be our hope for the future."*[50]

Aboriginal and Torres Strait Islander young people are a highly traumatised cohort, and as a result have higher rates of mental health and alcohol and other drug issues. Aboriginal and Torres Strait Islander communities are also disproportionately impacted by FASD,[51] with a rate of up to 12 per cent of births in some communities.[52]

A decolonising and human rights approach to FASD in justice contexts

Young people with FASD are at risk of involvement with the justice system as so many aspects of their lives remain fragmented including a lack of a secure home environment, early exposure to substance use, entrenched cycles of poverty, leaving school early, limited employment opportunities, and a lack of support for their disability.[53]

The prevention of criminalisation of people with FASD involves helping to prevent the criminalisation of Aboriginal and Torres Strait Islander peoples. This requires taking a decolonising and human rights approach based on self-determination. A decolonising process involves expanding the role of Indigenous owned and place-based processes and services embedded in Indigenous knowledge.[54] This means building local community capacity in Aboriginal community-controlled services, such as Winnunga Nimmityjah Aboriginal Health and Community Services,[55] to establish a community owned and managed (not fly-in / fly-out) FASD diagnostic service. It also involves mandating culturally-safe, professional development for all relevant professionals, delivered face-to-face.

Recommendation 1. Implement a decolonising and self-determination approach to preventing criminalisation of people with FASD, by ensuring that any interventions (including assessment, diagnostic and support services), build local community capacity in Aboriginal community-controlled services and all training for relevant professionals is culturally secure.

Human rights and disability discrimination

In 2004, the ACT was the first jurisdiction in Australia to enact a Human Rights Act.[56] The Act provides an explicit statutory basis for respecting, protecting and promoting fundamental human rights. The majority of these rights reflect Australia's international human rights obligations. Each time a new bill is presented to the ACT Legislative Assembly, the Attorney-General must prepare a compatibility statement for the Legislative Assembly. This must state whether the bill is consistent with human rights, and if not, how it is inconsistent.

These rights include the right to recognition and equality before the law. However, people with FASD do not experience equitable justice, as demonstrated by the over-representation of people with FASD detained in the justice system. Human rights legislation also covers the prevention of discrimination against First Nations peoples, people with disability like FASD, people with mental illness (including AOD dependence), and people incarcerated in the criminal justice system.

International obligations

In 2019, the United Nations released the following General Comments regarding articles 37 and 40 of the '*Convention on the Rights of the Child*', (which Australia is a party to), focussing on children's rights in justice systems:

> *"**Children with developmental delays or neurodevelopmental disorders or disabilities (for example,** autism spectrum disorders, **fetal alcohol spectrum disorders** or acquired brain injuries) **should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility**. If not automatically excluded, such children should be individually assessed."*[57]

Stigmatisation of disability, mental illness and AOD dependence.

Individuals with disability, mental health and AOD issues experience stigma that is pervasive and damaging to their quality of life. There is also evidence to suggest that stigma associated with FASD in particular is multi-layered and magnified in several ways. [58] These include individual and familial stigma, maternal stigma, cultural stigma, and mental health and AOD dependence stigma. This stigmatisation can lead to people being concerned about identifying as having a FASD diagnosis.[59]

Governments can help eliminate stigma by:

- Improving awareness in services, with anti-stigma training and resources.
- Positive portrayal of people in media and other public documents, promoting hope not fear.
- Engaging with people with lived experience to 'co-produce' policies, programs and services.
- Providing more equitable access to adequately funded support services.
- Treating health and disability issues as health and health and disability issues, not justice issues.
- Using non-stigmatising language that acknowledges social determinants of health.

Recommendation 2. Reduce the stigmatisation of people with FASD and other disabilities, people with alcohol and/or other drug (AOD) issues and people engaging with the justice system. This includes implementing anti-stigma training, positive portrayals of people with FASD and other disabilities, and by using non-stigmatising language that acknowledges the social determinants of health.

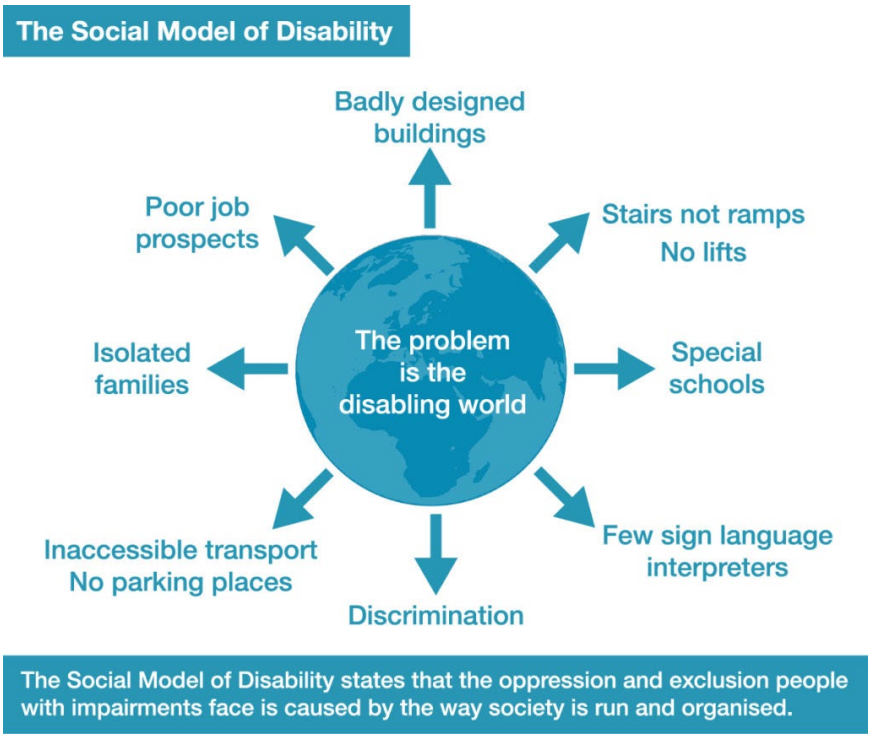
Social model of disability

The ACT Government has an obligation to follow the National Disability Strategy 2021 – 2031,[60] which is based on the social model of disability. This model recognises that attitudes, practices and structures are disabling and can prevent people from enjoying economic participation, social inclusion and equality. This is not an inevitable result of an individual's impairment.

Responses to the over-representation of people with FASD (and other disabilities) in justice settings need to follow the *Social Model of Disability* in re-framing the systems as having the deficits, rather than people with disabilities. Issues of mental health and AOD dependence must be framed as health issues, not justice issues, that acknowledge the social and commercial determinants of health.

Two Models of Disability (from Inclusion London)[61]

This is a diagram of the traditional Medical Model of Disability, which the Social Model was developed to challenge.



Recommendation 3. Adopt the Social Model of Disability within the ACT Disability Strategy and the ACT Disability Justice Strategy Action Plan, recognising that attitudes, practices and structures are disabling and can prevent people from enjoying participation, inclusion and equality.

People with lived experience of FASD and criminal justice

The design of responses to the over-representation of people with FASD (and other disabilities) must centre the voices and participation of people with lived experience of FASD and other disabilities, of AOD dependence and of incarceration. This co-production must involve genuine empowerment with self-directed ownership. FARE has established a working group of people with lived experience of FASD, and is establishing a further network of people with lived experience of alcohol harm, in partnership with VicHealth, in Victoria.

Recommendation 4. Establish a lived experience advisory group to centre the voices of people with lived experience of FASD and other disabilities, of AOD dependence and of incarceration. Ensure co-production of policies and programs targeting the prevention of criminalisation of people with FASD.

Recommendation 5. Implement a human rights approach to preventing criminalisation of people with FASD, that responds to health and disability issues, (such as FASD and AOD dependence), as health and disability issues, not as criminal justice issues. This includes implementing Recommendation 4 of the 2019 ACT Auditor-General's Report '*Obligations under the Human Rights Act 2004*': *"The Justice and Community Safety Directorate and Community Services Directorate should include, in key decision-making documents, a section for the explicit consideration and documentation of human rights in the decision."*

Criminalisation of people with FASD

Over-representation and inequitable justice

Criminal justice systems are intended to provide equitable justice for all citizens, however people with FASD do not experience equitable justice. This is demonstrated by the over-representation of people with FASD detained in the criminal justice system. Representative research at the Banksia Hill Youth Detention Centre in Western Australia identified that more than a third of the young people screened in detention were diagnosed with FASD. Researchers suggested this may be an under-estimate due to, for example, the lack of confirmation of prenatal alcohol exposure, suspecting that almost half of these young people may have FASD.[62] This research gives an indication of how significant a problem this is across Australia, the extent of which the community is only beginning to grasp.

Misinterpreting neuro-behavioural symptoms

The physical, emotional, social and learning challenges that people with FASD experience, can present as behaviours and attitudes that can be misinterpreted as intentional criminal behaviour or as defiance towards justice professionals. These behaviours and attitudes include the following:

FASD neuro-behavioural symptoms[63]

- **Feelings and empathy.** Difficulty identifying feelings, lacking empathy or seeming disrespectful. Misses social cues.
- **Planning and memory.** Difficulty keeping appointments or following through. Memory problems, trouble with planning, difficulty organising or sequencing (e.g. breach bail or sentence conditions)
- **Cause and effect consequences.** Difficulty accepting consequences. Difficulty forming associations and linking cause and effect (e.g. between offence and sentence)
- **Learning from mistakes.** Difficulty learning from mistakes. Difficulty integrating, or remembering (e.g. may lead to re-offending)
- **Adapting.** Difficulty adapting to new situations such as community-based orders and incarceration. Maybe be seen as 'oppositional'.
- **Takes time.** Slow cognitive pace, seems to be ignoring, or takes more time (e.g. answering questions, coping with cognitive behavioural therapy programs).
- **Impulsive and risky.** Difficulty behaving safely. Difficulty thinking in a sufficiently abstract way so cannot predict outcomes, even if they seem obvious (e.g. consequences of risky behaviours).
- **Speech and language.** Difficulty with communicating.
- **Suggestible and confabulation.** Difficulty being truthful and may be highly suggestible. May confabulate, (i.e. fabricate imaginary experiences as compensation for loss of memory).

These behaviours and attitudes are a result of the brain-based disability and the functional capacity of people with FASD, not wilful criminal acts. Yet, without accommodation, these behaviours and attitudes can result in unjust engagement with the criminal justice system, which has contributed to the significant over-representation of people with FASD in criminal justice systems.

4. ACT justice system

The ACT justice system is overseen by the ACT Justice and Community Safety Directorate and the ACT Community Services Directorate. The ACT Justice and Community Safety Directorate, through ACT Corrective Services, operates the *Alexander Maconochie Centre*. The ACT Community Services Directorate operates the *Bimberi Youth Justice Centre* and Child and Youth Protection Services. Being the smallest jurisdiction in Australia, the ACT is also unique, being the only State or Territory where the Australian Federal Police (AFP) provide community policing through ACT Policing.

The ACT has a Restorative Justice Unit whose objective is to provide restorative justice to members of the ACT community who have been affected by an offence, in a forum that provides:[64]

- victims with an opportunity to talk about how the offence has affected them,
- offenders with an opportunity to accept responsibility for their actions,
- victims, offenders and supporters an opportunity to discuss the harm and what needs to be done to repair that harm, and
- offenders with an opportunity to repair the harm done by the offence.

The Restorative Justice Unit could be used to bring together networks to provide culturally / neuro-developmentally responsive ways for dealing with offenders suspected of having FASD.

Challenges for the ACT criminal justice system

The ACT Government's '*Reducing Recidivism in the ACT by 25% by 2025*' (RR25BY25) document, outlines some of the challenges facing the ACT criminal justice system:[65]

- **Increase in prison population.** There has been a significant growth in the number of people detained at the *Alexander Maconochie Centre* in recent years. Numbers have risen from 268 detainees in 2012, to 429 detainees in 2019, an increase of 60 per cent.
- **Increase in recidivism.** Re-offending rates, (within two years of release), have increased in the ACT from 38.7 per cent in 2014–15 to 42.4 per cent in 2018–19. When including those returning to Community Corrections, the ACT has the highest recidivism rate of any Australian State or Territory of 71.3 per cent.[66]
- **Increase in costs.** ACT crime rates are going down, but incarceration levels continue to rise. The ACT criminal justice system has experienced an increase in prison population, costs and recidivism.[67] The ACT justice system costs $270 million annually and is estimated to increase to $337 million by 2025.

Reducing the number of people with FASD engaging with the criminal justice system can contribute to reducing the prison population, and the rate of recidivism. This will contribute to reducing the need for an expensive expansion of the Alexander Maconochie Centre in Canberra. In a significant Australian first, the ACT government is redirecting $132 million over four years, that would have otherwise been spent expanding prisons, towards programs focused on rehabilitation and reintegration.[68]

Legislative changes, problematic AOD use, and other social determinants are significant contributors to increasing contact with the ACT criminal justice system:[69]

- **Changes in justice legislation and practices.** More awareness of domestic, family and sexual assault, more effective policing strategies, and the reduced rates of bail are contributing to higher rates of incarceration.
- **Social disadvantage.** Social issues like housing, unemployment, poverty and family trauma, particularly among young people, also have an impact on increasing risk of contact with the ACT criminal justice system. [70]

- **Alcohol harm.** In 2016, more than one third (36 per cent) of people entering detention in the ACT criminal justice system are reported as engaging in harmful or likely dependent alcohol use in the 12 months prior to their current incarceration.[71] In 2018, almost one third (31 per cent) were reported to be at high risk of alcohol harm.[72]

Criminal justice system elements and FASD impacts

FASD affects an individual across all aspects of the criminal justice system, from arrest to incarceration, this then effects their experience of equitable justice. There are many elements of the criminal justice system that impact on whether people with disabilities, like FASD, experience equitable justice. These include the following:

Area (Professions)	Investigation (Police)	Adjudication (Lawyers and Judges)	Corrections (Correctional Officers)
Elements	• Arrest • Offences and charges • Culpability	• Fitness to plead • Remand and bail • Defence and evidence • Sentencing, mitigating circumstances • Diversionary programs	• Incarceration • Prison services • Parole and recidivism

If a person's condition, such as FASD, can be identified and appropriate accommodations made, the courts have the discretion to use referral or diversionary pathways, where they exist. The reforms needed are adequately resourced screening and referral for assessment, professional training and court-ordered assessments and reports (backed by adequately funded support services). This, along with adequate FASD accommodations, could have direct impact on fitness to plead and sentencing, such as conditional suspended sentences and diversionary pathways.[73]

Currently, mental health assessment reports are funded by ACT Corrections, not ACT Courts, and only include mental health treatment history, not active assessments. According to our consultation, mental health court reports appear not to reference FASD, despite the evidence of FASD prevalence with people coming into contact with the criminal justice system.

Raising the minimum age of criminal responsibility

The ACT Government is the first Australian jurisdiction to commit to raising the minimum age of criminal responsibility from 10 to 14 years old, in line with calls from numerous bodies including the United Nations[74] and the Australian Human Rights Commission[75]. This is a significant step to preventing the criminalisation of children, especially those living with FASD. Alongside this legislative change, the ACT government has been investigating the implications for how to support young people to avoid contact with the criminal justice system.

Given the higher prevalence of FASD currently present within youth justice settings, appropriate screening, diagnosis and support is critical to improving the lives of these children and to preventing interaction with the criminal justice system.

Recommendation 6. Fully fund the reforms to service system identified in the '*Review of the service system and implementation requirements for raising the minimum age of criminal responsibility in the ACT*'. These include: *early identification and help, strengthening universal settings, improved integration of responses, building workforce capacity, building more trauma-informed services, a self-determined Aboriginal and Torres Strait Islander response, an independent authority, and a children's wellbeing and safety framework*.

ACT wellbeing and justice strategies

Below are strategies that guide the ACT Government in achieving wellbeing and justice outcomes, which have been highlighted here due to their relevance to preventing the criminalisation of people with FASD. Recommendations made in this submission align with these strategies to ensure they are meeting stated ACT Government objectives.

Preventing the criminalisation of people with FASD involves reforming more than just the ACT criminal justice system. There are multiple connected programs and services within multiple ACT directorates that must be addressed. The ACT Wellbeing Framework is an overarching structure that reflects this inter-connectedness.

ACT Wellbeing Framework

The ACT Government has developed a Wellbeing Framework to better understand the impact of its policies and proposals on the wellbeing of people, institutions and environment in the ACT. [76] The ACT Government has invited people engaging with the budget consultation process to consider the Wellbeing Framework. [77]

The Wellbeing Framework has 12 different domain areas and a total of 56 indicators across those 12 domains. FASD and criminal justice engages with over half the Wellbeing Indicators in all 12 Domains of the Framework, including personal wellbeing, access to services, early childhood education, learning growth, equity of educational outcomes and student belonging (see the table below).

FASD and Criminal Justice links with ACT Wellbeing Framework Indicators and Domains

Domain	Relevant Wellbeing Indicator	Connection with FASD & Justice (at risk of, or need support for)
Personal wellbeing	• Personal wellbeing	• Motor skills, physical health, learning, memory, attention, communication, emotional regulation and social skills
Access and connectivity	• Access to services	• Inequitable access to support services, inequitable justice
Economy	• Income inequality	• Unemployment • Diagnosis slow, complex and expensive, NDIS approval is also slow and complex
Education and life-long learning	• Early childhood education • Learning growth • Equity of educational outcomes • Student belonging • Learning for life	• Learning, memory, attention, communication • Social skills • Education • Late diagnosis impacts on neuro-development
Environment and climate	• Connection to nature	• Mental health support, social skills (Green Spaces)
Governance and institutions	• Access to justice and restorative practice • Human rights	• High prevalence of FASD in criminal justice system • Discrimination, participation, exclusion, lack of equity and access
Health	• Overall health • Best start to life • Life expectancy • Mental health • Access to health services • Healthy lifestyle	• Physical health • Motor skills, memory, attention, communication • Mental health • Problematic alcohol and other drug use

Domain	Relevant Wellbeing Indicator	Connection with FASD & Justice (at risk of, or need support for)
Housing and home	• Homelessness • Housing affordability and availability	• Unemployment • Homelessness • Diagnosis slow, complex and expensive, NDIS approval is also slow and complex
Identity and belonging	• Sense of belonging and inclusion • Valuing Aboriginal and Torres Strait Islander cultures and recognising our Traditional Custodians	• Social skills • High prevalence of Aboriginal and Torres Strait Islander peoples with FASD in criminal justice system
Living standards	• Income levels • Cost of living	• Unemployment • Diagnosis slow, complex and expensive, NDIS approval is also slow and complex
Safety	• Feeling safe • Victims of crime • Emergency services	• Suggestibility can place children < minimum age of criminal responsibility at risk of being manipulated to front crimes • Lack of awareness of FASD by police and justice professionals
Social connection	• Sense of social connection • Levels of loneliness • Participation in community events and activities	• Social skills • Memory, attention, communication • Problems with parenting
Time	• Unpaid work including caring	• Diagnosis slow, complex and expensive, NDIS approval is also slow and complex

Disability Justice Strategy 2019-2029 - address unequal access to justice in the ACT

Over the next ten years the Disability Justice Strategy[78] will guide an important shift in how the justice system interacts with people with disability. In order to be effective, the actions will need to be innovative, consultative and responsive to changing circumstances. The First Action Plan 2019-2023 sits under the Disability Justice Strategy and describes the first four years of work and the commitments made by stakeholders to ensure the ACT provides equal access to justice for people with disability.[79]

Recommendation 7. Fully fund the implementation of the ACT Disability Justice Strategy Action Plans, including actions to improve education, screening, referral and assessment, service delivery and data.

Reducing Recidivism in the ACT by 25% by 2025 (RR25BY25)

The ACT Government is planning to significantly reduce recidivism by implementing the '*Reducing Recidivism in the ACT by 25% by 2025'*[80] plan which includes the following related Pillars:

- Pillar 3. Supporting people with substance use disorders in the justice system
- Pillar 4. Supporting people living with a mental illness or disability in the justice system.

Building Communities Not Prisons – ACT Justice Reinvestment Strategy

The ACT Government is taking a justice reinvestment approach to redirect funding away from building new prisons to invest in prevention and early intervention, with adequately funded supports and services.

Justice Reinvestment is about developing a more cost-effective approach to improving criminal justice outcomes by reducing crime and diverting offenders, and those at risk of becoming offenders, from the criminal justice system. The ACT Justice Reinvestment program, '*Build Communities Not Prisons*',[81] includes providing early support for people living with a mental illness or disability.

Multi-directorate co-operation

Most social, health and wellbeing issues benefit from an improved co-operation between government departments. However, for the multi-faceted disability of FASD, this co-operation is critical.

Preventing the criminalisation of FASD spans mental and physical health, education, community services, disabilities, child protection, youth justice, corrective services. This would require the combined and co-ordinated efforts of multiple ACT Directorates. In some cases, new program initiatives may rely on information-sharing from more than one Directorate. In others, an investment in one Directorate will mean a significant saving in another.

To succeed, the ACT Government must take a whole-of-government approach to preventing the criminalisation of people with FASD. This could potentially make use of the ACT Disability Justice Strategy Reference Group.

Recommendation 8. Take an integrated, whole-of-Government approach to preventing the criminalisation of people with FASD, that facilitates information sharing and decision-making about all disability programs and funding. This could be through the Disability Justice Reference Group, and would involve the Health, Education, Justice and Community Safety, and Community Services Directorates.

5. Community support

FASD is caused by prenatal alcohol exposure and is therefore theoretically preventable. However, many of obstacles to prevention are recognised social determinants of health. For example, experiences of early life trauma; stressful life events; conflict with family members; intimate partner violence; societal and peer pressures; having a partner who uses substances; a history of child welfare involvement; and mental health challenges are all associated with increased risk for drinking during pregnancy. [82]

While prevention of FASD in the first place is a priority, supporting people with FASD is essential. The secondary intervention to prevent people with FASD from coming into contact with the criminal justice system is *in the community*, making structural and targeted improvements to health, education, child protection and community services.

Systemic reform to address gaps in the service system

The ACT Minimum Age of Criminal Responsibility Review published its Final Report in August 2021,[83] which included the following gaps in the ACT service system that require reform:

- lack of coordination and integration across the service system,
- demand outstrips the availability of services,
- children aged 10–13 are commonly not eligible for a range of services,
- range of workforce capability issues, including the structure of funding arrangements, workforce shortages, and the need to develop a trauma-informed workforce,
- limited prevention, early intervention and individualised support services for children.

Addressing these gaps will contribute to the goal of preventing criminalisation of people with FASD. This means improving health, education, child protection and community services.

Priority groups

In order for the ACT government to focus and prioritise the service improvement to prevent criminalisation of people with FASD in the community, it is important to target support to those most at risk, as early as possible. These include:

- children in out-of-home care,
- some Aboriginal and Torres Strait Islander populations, where there is high risk alcohol use,
- children of women who are alcohol dependent, and
- those referred to child mental health services.

Inter-generational trauma and FASD

Researchers have identified multi-generational contributions to the development of FASD. It is common for FASD to be present across generations and siblings, for example in one research study all six families had siblings with FASD.[84] In another study, grandmothers of children with FASD were found to be more likely to have histories of trauma, injuries, and alcohol use, than grandmothers of children without FASD.[85] Similarly, individuals with FASD report high rates of intergenerational trauma.

To adequately prevent the criminalisation of people with FASD, requires breaking the following predictable pathway:[86]

Child protection and out of home care

Research shows that children with FASD are overrepresented in out-of-home care, and that factors contributing to youth involvement with the justice system include involvement in out-of-home care (including foster care and group homes).[87] Many children with FASD continue to go undetected and, subsequently, go without adequate support in out-of-home care. There are high rates of misdiagnosis and missed diagnosis rates in children who are in out-of-home care. Without diagnosis, we are unable to provide appropriate supports and interventions for those impacted by FASD.

When there is inadequate FASD screening referral, assessment and diagnosis, the implications for the out-of-home care sector include:[88]

- inappropriate case management,
- inadequately trained and supported foster caregivers,
- ineffective parenting practices and/or behavioural interventions that exacerbate the child's condition,
- other inappropriate labels attached to the child's symptoms,
- availability of appropriate educational supports will be compromised,
- greater risk of placement breakdown or multiple placements resulting in poor outcomes,
- inappropriate medications may be prescribed,
- increased risk of developing secondary issues that lead to serious medical, social and legal consequences for the child, the family and for society, and
- the child's chances of reaching their full potential will be severely compromised.

Mandatory training for relevant professionals

Health, education, community services and child protection professionals are often the first point of contact for a person suspected of having FASD. They are likely to be among those who have the earliest opportunity to identify the possibility of FASD. The earlier FASD is identified, the earlier supports can be put in place which can have positive life outcomes, including preventing criminalisation. However, there is a lack of awareness and understanding of FASD among relevant professionals, leaving them lacking in confidence to identify potential FASD. In some cases, there is still a misconception that FASD is only a visible disability (e.g. features facial characteristics).

One pathway for identifying and responding to children suspected of having FASD is in the school system. As the Senate FASD Inquiry recommended, Governments should ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and students with FASD and suspected FASD, irrespective of IQ level.

This identification and response relies on these professionals having an awareness and understanding of FASD, which results from professional development that is ideally:

- mandatory for all relevant professionals,
- culturally secure,
- delivered face-to-face,
- based on expert, evidence-based clinical knowledge, and
- centres the voice of lived experience.

This FASD professional training is already available and being delivered around Australia, for example by such clinical and lived experience experts as the following:

- Dr Hayley Passmore, Researcher, Reframe Training, Project Lead, Telethon Kids Institute.
- Dr James Fitzpatrick, Patches Assessment Services, (Subiaco, Broome, Darwin, Newcastle, Adelaide and Hobart).

- Dr Natasha Reid, Clinical Psychologist and Research Fellow, the Child Health Research Centre, Faculty of Medicine, University of Queensland.
- Dr Robyn Williams, Nyoongar woman and Senior Research Fellow, Curtin Medical School.
- Dr Vanessa Spiller, Clinical Psychologist, JumpStart Psychology, Qld.
- Prue Walker, VicFAS Service Coordinator, Monash Health.
- The National Organisation for FASD Australia, (NOFASD).

Recommendation 9. Implement mandatory FASD professional development for all health, education, child protection and community services professionals, within the broader disability context, to improve awareness, understanding and capacity. This must be culturally secure and ideally be delivered face-to-face. This includes implementing recommendation 23 of the Australian Government Senate FASD Inquiry: *"Provide all educators with professional development training in the awareness, understanding and management of FASD."*

Access to assessment, diagnostic services and support

Screening and early intervention

By the time children with FASD interact with the justice system, unmet needs have often multiplied and become more complex. The complexity and clustering of risks and unmet needs increase the likelihood of future problems, including ongoing contact with criminal justice. This highlights the importance of early, coordinated and sustained help for children with FASD and their families.

There are no specific FASD screening tools that are recommended for use in Australia.[89] In 2021, the Western Australia Department of Health published an evaluation of eight FASD screening tools, but could not recommend the use of any of them.[90] The report made specific recommendations about each of the tools, which can help the future development of a validated FASD screening tool. The report also identified the potential benefits and harms of FASD screening and assessed the different approaches to FASD screening (universal, targeted and selective).

This screening needs to occur as early as possible, with the most likely contact points such as child health nurses, paediatricians, early childhood education, schools, GPs and child protection services.

This would involve GPs, midwives, gynaecologists, teachers, child protection workers, and social workers asking about prenatal alcohol exposure and neurodevelopmental concerns, as early as possible, in an informed, supportive and confidential manner. It also means those professionals having access to any available health data where they might be able to gather similar information.

If prenatal alcohol exposure or neurodevelopmental concerns are identified by the professionals, then a referral to an appropriate assessment and diagnostic service needs to be available.

Establishing a FASD diagnostic service

Specific funding and resourcing are needed for assessment and diagnosis of FASD. Diagnosis of FASD is complex, time-consuming and expensive and so it becomes difficult to access and many people miss out on the treatment and support that a diagnosis facilitates. Receiving a diagnosis is critical to children being supported appropriately to reach their full potential. To ensure that this can occur, it is important that there are enough health professionals with the expertise required to undertake a FASD diagnosis.

Australia now has a National FASD Diagnostic Tool providing the necessary clinical guidance on diagnosing FASD.[91] However, there are insufficient diagnostic services available, and the ACT does

not have a diagnostic clinic. This means that families seeking a diagnosis, which involves months of appointments, need to travel to outside the ACT, such as to Sydney. The ACT government should establish a FASD diagnostic service within the ACT, that is culturally secure and builds capacity in Aboriginal community-controlled services, such as Winnunga Nimmityjah Aboriginal Health and Community Services,[92] to establish a community owned and managed FASD diagnostic service. Assessment and diagnostic services for FASD can be embedded within already existing services, e.g. Aboriginal Community-Controlled Health Services.[93]

There are various public and private FASD diagnostic services around Australia. These include, but are not limited to:

- Central Australian Aboriginal Congress, Alice Springs, NT
- Coastal Developmental Paediatrics, Caloundra, Qld (Dr Heidi Webster, Developmental Paediatric Consultant)
- FASD Diagnostic Clinic Gold Coast, Child Development Services Gold Coast Health, Qld (Dr Doug Shelton, Clinic Director)
- Gidgee Healing Aboriginal Community Controlled Health Service, Mount Isa, Qld
- NSW FASD Assessment Service at the Children's Hospital at Westmead, NSW (Dr Elizabeth Elliot, Consultant Paediatrician)
- Patches Assessment Services, National FASD Assessment Network, Subiaco, Broome, Darwin, Newcastle, Adelaide and Hobart (Dr James Fitzpatrick, CEO)
- University of Queensland Neurodevelopmental Clinic (Dr Natasha Reid, Clinical Psychologist)
- Victorian Fetal Alcohol Service (VicFAS) at Monash Children's Hospital, Melbourne, Vic (Dr Katrina Harris, Developmental Paediatrician).

The FASD Hub Services Directory has further details of available services.[94]

A diagnostic service will also need to be provided in the criminal justice system. This could be an outreach service from the community service, or a service based in the detention centres. (See details in the next '*Justice reform'* section.)

One example of a private clinic model is the Patches Assessment Service. Patches has worked with other services (government child development services and independent hospital providers) in various states to help establish a sustainable private FASD assessment model. The Patches National FASD Project is an extension of the National FASD Diagnostic Services and Models of Care Project. From 2021 to 2024, this project's goal is to ensure continued FASD diagnostic services nationally by maintaining established service locations as well as implementing services in new locations. Patches have recently commenced services completing assessments in Adelaide and Hobart, and are close to delivering assessments in Shepparton (Vic) and Newcastle (NSW).

Models of Care

One example of a FASD Model of Care is the Patches Model of Care (shown in Appendix A). This Model shows stages in an integrated pathway for people with FASD:

1. Reason for Referral
2. Screening
3. Support / assessment service providers
4. Assessment team
5. Diagnoses
6. Service and funding for those diagnosed with significant functional impairment
7. Service and support.

These operate in the early childhood (0 to 5 years), education (5 years and over) and justice systems.

Other Models of Care include the Multidisciplinary Assessment Team Model of Care at the Children's Hospital at Westmead CICADA Centre.[95]

Estimated costs of assessment and diagnosis

Investments in preventive health, including in preventive FASD interventions, pay for themselves in reduced health and other social system costs including, in the case of FASD, reduced criminal justice costs. The cost of implementing the changes can be derived from existing indicative costs shown in the three different costing models below (details in Appendix B).

1. FARE 2016 Pre-Budget submission to the Commonwealth Treasury.[96]

An indicative budget of **$3.1 million** over three years would allow for the creation of a FASD Clinical Network and the establishment and continuation of FASD diagnostic clinics across Australia. This included a costing of **$729,000 over 3 years to establish a FASD Diagnostic Clinic in Goulburn.**

2. 2021 Review of Service System and implementation requirements for minimum age of criminal responsibility in the ACT.[97]

This model was developed for raising minimum age of criminal responsibility, and involves a multi-disciplinary therapeutic panel, which is also needed for FASD diagnosis (although the specific professional disciplines of the panel would vary for FASD). Estimated costs of a Multidisciplinary Therapeutic Panel:

- **Independent Chair** x 1: $875 per day or $32,745 per year.
- **Members** x 8: $800 (Per Diem) Sitting days minimum 12 per paid member.
- **Secretariat Support**: SOG B x 1 EFT $131,773 + oncosts and ASO6 x 1 EFT $88,899 + oncosts.

This (non-FASD panel) costing works out at approximately $990,000 (plus on costs) over 3 years.

3. Estimated costs of individual assessments provided by Patches.

- **Screening:** approximately **$1,000.**
- **Full diagnostic assessment:** approximately **$4,450,** with Paediatrician, Psychologist, and Speech Pathologist, including administration (at an established clinical service).

Recommendation 10. Implement adequately funded, neuro-developmental (including FASD) assessment and diagnosis, within the broader disability context, in health, education and child protection contexts, by building capacity in community owned and managed organisations. This includes implementing recommendation 24, 26 and 27 of the Senate FASD Inquiry: *"Ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level. All children and young people entering the child protection systems are screened for FASD."*

Access to support for people with FASD, their families and carers

Once assessment and diagnostic services identify people with FASD, access to appropriate supports needs to be provided, for people with FASD, and for their families and carers. As demonstrated above, FASD impacts on people's wellbeing across all of the domains in the ACT Wellbeing framework. People with FASD, their families and carers, need support for housing, healthcare, education, disability, employment and other social services.

Recommendation 11. Implement effective referral pathways to appropriate and adequately funded community services for people with FASD, their families and carers, including housing, healthcare, education, disability, employment, and other social services.

Critical to the provision of community support to people with FASD is ensuring they can access the NDIS and DSP. Currently there are barriers to access and the eligibility is difficult for both NDIS and the Disability Support Pension (DSP).

Recommendation 12. Work with the Commonwealth Government to address barriers to access and eligibility with both the National Disability Insurance Scheme (NDIS) and Disability Support Pension (DSP). This includes advocating for full implementation of recommendations 21 and 22 of the Senate FASD Inquiry i.e. "*to include FASD in the List of Recognised Disabilities and that the eligibility requirements for the Disability Support Pension be reviewed to include individuals with FASD with an IQ above the low range".*

6. Justice reform

There is an over-representation of people with FASD among people detained in the criminal justice system. Representative research at the Banksia Hill Youth Detention Centre in Western Australia identified that more than a third of the young people screened in detention were diagnosed with FASD. [98] This means that people with FASD do not experience equitable justice. Supporting people with FASD in the criminal justice system can help reduce further criminalisation, and reduce recidivism.

Systemic barriers – exclusion of NDIS, DSP, PBS and Medicare

People who are incarcerated are excluded from the National Disability Insurance Scheme (NDIS), Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare. The exclusion of people in prison who have a cognitive disability from essential health and social security supports represents a substantial barrier getting adequate support, care and protection for their complex needs. Screening, diagnosis and support should be covered and made available for people.

The Australian Government needs to restore NDIS, Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare eligibility for incarcerated people. These are all federal responsibilities, and the ACT Government can advocate to the Commonwealth Government to restore equitable access to these essential health supports.

Recommendation 13. Advocate to the Commonwealth Government to restore eligibility of people in the ACT justice system to universal services, i.e. National Disability Insurance Scheme (NDIS), Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare.

FASD training, practices and resources

Given the higher prevalence of FASD among people who come into contact with the justice system, it is crucial that police, lawyers and the judiciary improve their understanding of how FASD impacts decision-making. Justice and legal professionals need multidisciplinary, trauma-informed, culturally-appropriate training about FASD and its medical, social and legal implications. [99] This can help them identify and manage people suspected of having FASD or other neurological disorders. People having disabilities and cognitive impairment (including FASD) can mean they do not have the cognitive capacity to form criminal intent and alternatives to criminal justice must be sought.

For the ACT justice system to adequately respond to people with FASD, it needs to establish adequately-funded, trauma-informed, and culturally secure awareness training, policies and procedures, professional development, and resources.

Analysis of past surveys of justice professionals in WA and Queensland have indicated some lack of awareness of justice implications of FASD. This table shows the number of survey respondents in justice professional surveys published in 2013:

	Judges	Lawyers	Corrections	Police
2011 Qld Survey[100]	49	39	0	0
2011/12 WA Survey[101]	30	25	152	215

The proportion of survey respondents believing that FASD was real was much higher in WA (80 per cent) than in Qld (50 per cent), noting the different groups surveyed (see above table). [102,103] Police were the least likely of all justice professionals to report dealing with FASD. A fifth (20 per cent) said

it had no impact on their work. Some said it was not on the radar.[104] Other comments by police interviewees include: "*Only relevant to the court*", "*FASD is no excuse*", also mentions of victims' rights and their job being to protect community. Some police officers indicated they believed it was not their role. Some prosecutors also indicated that it was not their role.

Proportion of participants who had ever suspected; recommended, or sent a person for a diagnostic assessment where FASD suspected; been informed or knew that a person had FASD.[105]

Justice professional	Suspected FASD (%)	Recommended, referred, sent for assessment (%)	Been informed of FASD (%)	Known case of FASD (%)
Judges	60.7	26.9	n/a	42.8
Lawyers	60.0	17.3	45.8	40.0
Corrections	67.0	16.3	39.2	52.5
Police	42.8	n/a	15.8	22.8

n/a: question not asked of judicial or police participants

Criminal justice system policies, training and practices

The above surveys found that 90 per cent of justice professionals surveyed had never engaged the services of a person trained to support people with FASD. Reasons given for not using FASD services or support include that no such service existed, or it was expensive or inaccessible, and so support was often dependent on family members.

It also found that 80 per cent of justice professionals surveyed said they never sent a suspect for FASD assessment. Reasons provided for not referring included that they did not know where to send them, it would not change the result, that there was no pathway or funding, or that there was limited capacity.

The survey also indicates that knowledge of FASD services is highest for corrections, and lowest for police.[106] Some justice professionals believed that identifying FASD may result in a longer sentence. One lawyer reported having a judge refuse to access FASD assessment. Another said they refused to plea until the suspect was assessed for FASD. The ACT criminal justice system needs continuing legal education (CLE) to incorporate FASD.

Justice resources

FASD is now included in the Equal Justice Bench Book (WA) and Equal Treatment Bench Book (Qld), and Equality before the Law Bench Book (NSW). All State and Territory Bench Books should include practices for dealing with people with FASD. A significant majority of respondents to previous surveys of justice professionals in WA and Queensland indicated that FASD guidelines would be useful.

The ACT does not appear to have a Bench Book to guide the decisions of the judiciary in human rights and discrimination matters.[107] This information could include referral information, list of experts, research, professional development and case law.

It is also important to share resources with the Aboriginal Legal Service (ALS) in the ACT, who represent clients in the family and criminal court.

Recommendation 14. Develop an ACT Bench Book for ACT Judicial Officers as a resource to guide them in providing accommodations, decision-making, and making appropriate referrals, for people with disabilities (including FASD). Such a resource would need to be culturally secure.

FASD accommodations

The following table lists ways that professionals can accommodate FASD values, and the underlying neurobehavioral symptoms.[108]

Value	Neuro-behavioural Symptom of FASD	Accommodations
Show emotion/ empathy/ be respectful	Difficulty identifying feelings/ lacks empathy/ seems disrespectful/ incorrigible. May miss social cues.	Help identify feelings – use colour or animals
Be responsible/ acting age	Immaturity	Reframe questions at appropriate level
Keep appointments/ follow through	Memory problems/ trouble planning/ difficulty organising/ sequencing (e.g. breach bail or sentence conditions)	Extra assistance in organising, break tasks into small steps. Opportunities for practice.
Accept the consequences	Difficulty forming associations and linking cause and effect (e.g. between offence and sentence)	Prevent problems (e.g. extra supervision)
Learn from mistakes/make good decisions	Difficulty integrating, remembering (e.g. may lead to re-offending)	Accept the need for re-teaching and factor in opportunities
Cooperate, be flexible Rigid.	Difficulty transitioning, adapting (e.g. to new situations such as community-based orders, incarceration). Maybe be seen as "oppositional".	Adjust workload into separate tasks to achieve closure of tasks. Provide adequate time.
Work fast	Slow cognitive pace, seems to be ignoring you, takes more time (e.g. answering questions, coping with cognitive behavioural therapy programs)	Give time, slow down, accept slower pace.
Behave in a safe way, set goals	Impulsive. May have difficulty thinking in a sufficiently abstract way so cannot predict outcomes (even if they seem obvious) (e.g. risky offending behaviours).	Prevent problems, build on strengths, use visual cues
Communicate	Speech and language problems	Avoid metaphor. Speak slowly and use concrete examples.
Be truthful, don't lie	Suggestible. Confabulate (may be a defensive response).	Avoid leading questions.
Be independent	Require community/ interdependence.	Help to develop links in the community (e.g. supervised court orders may offer an opportunity to develop links)

Recommendation 15. Implement mandatory FASD professional development for all justice professionals, within the broader disability context, to improve awareness, understanding and capacity. This must be culturally secure and ideally be delivered face-to-face. This includes implementing recommendation 28 of the Senate FASD Inquiry: *"Provide further funding to train custodial officers in FASD-specific strategies for dealing with youth with FASD or suspected FASD in correctional facilities."*

Access to assessment, diagnostic services and support in the criminal justice system

To access government support available for people with disability, and to have your disability taken into account in the criminal justice system, generally you need to meet two criteria: you need to have a type of disability that falls within the relevant definition in the law or policy, and you need to have certain impairments as a result of that disability.[109] For people with FASD coming into contact with the criminal justice system this can mean having to meet some criteria for cognitive impairment that do not match FASD characteristics, for example needing to be assessed as having an IQ below 70.

Screening processes

There have been some notable efforts to establish FASD screening methods for people in justice settings. These include training correctional officials to identify FASD, and intensively screening all inmates via medical evaluation. However, there is only one early study where researchers empirically evaluated a screening tool in a correctional environment. [110] As noted in the '*Community support'* section, as yet, there are no validated, standardised methods for screening offenders for FASD, including in Australia.[111] However, clinical research is continuing efforts to develop such a validated screening tool, including the necessary protocols.[112]

While there are no specific screening tools, screening processes can be implemented into practice. This includes:

- Gathering information about prenatal alcohol exposure – through reviewing available birth, child protection and health records.
- Undertaking appropriate developmental screening of all young people involved with youth justice (e.g. using validated developmental screeners).
- Inclusion of screening for physical signs of FASD in health checks (i.e. facial features, minor dysmorphology and reduced head circumference).
- If concerns are identified regarding prenatal alcohol exposure, development or physical features appropriate referral pathways for further assessment need to be available.

Establishing a FASD diagnostic service for the criminal justice system

As described above, appropriate assessment and diagnostic pathways need to be available when concerns are identified for young people involved with youth justice.

As shown in the previous '*Community support'* section, the Patches Models of Care (see Appendix A), demonstrate one set of stages in an integrated pathway for people with FASD. Such Models of Care operate in the early childhood (0 to 5 years), education (5 years and over) and justice systems.

The design of the '*FASD diagnostic service'* in the '*Community support'* section needs to be adapted for the youth and adult justice contexts. It may be cost-prohibitive to develop separate diagnostic services located within the Bimberi Youth Justice and Alexander Maconochie correctional centres. This means an effective outreach service would need to be developed from the clinic established in the community.

Estimated costs of screening and diagnosis in the criminal justice system

The indicative costs to establish these services could be based on the estimates in the previous section on '*Community support'* under '*Estimated Costs of Screening and Diagnosis' (see Appendix B for details.)*. However, these need to be adapted to the specific (outreach) model for the criminal justice system.

Access to support in the criminal justice system

Once screening, referral processes and appropriate diagnostic services identify people with FASD, access to appropriate supports needs to be provided for both suspects and convicted offenders. This begins with referrals from police and judges to support services.[113] Judges need to consider culturally secure, diversionary alternatives in the community with appropriate supports. This should replace breaches of orders with onerous consequences. An example of the required support includes helping people with FASD to navigate NDIS applications.

Another area of valuable support can be provided within the pre-release stage. After diagnosis and support to obtain NDIS access prior to release, people with FASD can receive upskilling to enable better reintegration success. This upskilling would entail capacity building of life and employability skills supported within a positive behavioural support framework.

Recommendation 16. Implement adequately funded, neuro-developmental (including FASD) assessment, diagnosis and support, within the broader disability context, in youth and adult justice systems by building capacity in community owned and managed organisations. This includes implementing recommendations 26 and 27 of the Senate FASD Inquiry: *"All children and young people entering youth justice are screened for FASD."*

Specialist court with culturally secure diversionary alternatives

A specialist disability court is an effective way for people with FASD engaging with the justice system to receive more equitable access to justice. This would provide reasonable disability accommodations, a requirement for Sentencing Report Writers to address FASD possibility where FASD is suggested, and appropriate alternative options for diversionary sentencing.

A community-focussed specialist court, drawing on international best practice examples – including the FASD Court in Manitoba, Canada,[114] and the New Zealand needs and cultural assessment model – can also prioritise Aboriginal leadership, knowledges, and pathways to recovery.[115]

Recommendation 17. Design and implement a disability specialist court, modelled on the FASD Court in Manitoba, Canada. This specialist court would be culturally secure, disability-accommodating (including FASD), and provide diversionary alternatives. This includes supporting recommendation 29 of the Senate FASD Inquiry: *"Fund an independent study into best-practice diversionary programs and alternative therapeutic facilities for individuals with FASD or suspected FASD within the justice system."*

7. Outcome evaluation

Intended outcomes

The intended outcomes from implementing the recommendations in this submission are that people with FASD are appropriately supported both in the community (to prevent them from engaging with the criminal justice system) and within the criminal justice system itself, (to prevent further criminalisation). This can be measured by the uptake of screening and referral processes and pathways, assessment and diagnosis, and support services within the community and in the criminal justice system, as well as in a reduction in people engaging with the criminal justice system, including a reduction in recidivism.

Required data collection

Current gaps in data collection should be assessed, as well as new data collection integrated with the establishment of screening and diagnosis services. This will allow for both a more accurate assessment of the prevalence of FASD in the ACT community, and the criminal justice system, and to facilitate the evaluation of this reform.

It can be difficult to obtain evidence of prenatal alcohol exposure due to its retrospective nature.[116] Collecting pregnancy data in a mandatory system, and accessing perinatal and early medical records is as important as current screening. However, identifying prenatal alcohol exposure also carries some risk with mothers who fear child protection consequences. GPs, midwives and gynaecologists should be trained and supported to collect accurate prenatal alcohol exposure, in an informed, supportive and confidential manner.

The ACT government needs to design an effective centralised reporting mechanism that collates the data collected from across different Directorates to analyse for regular reporting on the progress towards outcomes. This mechanism should be incorporated into the ACT Government's implementation of raising the minimum age of criminal responsibility.

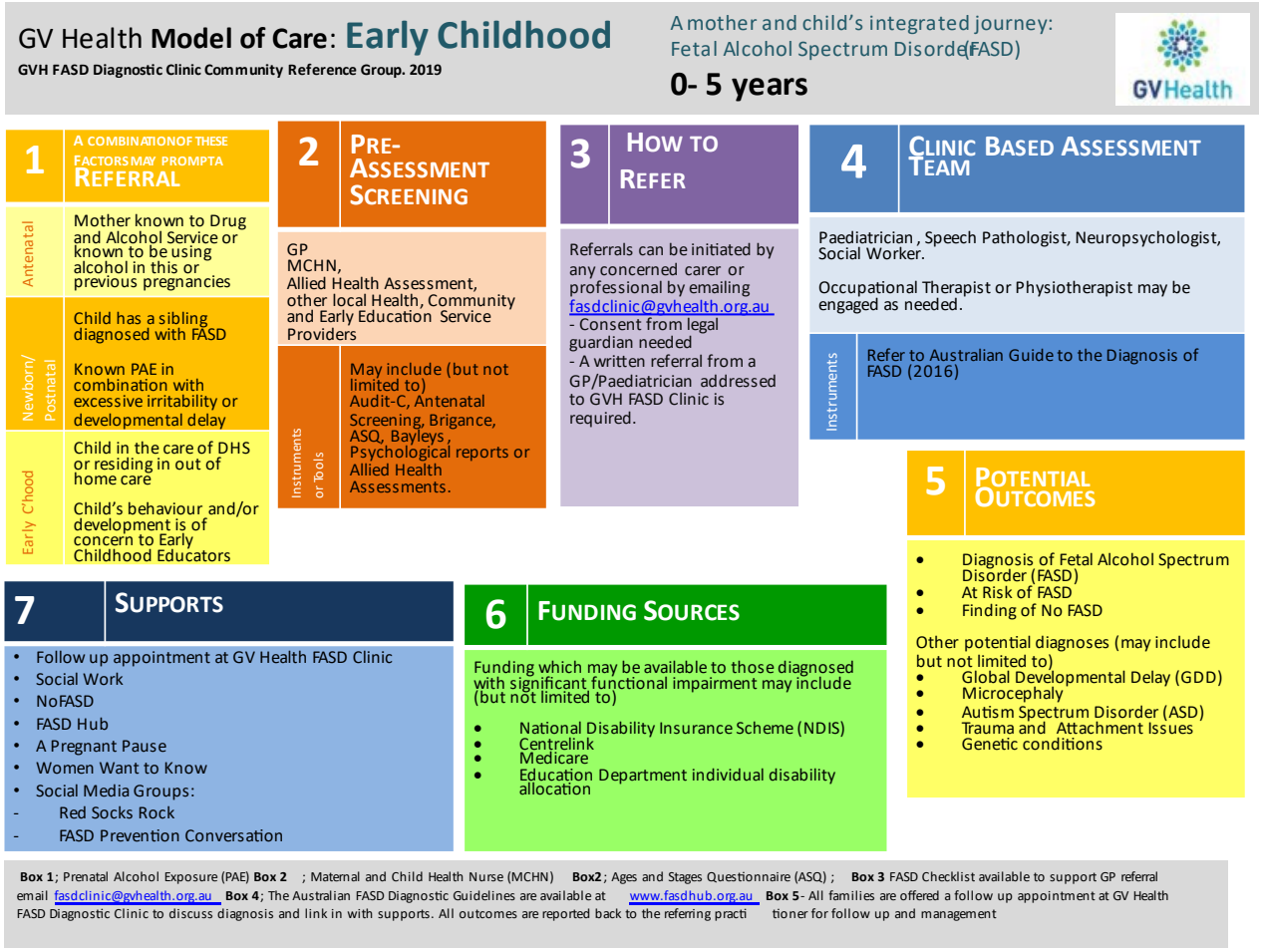
As observed above, FASD and criminal justice engages with much of the ACT Wellbeing Framework.[117] The data being collected as Wellbeing Indicators for the Framework, can also be used by the ACT Government to assess the successful implementation of the recommendations in this submission. This can include using the Wellbeing Impact Assessment template developed to better understand the impact of policies and proposals on the wellbeing of ACT people, institutions and environment.[118]

Recommendation 18. Improve data collection to better inform FASD policy and program responses, by ensuring information about prenatal alcohol exposure is collected in an informed, supportive and confidential manner, and prenatal alcohol exposure and diagnostic records are made accessible to all relevant health and justice staff. This includes fully implementing recommendation 3 of the Senate FASD Inquiry: *"Implement mandatory reporting on standardised data for maternal alcohol consumption in the Perinatal National Minimum Data Set."*

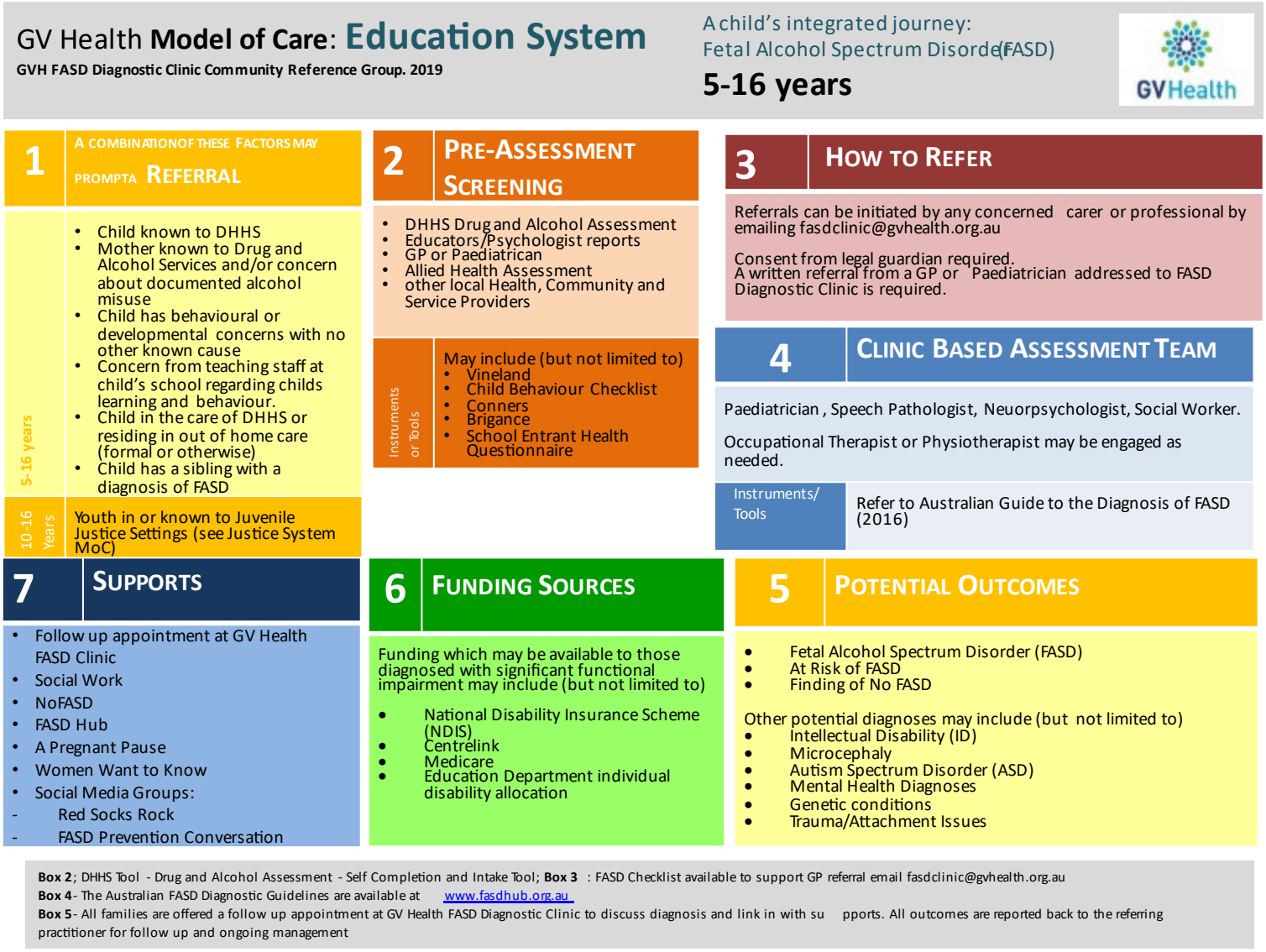
Appendices

Appendix A: Models of care for early childhood, education & justice systems

Model of care – early childhood (0 to 5 years)[119]



Model of care - education (5 years and over)



Model of care - justice (10+ years pre-Raising minimum age of criminal responsibility and 14+ years post-Raising minimum age of criminal responsibility)

GV Health **Model of Care**: **Justice System**

GVH FASD Diagnostic Clinic Community Reference Group. 2019

A young person's integrated journey:
Fetal Alcohol Spectrum Disorder (FASD)

10- 16 years

GV Health

1 A COMBINATION OF THESE FACTORS MAY PROMPT A REFERRAL

- Young person has come to the attention of police
- Young person in the care of DHHS or residing in out of home care (formal or otherwise)
- Young person has a sibling with a diagnosis of FASD
- Young person with developmental or behavioural concerns with no other known cause
- Young person or their family members are known to alcohol and other drug service providers.
- Magistrates request

2 SCREENING

- Drug and Alcohol Assessment Tool
- DHHS Tool- Drug and Alcohol Assessment- Self Completion Tool and Intake Tool
- Psychosocial Assessment for case planning
- Pre-sentence reports
- Legal Aid

3 HOW TO REFER

Referrals can be initiated by any concerned carer or professional by emailing fasdclinic@gvhealth.org.au. Consent from legal guardian required
A written referral from a GP or Paediatrician addressed to FASD Diagnostic Clinic will be required.

4 ASSESSMENT TEAM

Paediatrician, Speech Pathologist, Neuropsychologist, Social Worker.

Occupational Therapist or Physiotherapist may be engaged as needed.

Instruments/ Tools: Refer to Australian Guide to the Diagnosis of FASD (2016)

5 POTENTIAL DIAGNOSES

- Fetal Alcohol Spectrum Disorder (FASD)
- At Risk of FASD
- Finding of No FASD

Other potential diagnoses may include (but not limited to)

- Intellectual Disability (ID)
- Microcephaly
- Autism Spectrum Disorder (ASD)
- Mental Health Diagnoses
- Genetic conditions
- Trauma/Attachment Issues

6 FUNDING SOURCES

Funding which may be available to those diagnosed with significant functional impairment may include (but not limited to)

- National Disability Insurance Scheme (NDIS)
- Centrelink
- Medicare
- Education Department individual disability allocation
- Justice/ court ordered funded therapy program

7 SUPPORTS

- Follow up appointment at GV Health FASD Clinic
- Social Work
- NoFASD
- FASD Hub
- A Pregnant Pause
- Women Want to Know
- Social Media Groups:
  - Red Socks Rock
  - FASD Prevention Conversation

Box 2; DHHS Tool - Drug and Alcohol Assessment - Self Completion and Intake Tool; **Box 3** : FASD Checklist available to support GP referral email fasdclinic@gvhealth.org.au
Box 4- The Australian FASD Diagnostic Guidelines are available at www.fasdhub.org.au
Box 5- All families are offered a follow up appointment at GV Health FASD Diagnostic Clinic to discuss diagnosis and link in with su pports. All outcomes are reported back to the referring practitioner for follow up and ongoing management

Appendix B: Indicative costings for FASD assessment and diagnosis

1. Indicative costing model for creation of a FASD diagnostic clinic in Goulburn

In 2016, FARE lodged a Pre-Budget submission to the Commonwealth Treasury[120] that included an indicative budget for the creation of a National FASD Clinical Network. The submission indicated that funding of $3.1 million over three years would allow for the creation of the National FASD Clinical Network and the establishment and continuation of FASD diagnostic clinics across Australia.

Establishment of a FASD diagnostic clinic in Goulburn

Item with presumed FTEs (requires updating)	Year 1	Year 2	Year 3	Total
Personnel Salaries include:	$139,436	$141,360	$141,360	$422,156
General paediatrician (0.1FTE)	$32,530	$32,530	$32,530	$97,590
Developmental paediatrician (0.125 FTE)	$41,000	$41,000	$41,000	$123,000
Clinical Psychologist (0.1FTE)	$12,000	$12,000	$12,000	$36,000
Speech Pathologist / Occupational Therapist (0.1FTE)	$11,000	$11,000	$11,000	$33,000
Social Worker (0.1 FTE)	$11,000	$11,000	$11,000	$33,000
Administrative officer (FTE 0.4)	$31,906	$33,830	$33,830	$99,566
Support for Rural Clinical Student placements	$27,767	$46,600	$49,458	$123,825
Assets: Equipment (psychological & developmental assessment tools, 3D FASD facial camera & photographic analysis software)	$20,000			$20,000
Administration / Overheads	$40,000	$50,000	$50,000	$140,000
Evaluation		$11,688	$12,039	$23,727
Total	**$227,203**	**$249,648**	**$252,857**	**$729,708**

2. Review of ACT minimum age of criminal responsibility implementation multidisciplinary panel

Multidisciplinary Therapeutic Panel. The Review of Service System and implementation requirements for minimum age of criminal responsibility in the ACT estimated costs for a Multidisciplinary Therapeutic Panel:[121]

- **Independent Chair** x 1: $875 per day or $32,745 per year, (Monthly meetings plus liaison with Wraparound Coordinator, Secretariat, other meetings).
- **Members** x 8: $800 (Per Diem) Sitting days minimum 12 per paid member.
- **Secretariat Support**: SOG B x 1 EFT $131,773 + oncosts and ASO6 x 1 EFT $88,899 + oncosts.

This (non-FASD panel) costing works out at approximately $990,000 (plus on costs) over 3 years.

3. Provided by Dr James Fitzpatrick of Patches Australia, Assessment Services

Screening: 2 hours assessment and report writing e.g. by an Occupational Therapist or Psychologist = Approximately **$1,000.**

Multi-disciplinary Diagnostic service:

- 12 to 18 hours **Psychologist** (information gathering, review of past reports and referral information, direct testing and scoring, report writing, and case conferencing)**.** Varies depending on complexity of assessment. Psychologist would complete between 2-3 full assessments and reports per week, at 1.0 FTE.

- 4 to 6 hours **Paediatrician** (information gathering, review of past reports and referral information, direct assessment, report writing, and case conferencing).
- 4 hours **Speech Pathologist / Occupational Therapist** (information gathering, review of past reports and referral information, direct assessment, report writing, and case conferencing).
- 4 hours minimum **Administration** per assessment at well-established clinic, with an efficient Admin process in place. Includes administration support of the referral process, clinical scheduling and communicating with clients and clinicians, pre population and post-editing of the report. In the initial stages of clinic establishment, a full time Admin support would likely be needed to deliver 3 assessments per month (based on set-up modelling for new sites).

Total cost approximately **$4,450** (or $7,500 for rural or remote service including travel) per full diagnostic assessment with Paediatrician, Psychologist, and Speech Pathologist / Occupational Therapist, including administration and overheads, for an established clinical service.

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