

Senate inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum:
Question on Notice Number 1

Response by Dr Kathryn Antioch
CEO, Guidelines and Economists Network International (GENI)
22 October 2020

Question 1 You recommend that “Political leaders expedite FASD costing studies through COAG, Department of Health, NHMRC or AIHW using international methodologies and evidence”. Does this imply the inclusion of a prevalence study? If not, is it feasible to cost FASD given prevalence in Australia has not been established, or would it be premature to do so? This question was raised by Senators after the public hearing and forwarded to Dr Antioch on 29 September 2020 requesting a response.

1. Overview

FASD encompasses four conditions resulting from exposure of an unborn baby to alcohol during pregnancy. These disorders include:

- Fetal Alcohol Syndrome (FAS)
- partial FAS (pFAS)
- alcohol-related neuro-developmental disorders (ARND)
- alcohol-related birth defects (ARBD)

These conditions represent a continuum of alcohol effect during fetal life on brain and face development and on general growth and development. (AIHW and University of NSW, 2014) ¹. Costing studies will require access to relevant utilization, resources, morbidity, and mortality FASD data. Such data will include health information about individuals with FASD. Data bases have improved over time in their capacity to capture data for such cases. The prevalence and incidence of FASD cases receiving care and services may be reflected in some routine data collections and surveys. These can be used to calculate costs of FASD. The quality of such data has improved in recent years given comprehensive national data collections, classification systems and methodologies by IHPA, NDIS, NDIA, AIHW, FASD Australia – The NHMRC Centre of Excellence and surveys. Costing methodologies and data sources for disability in Australia developed by the Productivity Commission are also important.

Initially, relevant data collections from existing national and state data bases should be identified. They should be explored to determine the extent to which they include data about cases with the diagnosis of Fetal Alcohol Spectrum Disorder (FASD). Relevant morbidity data bases could relate to hospitals, medical services, perinatal collections, congenital anomalies data, community care and disability services. Further, any data being compiled by the NHMRC, IHPA, NDIS, NDIA Centre for Excellence on FASD, surveillance units and other organisations such as AIHW would be considered.

International methodologies and evidence can provide insights on costing methodologies and the type of data that could be collected and analysed. Depending on the scope and perspective of the costing studies, a decision would be made concerning whether other societal components beyond health and disability would be included such as special education, justice, and criminal system. The inclusion of both direct, indirect, and intangible costs in the data collections would require consideration.

Depending on the extent of data already routinely available in data bases, there may be a requirement to use survey data to provide additional information and then related modelling on data from such surveys. An analysis of the data in these surveys and the potential to add new data items could be considered to assist a costing study. The quality and date of the data collections would require careful consideration, including the surveys outlined in sections 2 and 3 below.

¹ AIHW and University of NSW (2014) Fetal alcohol spectrum disorders: Strategies to address information gaps
<https://www.aihw.gov.au/getmedia/fa89bb23-bd33-43f5-bec5-f908af970407/18283.pdf.aspx?inline=true>

The organisations that can assist in exploring these issues are National Cabinet, Department of Health, NHMRC, IHPA, NDIS, NDIA, Productivity Commission and the AIHW. The RACGP, RACP and AMA can also provide input as required. The initial deliberations should involve a national perspective to ensure national consistency and efficiency of approach. Further insights are outlined below. This includes data gaps identified by AIHW and University of NSW during 2014 in section 2, more recent developments by the AIHW in section 3, data collections by IHPA in section 4, NDIS, NDIA and the Productivity Commission in Section 5. Section 6 discusses some international methodological and data collection frameworks for costing studies that may be instructive for Australian analyses. The recommendations arising from this analysis are included in Section 7, page 12

2. Australian reviews of FASD data gaps in 2014: AIHW and University of NSW

The AIHW and University of NSW (2014)¹ highlighted in 2014 that there was limited incidence and prevalence data concerning Fetal Alcohol Spectrum Disorders (FASD) in Australia and internationally. This reflected the low level of awareness by clinicians of FASD conditions, diagnosis complexity and a lack of nationally agreed and consistent diagnostic criteria and definitions. The AIHW report found that the quality of information available in existing data collections is variable and incomplete for ascertaining Fetal Alcohol Syndrome cases.

There has been a lack of information concerning other disorders in the spectrum. Regular surveillance and monitoring are priorities for determining incidence and prevalence. The most feasible medium-term model for FASD data collection is to enhance the scope of national and jurisdictional congenital anomalies collections to include FASD. In the short term, a program of data development regarding FASD, utilizing record linkage to monitor 'statistical FASD' could provide more complete data. A national data repository on FASD would enable appropriate resources and services to be delivered to those FASD cases and their families and provide support to clinicians and researchers¹. Some collections that were assessed by the University of NSW and AIHW for content relevant to FASD include:

- *Perinatal collections (national, state and territory) contain some FASD-related information concerning maternal use of alcohol and fetal growth retardation.* All perinatal collections include data on birthweight for gestational age (a widely used proxy measure of fetal growth). Additional anthropometric information is obtained by some jurisdictional collections.
- *Congenital anomalies data (national, state and territory) includes reports of problems evident at birth, including facial features.* The collections use the International Statistical Classification of Diseases, 9th Revision, British Paediatric Association (ICD-9-BPA)/ International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) codes to flag various anomalies. *However, maternal consumption of alcohol during pregnancy is not included in these collections. Therefore, FASD-type symptoms and anomalies cannot be flagged as FASD.*
- *National Hospital Morbidity Database, an ongoing collection, contains information about growth retardation, neuro-developmental disorders and birth defects.* Data concerning the mother who may be admitted due to alcohol-related illnesses or conditions is included. *It relates to the extreme end of the spectrum of various conditions, and may lack the sensitivity to detect many cases of FASD in the community.*
- *The Australian Paediatric Surveillance Unit collection, is the most relevant collection, contained information on all domains of alcohol exposure: facial features, growth retardation, neuro-developmental disorders and birth defects.* However, only data included is from January 2001 to December 2004 and is restricted to a diagnosis of FAS, the most severe form of FASD.
- *Bettering the Evaluation and Care of Health survey* collects health-related information from a sample of GPs, including alcohol use during pregnancy. It excludes information about the female's children so as to relate this to a potential or definitive FASD diagnosis.
- *National Aboriginal and Torres Strait Islander Social Survey* monitors changes in social circumstances, including health, of Indigenous Australians. Some limited data concerning alcohol use in pregnancy by Indigenous women is included in the survey. However, it does not provide information concerning FASD.

- *Footprints in Time*: longitudinal study of Indigenous children includes high-quality qualitative and quantitative data to monitor the gap in life circumstances of non-Indigenous and Indigenous children. *Data concerns antenatal care and health risk behaviours such as alcohol consumption and smoking during pregnancy.*
- *Healthy for Life program* aims to improve the health of Aboriginal and Torres Strait Islander mothers, children and babies. It aims to improve capacity of Indigenous primary health-care services, especially maternal and child health services and chronic diseases care. *Alcohol use by Indigenous mothers during pregnancy is included.*
- *National Drug Strategy Household Survey*, a cross-sectional survey of people aged 12 years or older living in Australian private dwellings, *includes specific questions on alcohol use in pregnancy.* It provides population-based data for validation of other data to determine alcohol use in pregnancy nationally. (AIHW and University of NSW, 2014)

More recent developments by the AIHW and IHPA are outlined below. Importantly, progress has been made in the National Perinatal Data Collection (NPDC), National Drug Strategy Household Survey (NDSHS), National Congenital Anomalies Data Collection and National Hospital Morbidity Database (NHMD).

3. AIHW National data: 2019

The AIHW manages several national databases that would be relevant to a national costing study on FASD. These data bases concern FASD or maternal consumption of alcohol during pregnancy as outlined below:

National Drug Strategy Household Survey (NDSHS)

NDSHS collects information concerning attitudes and perceptions on alcohol, tobacco consumption, and illicit drug use among the general population in Australia. The latest NDSHS, found 56% of females did not drink alcohol during pregnancy. Of those who did, most drank infrequently (monthly or less), consuming 1–2 standard drinks. Among pregnant women who drank alcohol during pregnancy in 2016:

- 81% drank monthly or less, and 16.2% drank 2–4 times a month
- 97% usually consumed 1–2 standard drinks.
- 49% of women consumed alcohol before they knew they were pregnant whereas 25% drank after they knew. (AIHW 2017², 2019³)

National Perinatal Data Collection (NPDC)

This national population-based cross-sectional data collection on pregnancy and childbirth is based on births reported to the perinatal data collection in each Australian jurisdiction. A standard de-identified extract is provided to AIHW annually to form the NPDC. The NPDC includes a voluntary non-standardised indicator on alcohol consumption during pregnancy since 2009. However, data have only been provided by 3 jurisdictions and data quality has not been assessed. (AIHW, 2019)³

Data development

Since 1 July 2019, the AIHW NPDC has included 6 voluntary standardised data elements relating to maternal consumption of alcohol during pregnancy:

Alcohol in pregnancy indicator:

² Australian Institute of Health and Welfare (AIHW) 2017. *National Drug Strategy Household Survey 2016: detailed findings*. Drug Statistics series no. 31. Cat. no. PHE 214. Canberra: AIHW

³ AIHW (2019) submission to the Senate inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD) <https://www.aph.gov.au/DocumentStore.ashx?id=5d24182e-8280-4dc8-82d6-e165e8bf089e&subId=674008>

- Female—alcohol consumption in the first 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N
- Female—alcohol consumption after 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N

Alcohol consumption frequency:

- Female—alcohol consumption frequency in the first 20 weeks of pregnancy, code N
- Female—alcohol consumption frequency after 20 weeks of pregnancy, code N

Number of drinks:

- Female—number of standard drinks consumed when drinking alcohol in the first 20 weeks of pregnancy, total N[NN]
- Female—number of standard drinks consumed when drinking alcohol after 20 weeks of pregnancy, total N[NN]

These data elements are consistent with the dose and frequency questions of the AUDITC— a brief alcohol screening tool that identifies hazardous drinking or active alcohol use disorders. All states and territories have agreed to collect these data items according to the specified standards. However, timeframes for national data availability are not known as the data elements are voluntary and jurisdictions are at various stages of implementation.

The data will be received by AIHW in late 2020 or early 2021. Data release will be subject to AIHW's assessment of data quality and completeness. Quality and completeness is expected to improve over time as data elements are fully implemented into jurisdictional perinatal data collections and subsequently provided to the NPDC. AIHW has developed the data elements with the National Perinatal Data Development Committee, National Maternity Data Development Project Advisory Group and Clinical Data Reference Group, with funding from the Australian Department of Health under the National Maternity Data Development Project. (AIHW, 2019)³

National Congenital Anomalies Data Collection

The AIHW has commenced establishing a national, ongoing congenital anomalies data collection, working with jurisdictions to determine the collection scope and possibly including FASD in future reporting.

National Hospital Morbidity Database (NHMD)

NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian public and private hospitals. AIHW (2019)³ indicates that there are very few hospital separations with principal diagnoses of Fetal alcohol syndrome (ICD-10-AM code Q86.0) (less than 10 separations in 2017–18) or Fetus and newborn affected by maternal use of alcohol (ICD-10-AM code P04.3) (no separations in 2017–18). These conditions are more likely to be recorded as additional diagnoses (AIHW, 2019)³ Further insights concerning IHPA hospital data are outlined below

4. Independent Hospital Pricing Authority (IHPA)

IHPA collects data for various classification systems that may be of relevance to a national costing study for FASD. The relevant ICD-10 CM hospital codes, classification, utilisation, and costs data for patients diagnosed with FASD in Australia could be explored with the IHPA and may involve diagnoses and/ or co-morbidities in IHPA's hospital data. The relevant services may involve

- Acute admitted
- Emergency department
- Non-admitted care (hospital outpatient clinics, community-based clinics, patient's home)
- Mental health (admitted, community)

- Sub-acute care
- Non-acute care
- Teaching training and research.

There are several classification systems for these hospital services which would be relevant to FASD costing studies. Table 1 below shows the classifications used across each of the patient service categories (IHPA, 2020)⁴

Table 1: IHPA classifications used across each of the patient service categories

| Service category | Classification | Current version* |
|---|--|---------------------------------------|
| Admitted acute care | International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), Australian Classification of Health Interventions (ACHI), Australian Coding Standards (ACS) | ICD-10-AM/ACHI/ACS Eleventh Edition |
| | Australian Refined Diagnosis Related Groups Classification (AR-DRGs) | AR-DRG Version 10.0 |
| Subacute and non-acute care | Australian National Subacute and Non-Acute Patient Classification (AN-SNAP) | AN-SNAP Version 4.0 |
| Emergency care | Emergency Department ICD-10-AM Short List (ED Short List) | ED Short List Eleventh Edition |
| | Urgency Related Groups (URGs) and Urgency Disposition Groups (UDGs) | URGs Version 1.4 and UDGs Version 1.3 |
| | Australian Emergency Care Classification (AECC) | AECC Version 1.0 |

⁴ IHPA (2020) website on classifications <https://www.ihipa.gov.au/what-we-do/classifications> accessed 4 October 2020

| | | |
|---|--|--------------------|
| Non-admitted care | Tier 2 Non-admitted Services Classification (Tier 2) | Tier 2 Version 6.0 |
| Mental health care | Australian Mental Health Care Classification (AMHCC) | AHMCC Version 1.0 |
| Teaching, training and research | Australian Teaching and Training Classification (ATTC) | ATTC Version 1.0 |

Source: IHPA, 2020 ⁴

Advice from IHPA during October 2020 highlights the following data issues for FASD concerning admitted and non-admitted patients, sub-acute, non-acute, mental health care, emergency department care and teaching training and research.

(a) Admitted Patients

With regards to admitted episodes of care, fetal alcohol syndrome/fetal spectrum disorder is classified to Q86.0 Fetal alcohol syndrome (dysmorphic) in ICD-10-AM, with fetal alcohol spectrum disorders listed as an inclusion term at this code. Conditions classified to this code currently are:

- Disorder/fetal alcohol spectrum
- Dysmorphism (due to) alcohol
- Fetus, fetal/alcohol/spectrum disorders
- Fetus, fetal/alcohol/syndrome (dysmorphic)
- Syndrome/fetal alcohol (dysmorphic)
- Syndrome/malformation, congenital, due to/alcohol

If this is assigned as principal diagnosis (and without an intervention that will drive grouping to the intervention partition) it will group to Z65 Congenital Anomalies and Problems Arising from Neonatal Period.

(b) Non-admitted Care

With regard to non-admitted care, fetal alcohol spectrum disorder is not listed as an inclusion term in any Tier 2 class. Service events could be grouped to a number of Tier 2 classes depending on the nature of the clinic attended, for example, 20.11 - Paediatric Medicine, 20.04 – Developmental disabilities or 40.55 Paediatrics. It would not be possible to identify these patients in the non-admitted hospital data sets.

(c) Sub-acute and non-acute (AN-SNAP) and Mental Health Care (AMHCC)

AN-SNAP and AMHCC are not diagnosis-based classifications and grouping would be based on reported variables for those episodes, such as level of functioning or phase of care. Episodes could be grouped to any of the end classes in either classification. However, the ICD-10-AM codes provided enable identification of these episodes in the admitted patient data regardless of care type or classification.

(d) Emergency Department Care

It is a similar scenario with regard to the emergency department classifications. A presentation with the Q86.0 ICD-10-AM code maps to the ED Short List Q89.9 Congenital malformation, unspecified. This code maps to Major Diagnostic Block 6 *Other presentation* in the URG classification and Emergency Care Diagnosis Group *E6090, Other factors influencing health status* in the AECC. Assignment to a final end class in either classification will depend on the combination of triage category, episode end status and other data items reported for the episode.

(e) Australian Teaching and Training Classification (ATTC)

The ATTC is not a patient classification but a classification of health professional trainees (IHPA, 2020a) ⁵ Inclusion of this category in a cost study would likely require some modelling techniques given it is not a patient classification.

IHPA holds cost and activity data and could use the above mentioned codes to identify episodes and costs in the admitted hospital setting. IHPA's Data Access and Release Policy<<https://www.ihipa.gov.au/publications/ihipa-data-access-and-release-policy-0>>, outlines the process for researchers to access IHPA data (IHPA, 2020a) ⁵

5. National Disability Insurance Scheme (NDIS)

Another area of costs concerning FASD involves the NDIS. Currently the NDIS only recognises Fetal Alcohol Syndrome under 'Congenital conditions - cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment.' Several organisations have made submissions to the National Disability Insurance Agency (NDIA) concerning the recognition of FASD as a neurodevelopmental disability and the need for recognition of severe impairment in three or more domains of functional impairment where confirmation of alcohol exposure cannot be confirmed. The NDIA has identified FASD as an important category of disability for consideration within the NDIS. Currently some families access support through the NDIS. (FASDHUB, 2020⁶ and NDIS, 2020⁷). Adults and children with FASD should be eligible for support through the NDIS given they likely have significant and permanent disability reducing their *functional capacity* such as the ability to perform age appropriate tasks and activities. Reduced *psychosocial capacity* may also be involved, which involves their ability to relate to others in personal relationships, school or work. (NOFASD, 2020)⁸

Future *FASD Costing studies* involving NDIS may be assisted with reference to the *NDIS Price Guide 2020-21 Version 1.0.9*, published 2 October 2020. This Price Guide sets out the price limits and associated pricing arrangements that the National Disability Insurance Agency (NDIA) has determined will apply to NDIS supports from 1 July 2020. (NDIS, 2020)⁹ A costing study for FASD would require early input from the NDIS and NDIA about the data availability for cases diagnosed with FASD within the NDIA's broader 'congenital condition' and given FASD's neurodevelopmental disability features. FASD specific costs for the NDIS supports referred to below for support items and support purposes of capital, core and capacity building could be explored. Further, the Productivity Commission could provide input on

⁵ IHPA (2020a) Personal communication from Joanne Fitzgerald 12 October 2020

⁶ FASDHUB, 2020 Managing FASD and NDIS <https://www.fasdhub.org.au/fasd-information/managing-fasd/NDIS/>

⁷ NDIS, 2020 Operational guidelines <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-b-permanent-conditions-which-functional-capacity-are-variable-and-further-assessment-functional-capacity-generally-required>

⁸ NOFASD (2020) Parents, carers and families /NDIS <https://www.nofasd.org.au/parents-carers-and-families/ndis/>

⁹ NDIS (2020) Price Guide 2020-21 Valid from 1 October 2020 Version 1.0.9 – Publication date 2/10/2020 <https://www.ndis.gov.au/media/2696/download>

costing other aspects of disability in the NDIS, including operational costs, linkage and capacity building activities and supports outside the scheme. These matters are more fully explored below.

NDIS Supports: Purpose, Categories and Items

This section describes how the NDIS categorises disability supports. These categories can be relevant to rules for participants about how they can spend their support budgets, and for providers when seeking payment for delivered supports.

(a) **Support Items**: Each support that a provider supplies to a participant can be classified as one of the support items listed in the *Price Guide* and the *NDIS Support Catalogue*. Providers claim payments against the support item that aligns to the service they have delivered.

(b) **Support Purposes**: NDIS participant budgets are allocated to three separate support purposes:

1. **CORE** - Supports that enable participants to complete activities of daily living. Participant budgets often have a lot of flexibility to choose specific supports with their core support budgets, but cannot reallocate this funding for other support purposes (i.e. capital or capacity building supports).

2. **CAPITAL** - Investments, such as assistive technologies - equipment, home or vehicle modifications, or for Specialist Disability Accommodation (SDA). Participant budgets for this support purpose are restricted to specific items identified in the participant's plan.

3. **CAPACITY BUILDING** - Supports that enable a participant to build their independence and skills.

(c) **Support Categories aligned to NDIS outcomes framework** Participant budgets are allocated at a support category level and must be used to achieve the goals set out in the participant's plan.

Support categories are aligned with the NDIS Outcomes Framework, which has been developed to measure goal attainment for individual participants and overall performance of the Scheme.

There are eight outcome Framework domains, assisting participants to conceptualise goals in various areas of their life. They also assist planners consider where such supports already exist and where further supports are required.

The domains include

1. Daily Living
2. Home
3. Health and Wellbeing
4. Lifelong Learning
5. Work
6. Social and Community Participation
7. Relationships
8. Choice and Control

All supports and services for NDIS participants must contribute to the achievement of their individual goals as outlined in the participant's plan. Support purpose categories are designed to align with the Outcomes Framework and the 15 support categories outlined below.

These assists participants choose supports that enable them achieve their goals, and providers to understand how the supports they provide contribute to the participant's goals.

The table below shows the links between support purpose types, domains in the Outcomes Framework and support categories. (NDIS, 2020)

Table 2 NDIS Price Guide Outcomes Framework: Budget Purpose, Outcomes and Support Category

| PURPOSE | OUTCOME DOMAIN | SUPPORT CATEGORY |
|-------------------|------------------------------------|--|
| CORE | Daily Living | 01 Assistance with Daily Life |
| | Daily Living | 02 Transport |
| | Daily Living | 03 Consumables |
| | Social and Community Participation | 04 Assistance with Social, Economic and Community Participation |
| | Work | 04 Assistance with Social, Economic and Community Participation |
| CAPITAL | Daily Living | 05 Assistive Technology |
| | Home | 06 Home Modifications and Specialised Disability Accommodation (SDA) |
| CAPACITY BUILDING | Choice and Control | 07 Support Coordination |
| | Home | 08 Improved Living Arrangements |
| | Social and Community Participation | 09 Increased Social and Community Participation |
| | Work | 10 Finding and Keeping a Job |
| | Relationships | 11 Improved Relationships |
| | Health and Wellbeing | 12 Improved Health and Wellbeing |
| | Lifelong Learning | 13 Improved Learning |
| | Choice and Control | 14 Improved Life Choices |
| | Daily Living | 15 Improved Daily Living Skills |

Source: NDIS, (2020)⁹

National Disability Insurance Agency (NDIA) and NDIS could be involved in further national costing studies. Further, the Productivity Commission (2017)¹⁰ identified factors that drive NDIS costs and these would be relevant to FASD costing studies also. Approximately 90% of NDIS costs are for individualised supports, but there are also the costs of operating the scheme and funding information, linkage, and capacity building (ILC) activities. Key factors relevant to costing studies are:

- scope of supports covered by the scheme
- quantity of supports received by participants
- number and characteristics of participants
- proportion of supports in a plan that is utilised by a participant
- price paid for supports under the scheme
- costs associated with operating the scheme.

The NDIS's culture also is a cost driver. Shifts away from the welfare culture of the prior disability systems to one of providing necessary supports and managing down the total cost of disability over a participant's lifetime is crucial for the scheme's financial sustainability. Other support systems can impact NDIS costs. The NDIS relies on supports and services outside the scheme, including informal supports such as family, friends, and neighbours. It also relies on community supports such as social, sporting and interest groups, and mainstream supports – health, public transport, and education. If these supports are unavailable, people with disability (including those with FASD) could seek NDIS funding to fill the gap (Productivity Commission 2017) ¹⁰. These issues would be considered in FASD costing studies. Methodologies used by the Productivity Commission would be carefully considered.

¹⁰ Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs: Study Report Overview: <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf>

6. International frameworks for costing studies: Lessons for Australia

A recent review by Andersson and Elliot (2018)¹¹ provides insights into the scope of costs included in international costing studies of FASD. They included well-defined measures of economic costs in the studies chosen for the systematic review. Studies were identified from Canada, USA, and New Zealand.

- *Direct costs of FASD (health care, criminal justice, education, other services)* in the total population ranged from CA \$762 million to \$10.5 billion annually.
- *Indirect costs from lost productivity* due to morbidity/premature mortality from FASD ranged from CA\$46.8 million to \$2.4 billion annually.
- *Criminal justice system costs* contributed most to the total financial burden of FASD (\$CA395 million to \$7.2 billion) followed by loss of productivity (CA\$46.8 million to \$2.4 billion).
- *Costs of health care* accounted for CA\$7 to \$265 million.

Andersson and Elliot (2018)¹¹ concluded that FASD places an enormous financial burden on individuals, families, and society. FASD is preventable and evidence-based prevention policy is required urgently. Costs of caring for individuals with FASD can be minimised by early diagnosis and interventions. Accurate economic analysis of the cost of FASD in Australia is required to underpin development of local public policy relevant to health, education, and justice systems. They identified a dearth of Australian data on its economic impacts to guide policy and health service planning. These studies included direct and indirect costs. Sectors included health, criminal justice, education, and other services and could be instructive in the Australian setting and explored further by national cabinet's deliberations. The methodologies used and scope or sectors included could be identified from those studies in the review (Popova, Lange, Probst, et al. (2017)¹², Burns, Breen and Bower (2013)¹³, Popova, Stade and Lange, et al (2012)¹⁴, Popova, Lange, Burd et al (2016)¹⁵. For example, the study by Popova et al (2012)¹⁴ used the following framework for identifying the following relevant costs

A. DIRECT COSTS

1. Direct health costs

- Acute care hospitalizations and hospital days
- Psychiatric hospitalizations and hospital days
- Specialized treatment (mental health & addiction; inpatient and outpatient)
- Ambulatory care (ER visits, day/night care visits & specialty/private clinic visits)
- Family physician visits Prescription drugs Speech & language interventions

2. Direct Law Enforcement Costs:

- Police

¹¹ Andersson E, Elliott E (2018) Economic costs of fetal Alcohol Spectrum Disorder (FASD) Journal of Paediatrics and Child Health 54 (Suppl. 2) (2018) 7–22 <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jpc.13946>

¹² Popova S, Lange S, Probst C, et al. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. Lancet Glob Health. 2017; 5, e290–e299 <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2817%2930021-9>

¹³ Burns L, Breen C, Bower C, et al. Counting Fetal Alcohol Spectrum disorder in Australia: The evidence and the challenges. Drug Alcohol Rev. 2013; 32(5): 461–467 <https://onlinelibrary.wiley.com/doi/abs/10.1111/dar.12047>

¹⁴ Popova S, Stade B, Lange S, Rehm J. A model for estimating the economic impact of fetal alcohol spectrum disorder. Journal of Population Therapeutics and Clinical Pharmacology. 2012; 19(1):51–65. <https://jptcp.com/index.php/jptcp/article/view/447/378>

¹⁵ Popova S, Lange S, Burd L, Rehm J. The economic burden of fetal alcohol spectrum disorder in Canada in 2013. Alcohol and Alcoholism. 2016; 51(3):367–75. <https://academic.oup.com/alcac/article/51/3/367/2888203>

- Courts
- Corrections (including probation)

3 Other direct costs

- Child welfare Special education
- Parent/caregivers skills programs
- Home support services
- Residential care facilities
- Long-term care
- Respite care
- Supportive housing
- Crisis intervention
- Administrative costs for transfer payments
- Social assistance for children with disabilities
- Job skills training
- Transition into adulthood and independent living
- Training of employers to adapt and accommodate FASD-affected staff
- Prevention and research
- Cost of developing and improving screening tools
- Cost of diagnosis

B. INDIRECT COSTS:

Productivity Losses of parents/caregivers and affected individuals:

1. Long-term disability
2. Premature mortality

C. INTANGIBLE COSTS

- Impact of FASD on caregivers
- Impact of FASD on affected individuals (Popova et al, 2012) ¹⁴

Another important systematic review undertaken by Greenmyer and Kambeitz et al (2018)¹⁶ identified similar scope for the sectors included in the cost analyses. They undertook a multi-country updated assessment of the economic impact of FASD in terms of the costs for children and adults. Thirty-two studies from 4 countries met the inclusion criteria (United States [n = 20], Canada [n = 9], Sweden [n = 2], and New Zealand [n = 1]). The economic impact of FASD was reported on *health care, special education, residential care, criminal justice system, productivity losses due to morbidity and premature mortality, productivity losses of caregivers of children with FASD and intangible costs*. The economic estimates varied considerably due to the different methodologies used by different studies. The mean annual cost for children with FASD was \$22,810 and for adults \$24,308. Residential costs for children with FASD were 4-fold greater than for adults with FASD. The costs of lost productivity for adults were 6.3-fold greater than for children.

Key issues for costing in the Australian context are data availability and the capacity of such data to model some of the costs. In my view the health services and disability costs would be a high priority to investigate initially. There are data available as outlined above which require further discussion with IHPA, NHRMC, Productivity Commission and FASD data stakeholders and AIHW. Data for the

¹⁶ Greenmyer JR, Klug MG, Kambeitz C, Popova S, Burd L. A Multicountry Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults. J Addict Med. 2018 Nov/Dec;12(6):466-473. doi: 10.1097/ADM.0000000000000438. [A Multicountry Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults.](#)

criminal justice and special education sectors would require further investigation. Further, some earlier Australian economic studies on prevention could be explored to determine how they costed FASD as part of their economic studies for Australia (Health Technology Analytics 2010)¹⁷

7 Recommendations

Recommendation 1 Political leaders expedite FASD costing studies through National Cabinet, Department of Health, NHMRC and AIHW, using international methodologies and evidence through:

- a) Creating a *National FASD Costing Steering Committee (NFCSC)* involving representatives from the abovementioned organisations and NDIS, NDIA, IHPA, Productivity Commission, RACP, RACGP, AMA, GENI and Peak FASD stakeholder groups.
- b) AIHW providing early input to the NFCSC on key issues impacting Australian FASD costing studies including data bases, surveys and disease costing modelling issues involving input from the following AIHW groups:
 - **Economics and Expenditure** (Mr Jason Thomson) of Hospitals and Expenditure Group.
 - **Indigenous and Maternal Health Group** (Dr Fadwa Al-Yaman)
 - **Health Group** (Dr Lynelle Moon), including Burden of Disease and Mortality; Chronic conditions; Population Health; and Screening and Analysis and Monitoring Teams.
 - **Community Services Group** (Ms Louise York)
 - **Data Strategies and Information Technology Group** (Mr Geoff Neideck)
 - **Primary Health Care Data** (Mr Conan Liu)
 - **PHN and Primary Health Reporting** (Dr Kerrin Bleicher)
- c) AIHW establishing a team within the Economics and Expenditure section to address FASD costing and economic studies in Australia, drawing on lessons from international methodologies and studies.
- d) IHPA CEO providing early input to the NFCSC on key FASD utilization and costing data and modelling issues for the following services that may involve cases with either a principal or secondary diagnosis of FASD:
 - Acute admitted
 - Emergency department
 - Non-admitted care (hospital outpatient clinics, community-based clinics, patient's home)
 - Mental health (admitted, community)
 - Sub-acute care
 - Non-acute care
 - Teaching training and research

¹⁷ Health Technology Analytics, 2010 Fetal Alcohol Spectrum Disorder (FASD) Exploratory economic analysis of different prevention strategies in Australia and New Zealand
[https://www.foodstandards.govt.nz/about/ips/foilog/documents/Health%20Technology%20Analysts%20Pty%20Ltd_Fetal%20alcohol%20spectrum%20disorder%20\(FASD\).pdf](https://www.foodstandards.govt.nz/about/ips/foilog/documents/Health%20Technology%20Analysts%20Pty%20Ltd_Fetal%20alcohol%20spectrum%20disorder%20(FASD).pdf)

e) NDIA providing early input to the NFCSC on:

- Utilization and costing data availability for cases diagnosed with FASD within the NDIA's broader 'congenital condition' and considering FASD's neurodevelopmental disability features.
- FASD specific costs for the NDIS support items and support purposes of capital, core and capacity, and potential to model such costs from existing data bases.
- Costing, in consultation with the Productivity Commission, other aspects of disability in the NDIS that could be allocated to FASD cases, including operational costs, linkage and capacity building activities and supports outside the scheme

Senate inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum:
Question on Notice Number 2

Response by Dr Kathryn Antioch CEO,
Guidelines and Economists Network International (GENI)
22 October 2020

Question 2 Given the international nature of your organisation, do you have a view on what regulatory or systemic international best practice with regards to is 1. Prevention, 2. Diagnosis of FASD and 3. Support for adults and children with FASD? (ie are there particular countries, systems, or programs they can point to? Is there anywhere where FASD is particularly well integrated into practice/systems?). This question was raised by Senators after the public hearing and forwarded to Dr Antioch on 29 September 2020 requesting a response.

Insights from systematic reviews of peer reviewed journal articles and work by the AIHW is included below to identify high quality evaluations of systematic best practice for prevention, diagnosis, and support for FASD. There were four areas identified that are relevant to the question. This includes (a) International FASD programs for indigenous communities (b) Cost effective international best practice preventive programs in Canada and the USA (c) FASD and the criminal justice system and (d) review of FASD developments in Australia for prevention diagnosis and interventions. The information builds on the evidence provided to the Senate Committee in Dr Antioch's two submissions to the Senate Committee that were discussed at the Public Hearing held 16 September 2020. The key recommendations arising from the analysis below are included in the final section, pages 8 to 10.

1. Interventions for the prevention and management of FASD in Indigenous communities

The AIHW and Australia Institute of Family Studies (2015)¹ published a review of interventions for the prevention and management of FASD in Indigenous communities. The study identified the programs that were effective. A review of 22 programs in the USA found that pre-natal health screening of all females to identify those with alcohol issues, followed by short, empathetic interventions by health professionals and motivational interviewing, was effective in causing females to reduce or cease drinking alcohol during pregnancy. Strong Spirit Strong Future is a Western Australian Indigenous-specific education campaign to increase awareness of NHMRC's recommendation to abstain from drinking alcohol during pregnancy. It was considered culturally appropriate. However, the effects of the campaign on drinking behaviour have not yet been evaluated. They concluded that there is evidence from USA and Canadian studies that programs can alleviate some of the effects of FASD, including:

- The parenting program Families Moving Forward assisted families and reduced behavioural problems among children aged 3 to 13 with FASD.
- Children's Friendship Training, neurocognitive habilitation therapy, and sustained attention training improved the skills of primary-school-aged children with FASD.
- Stimulants and antipsychotic medications were effective in reducing hyperactivity among children with FASD (See AIHW and AIFS, 2015 for a review)

They found that the following strategies have been shown to reduce alcohol-related harm in Australian Indigenous communities. These strategies have the potential to reduce FASD rates by decreasing overall drinking levels, including the number of women drinking alcohol during pregnancy, and how much they drink:

- supply-reduction strategies such as increasing the price of alcohol, restricting trading hours, decreasing the number of outlets selling alcohol, dry community declarations, and culturally sensitive enforcement of existing laws

¹ AIHW and Australia Institute of Family Studies (2015) Fetal alcohol spectrum disorders: a review of interventions for prevention and management in Indigenous communities *Resource sheet no. 36* prepared by the Closing the Gap Clearinghouse February 2015

- demand-reduction strategies such as early intervention, providing alternative activities to drinking alcohol, and providing treatment and ongoing care to reduce relapse rates harm-reduction strategies such as community patrols and sobering-up shelters (AIHW and AIFS 2015)

The review found that targeting or shaming women for drinking alcohol while they are pregnant is not effective in causing them to reduce their alcohol intake. (AIHW and AIFS 2015) . Further details of the programs reviewed are available at the AIHW website.

More recently, systematic reviews were identified through a PUBMED search using search terms ‘Fetal Alcohol spectrum Disorder (FASD) filtered by systematic reviews from 2015 to 2020. This search identified 26 journal articles with three reviews selected for more in-depth review to address this Senate Committee Question on Notice. The study by Symons, Pedruzzi and Bruce et al (2018)² concerned prevention interventions to reduce prenatal alcohol exposure and FASD in indigenous communities. The systematic review updated the evidence for the effectiveness of FASD prevention interventions in Indigenous/Aboriginal populations internationally, and in specific populations in New Zealand and North America. It formulated recommendations for future work. They searched MEDLINE, Embase, CINAHL Plus, Web of Science, PsycINFO, SocINDEX, and Informit databases from inception to August 2017. They included all intervention and prevention papers published but excluded interventions focusing on the workforce.

They found significant heterogeneity in the ten included studies. Populations targeted included non-pregnant women of child-bearing age, pregnant women, school children and the public. Study designs included one randomised controlled trial, five cohort studies with pre-post design, one cross-sectional study with different pre-and post-intervention groups, and four studies collected post-intervention data. Studies assessed changes in knowledge, and/or changes in risk for prenatal alcohol exposure including self-reported alcohol consumption, use of birth control or a combination of both. One study was conducted in Australia and nine in the US (Symons, et al 2018).²

The methodological quality of all studies was rated as ‘Poor’ using the systematic review assessment tools developed by The National Heart, Lung and Blood Institute. Studies were subject to substantial bias due to lack of control groups, high loss to follow-up, and reliance on self-report measures to assess the main outcome. They concluded that there is little evidence that previous interventions aiming to reduce the risk of prenatal alcohol exposure or FASD in Indigenous populations have been effective. Future intervention studies should address the historical context and cultural factors that are vital to successful work with Indigenous populations. Further, they should be designed, implemented, and evaluated using rigorous methods. An overview of the studies reviewed are included in the table at attachment 1 which outlines the general characteristics of the programs and the results of the evaluations (See **Attachment 1**) (Symons, et al, 2018)²

2. Cost effectiveness of best practice FASD prevention programs in USA and Canada: Value for Money

Greenmyer, Popova and Klug et al (2020)³ undertook a systematic review of published literature on the cost of, and savings from, FASD evidence-based prevention programs. Their analysis provides insights on international cost-effective best practice prevention programs in the USA and Canada concerning the prevention of FASD, which is well integrated into practice and national systems.

They undertook two separate search strategies: to review (1) existing studies on costs of primary prevention of FASD in USA and Canada and (2) existing studies on national costs of FASD in those countries. The first search strategy was used to determine the cost of prevention efforts in existing programs. Literature published before June 2017 concerning studies reporting the cost of prevention for FASD.

² Symons M, Pedruzzi RA, Bruce K, Milne E. A systematic review of prevention interventions to reduce prenatal alcohol exposure and fetal alcohol spectrum disorder in indigenous communities. BMC Public Health. 2018 Nov 3;18(1):1227. doi: 10.1186/s12889-018-6139-5.

³ Greenmyer JR, Popova S, Klug MG, Burd L. Fetal alcohol spectrum disorder: a systematic review of the cost of and savings from prevention in the United States and Canada. Addiction. 2020 Mar;115(3):409-417. doi: 10.1111/add.14841. Epub 2019 Dec 11.

PubMed, Cochrane Database of Systematic Reviews and Google Scholar were searched using keywords: 1 Disease conditions: 'fetal alcohol', FASD, FAS, pFAS, fetal alcohol effects (FAE), ARND, ARBD, prenatal alcohol exposure; and 2 Cost: prevention: 'cost of prevention', cost, economic, social cost, economic cost.

The second search strategy was a recently published systematic literature search that included the national costs of FASD in Canada and the USA. The study was used to determine the country-wide cost of FASD, the approximate percentage of total cost that is dedicated to prevention and research, and the present discounted value in the countries that studied the cost of prevention of FASD. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 checklist was referenced to ensure a standardized approach and minimize error and bias. Studies were assessed using the 24-item Consolidated Health Economic Evaluation Reporting Standards (CHEERS checklist). The 19-item Consensus on Health Economic Criteria (CHEC) list was also used.

Studies that reported the cost of primary prevention of FASD were analysed. They present a model for Canada and USA of projected savings based on expansion of existing evidence-based prevention models. They found that applying evidenced-based prevention programs to women at highest risk to have a future child with FASD greatly reduces the cost of prevention. In the USA, one case of FASD can be prevented for as low as USD \$20 200 – 47 615. Cost of prevention is considerably less expensive than cost of care for a case of FASD. Expansion of risk-based prevention strategies for FASD in USA and Canada would be an economically efficient and worthwhile investment for society. Further details of these programs are outlined below.

Greenmeyer, et al (2020) ³ note that the Parent–Child Assistance Program (P-CAP) is an evidence-based prevention program for alcohol and drug-exposed births that uses harm reduction mentorship, case management and home visitation and (Ernest, Grant and, Streissguth et al 1999)⁴. The program was launched by the University of Washington. The PCAP has been replicated at 40 sites in Canada (<http://depts.washington.edu/pcapuw/>). The program enrolls high risk (substance-using) women who are pregnant or up to 6 months postpartum. FASD programs have successfully reduced maternal drinking during pregnancy and its prevalence. They have also generated exceptionally large economic and social benefits (Astley, 2004)⁵

Table 3 summarizes the results of the literature review and includes data relevant to the cost of preventing one case of FASD. Astley et al. studied the P-CAP model in Washington State (Astley, Bailey, Talbot 2000)⁶. They reported that by treating women who have had a previous child with FASD (the highest-risk population) the cost to prevent one case of FASD was \$47 615 (converted to 2017 USD\$). Burd et al. conducted a cost analysis in the United States that estimated the cost to prevent FASD based on maternal risk factors (Burd, Cotsonas-Hassler and Martsolf et al 2003)⁷. The cost estimates of preventing one case of FASD varied greatly based on the risk factors of the treated female. The estimated cost per prevented case of FASD was \$134 810 000 among women who drink compared to \$20 200 for the highest-risk population: a 6674-fold cost reduction. The highest-risk patient populations were women who were heavy drinkers and smokers with low income (\$316 800 in 2017 USD\$ to prevent one case) and women who have had a previous child with FAS (\$20 200 in 2017 USD\$). One study examined costs from 366 women who utilized the P-CAP model in Alberta, Canada, from 2008 to 2011 (Thanh, Jonsson, Moffat et al 2015)⁸. The decision analytical modelling technique utilized in that study estimated that the cost of preventing one case of FASD by treating women with heavy alcohol consumption in the P-CAP program shown in table 3 below averaged \$102,914 (range = \$76 390–162 329) in 2017.

⁴ Ernst C. C., Grant T. M., Streissguth A. P., Sampson P. D. Intervention with high-risk alcohol and drug-abusing mothers: II. Three-year findings from the Seattle model of paraprofessional advocacy. *J Community Psychol* 1999; 27: 19–38.

⁵ Astley S. J. Fetal alcohol syndrome prevention in Washington state: evidence of success. *Paediatr Perinat Epidemiol* 2004; 18: 344–51.

⁶ Astley S. J., Bailey D., Talbot C., Clarren S. K. Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children. *Alcohol Alcohol* 2000; 35: 499–508.

⁷ Burd L., Cotsonas-Hassler T.M., Martsolf J., Kerbeshian J. Recognition and management of fetal alcohol syndrome. *Neurotoxicol Teratol* 2003; 25: 681–8.

⁸ Thanh N., Jonsson E., Moffat J., Dennett L., Chuck A., Birchard S. An economic evaluation of the parent-child assistance program for preventing fetal alcohol spectrum disorder in Alberta. Canada. *Adm Policy Ment Health* 2015; 42: 10–8.

Table 3 Systematic review results: estimated cost of prevention of one case of FASD in the United States and Canada.

| <i>United States (all costs in USD\$)</i> | | | |
|---|--|---|--|
| <i>Source</i> | <i>Risk factors or patient population</i> | <i>Cost to prevent 1 case (reported in year of study)</i> | <i>2017 Equivalent</i> |
| Burd <i>et al.</i> 2003 [29] | Weekly alcohol use, no binges | \$100 000 000 | \$134 810 000 |
| | Frequent drinkers, non-smokers | \$3 450 000 | \$4 651 000 |
| | Heavy drinkers, low-income, smokers | \$235 000 | \$316 800 |
| | Women who have had a previous child with FAS | \$15 000 | \$20 200 |
| Astley <i>et al.</i> 2000 [28] | Women who have had a previous child with FAS | \$33 000 | \$47 615 |
| Canada (all costs in CAD\$) | | | |
| Thanh <i>et al.</i> 2015 [30] | Heavy alcohol consumers | \$97 000 (range = \$72 000–153000) | \$102 914 (range = \$76 390–162329) |

FAS = fetal alcohol syndrome; FASD = fetal alcohol spectrum disorder.

Source: Greenmyer, Popova, Klug, Burd, (2020)³

An intervention program in USA that focused on females who have previously given birth to a child with FASD could cost as low as \$20 200 USD per case prevented, and saving society USD \$1 235 800 (net) based on present discounted value of life-time cost (Lupton, Burd and Harwood 2004)⁹. This is a 62-fold cost reduction for females with a high recurrence risk. Prevention efforts that treated women of low socio-economic status who are heavy drinkers and smokers (\$316 800/case prevented) would save society USD \$939 200 per case prevented. Similar findings have been reported in separate locations inside USA and Canada in the P-CAP model of prevention (Astley, Bailey and Talbot *et al* (2000)⁶, Thanh, Jonsson, Moffat *et al* (2015)⁸

The cost of raising a child with FAS would be approximately 30 times the cost of preventing one case of FASD (Astley, Bailey and Talbot *et al* 2000)⁶. Funding cost-effective FASD prevention can provide greater than 700% return on the investment (Thanh, Jonsson, Moffat *et al* 2015)⁸. These savings estimates are conservative given they do not include savings associated with other benefits of P-CAP (Grant, 2013)¹⁰, Thanh Jonsson, Moffat *et al*, (2015)⁸. If 1% of estimated 2017 costs associated with care of people with FASD in USA or Canada was allocated to prevention in high risk females, the economic benefit over the individuals' life-times would be extraordinary. These data demonstrate the economic acuity of utilizing prevention models that utilize maternal risk stratification Greenmyer *et al* (2020)³ conclude that cost-effective prevention strategies should utilize targeted interventions prioritizing females with the highest risk: (1) those who have had a previous child with FASD; and (2) women of low socio-economic status who are heavy drinkers and smokers and have poor diets (Burd, Cotsonas-Hassler and Martsolf *et al* 2003)⁷. Further, the intangible costs (suffering) that could be alleviated by cost-effective interventions should encourage policymakers to invest in prevention of FASD based on risk assessment.

3. The justice system and FASD

Involvement in the criminal justice system has increasingly emerged as a negative consequence for some individuals with FASD (Flanningan, Pei, and Stewart *et al* 2018)¹¹. Several countries are examining ways in which policy or legislation can be developed to better respond. Flanningan's *et al* (2018)¹¹ review identified key aspects of the justice system and identified new pathways for policy and law in for FASD in the justice system.

⁹ Lupton C., Burd L., Harwood R. Cost of fetal alcohol spectrum disorders. *Am J Med Genet C Semin Med Genet* 2004; 127C: 42–50.

¹⁰ Grant T., Casey Family Programs. Parent–Child Assistance Program Outcomes Suggest Sources of Cost Savings for Washington State. Washington, DC: University of Washington; 2013.

¹¹ Flanningan, K, Pei J and Stewart M (2018) Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review *Int J Law Psychiatry*. Mar-Apr 201 8;57:42-52. doi: 10.1016/j.jljp.2017.12.008. Epub 2018 Feb 3.

During 2012, the American Bar Association (ABA, 2012)¹² passed a resolution to support the “passage of laws, and adoption of policies at all levels of government” to better address the needs of FASD cases. During 2010 and 2013, the Canadian Bar Association (CBA) passed resolutions requesting all levels of government to “allocate additional resources for alternatives to the current practice of criminalizing individuals with FASD,” (CBA, 2010)¹³ and to “improve access to justice” and accommodate FASD (CBA, 2013)¹⁴. During 2013, A Consensus Development Conference in Canada focussed on legal issues associated with FASD. The expert jury heard testimony, deliberated, and generated dozens of recommendations for reforms in policy and practice, and established the consensus that further evidence is required (Institute of Health Economics, 2013)¹⁵.

Efforts to change the Canadian justice system have been pursued through amending the Criminal Code, although no bills have been successfully passed to date. The most recent, Bill C-235, was introduced in 2016 to establish FASD as a mitigating factor in sentencing and grant power to judges, through expedited processes, to order assessments of cases with a suspected diagnosis of FASD. The Truth and Reconciliation Commission of Canada (2015)¹⁶ released many calls to action concerning the ongoing impacts of colonialism and residential schools on Indigenous populations, two of which focused specifically on FASD: one on justice reform and the other on prevention (Flannigan, Pei, and Stewart et al 2018). Given these developments, Flannigan et al (2018)¹¹ undertook a systematic review to provide a global overview of the evidence concerning individuals with FASD or PAE who are involved in the criminal justice system. A key imperative was to identify ways to incorporate an evidence-based foundation and effective programming to best support individuals with FASD, with impacts extending across sectors. They reviewed the literature between June 2016 and April 2017 using: CanLII, Canadian Public Policy Collection, Cochrane Database of Systematic Reviews, ERIC, LegalTrac, National Criminal Justice Reference Service Abstracts Database, PsycINFO, PubMed, Sociological Abstracts, Social Services Abstracts, and Web. They selected 25 articles from 1855 for in-depth review. The results of the review are summarised in the table in **Attachment 2**

Implications for new developments in policy and practice

Although FASD seems overrepresented in the criminal justice system, there is no singular profile differentiating FASD cases from those without, particularly pertaining to risk. FASD is not the only disability with high prevalence in the justice system. Stinson and Robbins (2014)¹⁷ identified other populations of incarcerated individuals with disabilities also struggling with psychopathology, histories of violence and criminality and early life adversity. Examination of best practices in justice services may not be diagnostically derived but rather individually informed based on risk factors indicative of complex needs. FASD cases are a very heterogeneous group, with varying life experiences, clinical profiles, and functional ability. Therefore, a “one size fits all” approach could be inappropriate for improving outcomes. Rather, developing intervention programs for offenders with “cognitive diversity,” incorporating a high degree of tailored flexibility could be preferable. *Expanding frameworks for considering FASD and criminality could potentially improve outcomes. Alternative justice measures such as mental health and wellness courts may be appropriate in some cases in pursuing best practice* (Flannigan et al, 2018)¹¹

¹² American Bar Association (2012). Resolution 112B. Retrieved from http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/Resolution_112B.authcheckdam.pdf.

¹³ Canadian Bar Association (2010). Resolution 10-02-A: Fetal Alcohol Spectrum Disorder in the criminal justice system. Retrieved from <http://www.cba.org/cba/resolutions/pdf/10-02-A.pdf>.

¹⁴ Canadian Bar Association (2013). Resolution 13-12-A: Accommodating the disability of FASD to improve justice services. Retrieved from <http://www.cba.org/cba/resolutions/pdf/13-12-A.pdf>.

¹⁵ Institute of Health Economics (2013). Consensus statement on legal issues of Fetal Alcohol Spectrum Disorder (FASD). Vol. 5 Retrieved from http://www.ihe.ca/documents/2013_Consensus_Statement_Legal_Issues_FASD.pdf.

¹⁶ Truth and Reconciliation Commission of Canada (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. Retrieved from http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Exec_Summary_2015_05_31_web_o.pdf.

¹⁷ Stinson, J. D., & Robbins, S. B. (2014). Characteristics of people with intellectual disabilities in a secure US forensic hospital. *Journal of Mental Health Research in Intellectual Disabilities*, 7(4), 337–358.

As societies move towards embedding FASD into legislation and having it serve as a mitigating factor in sentencing, there is a need to clarify that FASD does not necessarily result in criminality. Rather, FASD might increase a cluster of risk factors which may involve engagement in the justice system.

The social determinants of health and issues underlying the criminal justice system phenomena should be addressed. This could involve *all* groups of marginalized individuals, including cases with FASD. Understanding the marginalization of FASD cases can inform programs and practices and enable individuals to live well-supported lives outside of the justice system. (Flanningan et al, 2018) ¹¹

There is a dearth of research on evidence-based justice interventions for offenders with FASD. There is no research to explore what forms of intervention may assist or harm individuals involved in the system. This hinders capacity to train professionals or to determine what training approaches are appropriate. Questions around whether cognitive impairment should be considered a mitigating or aggravating factor are highly contentious and require greater clarity through research. The link between FASD, early delinquency, other potential risk factors and later legal involvement could be explored to identify mechanisms to divert youth away from a pathway into the justice system. Other areas to investigate include the limits and potential of risk measures traditionally used in the justice system, which might negatively impact individuals when the full context is not adequately explored, and where disability may impact the application of these tools. The prevention of criminal behaviour is a critical area to investigate. (Flanningan et al, 2018) ¹¹

4. Review of FASD in Australia

Reid (2018)¹⁸ reviewed FASD in Australia in the context of the Commonwealth FASD Strategy (2018–2028) and significant Australian Government funding for the expansion of FASD prevention, diagnostic and intervention services. She identified some international developments and areas for future research and service delivery which are outlined below.

Prevention

Canadian experts describe a four-part framework to categorise initiatives required for the effective FASD prevention:

- Level 1: public awareness and broad health promotion
- Level 2: conversations about alcohol use, pregnancy planning and contraceptive use with women of reproductive age and their support networks
- Level 3: specialised holistic support for pregnant women and their support networks, including addressing relevant social and environmental factors
- Level 4: postpartum support for new families to maintain changes and support for child assessment and development (Poole, Schmidt, Green 2016)¹⁹.
- They recommend that all these initiatives could be provided in conjunction with supportive alcohol policies (Poole et al 2016) ¹⁹

In Australia, some FASD prevention projects are based on the four-part model in WA, NSW and NT. In WA, drinking rates in a high-risk community decreased from over fifty percent to less than one-fifth of females (Fitzpatrick and Pestell 2016)²⁰. Reid (2018) ¹⁸ argues that broader implementation of this multi-level prevention strategy can potentially significantly reduce the risk of having children with FASD.

¹⁸ Reid N. Fetal alcohol spectrum disorder in Australia: What is the current state of affairs? Drug Alcohol Rev. 2018 Nov;37(7):827-830. doi: 10.1111/dar.12855. Epub 2018 Aug 15. PMID: 30109741

¹⁹ Poole N, Schmidt RA, Green C, Hemsing N. Prevention of fetal alcohol spectrum disorder: current Canadian efforts and analysis of gaps. Subst Abus 2016;10:1–11.

²⁰ Fitzpatrick JP, Pestell CF. Neuropsychological aspects of prevention and intervention for fetal alcohol spectrum disorders in Australia. J Pediatr Neuropsychol 2016;3:1–15

Diagnosis and intervention

Reid (2018)¹⁸ highlighted that the release of the ‘Australian guide to the diagnosis of FASD’ (Bower and Elliott 2016)²¹ will provide momentum for increased understanding, recognition and diagnosis of FASD in Australia. Antioch (2020) identified the high priority requirement to urgently update the ‘Australian guide to the diagnosis of FASD’ dated February, 2020 given new evidence published from 2016 to 2020 is not yet included in the 2020 Guide. (See Antioch’s two inquiry submissions and Commonwealth of Australia Proof Committee Hansard 16 September, 2020 pages 23 to 27).

Reid (2018)¹⁸ identifies some important issues concerning the FASD *assessment process* as an area requiring research focus. The ‘gold standard’ involves multiple days of assessments, followed by a multidisciplinary case-conference. This process is very labour intensive and not cost effective nor feasible in remote or high-risk areas (Reid, 2018)¹⁸. A promising method is the Emory Neurodevelopment and Exposure clinic in the USA involving a tiered approach to assessment (Coles, Gailey and Mulle et al 2016)²², streamlining clinical services and triage to those most in need of more thorough assessment. A focus on screening and access to diagnostic and intervention services in high-risk populations, specifically the out-of-home care and the justice system, is vital. Appropriate diagnosis of children in out-of-home care can enable suitable placements and caregivers. This can potentially decrease costly and traumatising placement breakdowns (Lange, Shield, Rehm et al 2013)²³. This is important, especially given the high rates of FASD in the youth justice system. (Passmore, Giglia, Watkins et al 2016)²⁴. Accurate FASD diagnosis is also imperative as individuals may experience a range of physical health difficulties.

The access and availability of interventions for individuals once they have received a FASD diagnosis is important. Caregivers have struggled to access support for their children following a diagnosis of FASD (Chamberlain, Reid and Warner et al 2017)²⁵. Reid (2018)¹⁸ suggested this may have been partly due to FASD not being recognised as a disability within Australian health and education systems. Therefore, children and their families did not receive any additional supports, unless their child had a comorbid diagnosis (e.g. intellectual disability, autism spectrum disorder). Reid (2018)¹⁸ expressed hope that the National Disability Insurance Scheme would address this into the future, so that individuals with FASD will be able to access appropriate ongoing support within a suitable funding framework (Dudley, Reibel and Bower et al 2015)²⁶.

There are several promising early interventions provided in Australia for neurodevelopmental problems. They may be more effective if these were adapted to suit the complex cognitive and learning needs of children with FASD (Olson and Montague, 2011)²⁷. There are several effective evidence-based

²¹ Bower C, Elliott EJ. On behalf of the Steering Group. Report to the Australian Government Department of Health: Australian guide to the diagnosis of fetal alcohol spectrum disorder (FASD). 2016.

²² Coles CD, Gailey AR, Mulle JG, Kable JA, Lynch ME, Jones KL. A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders. *Alcohol Clin Exp Res* 2016;40:1000–9.

²³ Lange S, Shield K, Rehm J, Popova S. Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. *Pediatrics* 2013;132:e980–e95

²⁴ Passmore HM, Giglia R, Watkins RE et al. Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 2016;6:e012184.

²⁵ Chamberlain K, Reid N, Warner J, Shelton D, Dawe S. A qualitative evaluation of caregivers’ experiences, understanding and outcomes following diagnosis of FASD. *Res Dev Disabil* 2017;63:99–106.

²⁶ Dudley A, Reibel T, Bower C, Fitzpatrick JP. Critical review of the literature: fetal alcohol spectrum disorders. Subiaco: Telethon Kids Institute, 2015

²⁷ Olson HC, Montague RA. An innovative look at early intervention for children affected by prenatal alcohol exposure. In: *Prenatal alcohol use and fetal alcohol spectrum disorders: diagnosis, assessment and new directions in research and multimodal treatment*, 2011:64–107.

interventions available internationally for school-aged children (Reid, Dawe, Shelton et al 2015)²⁸. They could be considered in Australia.

Reid (2018)¹⁸ suggests the following initiatives:

- ascertain FASD prevalence in the general population to inform service needs and enable measurement for future intervention efforts
- improve prevention of FASD through broad implementation of approaches such as the Canadian four-part framework (Poole et al 2016)¹⁹, which can be tailored for individual community needs.
- increase availability of diagnostic and intervention services for high-risk populations such out-of-home care and justice systems, to facilitate early access to required support.
- expand FASD training for professionals to guarantee the successful dissemination and implementation of prevention, diagnostic and intervention efforts.

5. Recommendations

1. Interventions for the prevention and management of FASD in Indigenous communities

Recommendation 1: In developing reforms concerning international best practice for prevention and management of FASD in Indigenous communities, careful consideration to be given to the following programs and systemic approaches.

A review of *prevention and management* of FASD in Indigenous communities by AIHW and AIFS (2015) identified effective programs. A review of 22 programs in USA found that pre-natal health screening of all females for identifying alcohol issues, followed by short, empathetic interventions by health professionals and motivational interviewing, was effective in reducing or ceasing alcohol consumption during pregnancy.

Canadian and USA evidence demonstrates that programs can alleviate some effects of FASD including:

- Children's Friendship Training, neurocognitive habilitation therapy, and sustained attention training improved the skills of primary-school-aged children with FASD.
- Parenting program Families Moving Forward assisted families and reduced behavioural problems among children aged 3 to 13 with FASD.
- Antipsychotic and stimulants medications were effective in reducing hyperactivity in children with FASD (AIHW and AIFS, 2015)

Some strategies have reduced alcohol-related harm in Australian Indigenous communities. They can potentially reduce FASD rates by decreasing overall drinking levels, including the number of women drinking alcohol during pregnancy and the quantity they drink:

- *supply-reduction strategies*: increasing alcohol prices, restricting trading hours, decreasing outlets selling alcohol, dry community declarations, and culturally sensitive law enforcement.
- *demand-reduction strategies*: early intervention, providing alternative activities to drinking alcohol, providing treatment and ongoing care to reduce relapse rates and harm-reduction strategies eg: community patrols and sobering-up shelters (AIHW and AIFS 2015)

²⁸ Reid N, Dawe S, Shelton D et al. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin Exp Res* 2015;39:2283–95.

Targeting or shaming women for drinking alcohol during pregnancy is not effective in reducing their alcohol intake.

The systematic review by Symons, et al (2018) concluded that there is little evidence that previous **prevention interventions** to reduce prenatal alcohol exposure and FASD in Indigenous/Aboriginal populations internationally, and in specific populations in New Zealand and North America, have been effective. The methodological quality of all studies was rated as 'Poor'.

2. Cost effectiveness of best practice FASD prevention programs in USA and Canada: Value for Money

Recommendation 2: The cost-effective Parent-Child Assistance Program (P-CAP) in the USA and Canada to be considered in the context of Australian reforms for FASD prevention programs.

- **The Parent–Child Assistance Program (P-CAP)** is an evidence-based prevention program for alcohol and drug-exposed births that uses harm reduction mentorship, case management and home visitation
- The P-CAP was launched by the University of Washington. The PCAP has been replicated at 40 sites in Canada (<http://depts.washington.edu/pcapuw/>). The program enrolls high risk (substance-using) women who are pregnant or up to 6 months postpartum. FASD programs have successfully reduced maternal drinking during pregnancy and its prevalence. They have also generated exceptionally large economic and social benefits (Astley, 2004)
- A model for projected savings in USA and Canada, based on expansion of existing *evidence-based prevention models*, found that applying them to women at highest risk to have a future child with FASD greatly reduces the cost of prevention.
- For the **P-CAP model in Washington State**, treating women who have had a previous child with FASD (the highest-risk population) incur a cost to prevent one case of FASD of US\$47 615. (Astley et al., 2000)
- Burd et al. (2003) estimated the cost to prevent FASD based on maternal risk factors in USA
 - Cost per prevented case of FASD was US\$134 810 000 for women who drink compared to US\$20 200 for the highest-risk population: a 6674-fold cost reduction.
 - The highest-risk patient populations were women who were heavy drinkers and smokers with low income (US\$316 800 to prevent one case) and women who have had a previous child with FAS (US\$20 200).
- Costs from 366 women who utilized the **P-CAP model in Alberta, Canada**, from 2008 to 2011 were examined. The cost of preventing one case of FASD by treating women with heavy alcohol consumption in the P-CAP program averaged US\$102,914 (Thanh et al, 2015)
- Cost-effective prevention strategies should utilize targeted interventions prioritizing females with the highest risk: those who have had a previous child with FASD; and women of low socio-economic status who are heavy drinkers and smokers and have poor diets.
- Expansion of risk-based prevention strategies for FASD in USA and Canada would be an economically efficient and worthwhile investment for society. (Greenmyer et al 2020)

3 The justice system and FASD

Recommendation 3: Reforms of the criminal justice systems and related policy and regulations in USA and Canada to improve the management of FASD cases to be considered:

- Involvement in the criminal justice system has been a negative consequence for some individuals with FASD. USA and Canada are examining ways in which policy or legislation can be developed to better respond, including initiatives by American Bar Association and Canadian Bar Association (CBA).
- During 2010 and 2013, the CBA passed resolutions requesting all levels of government to allocate additional resources for alternatives to the current practice of criminalizing individuals with FASD, and to improve access to justice to accommodate FASD.

- Efforts to change the Canadian justice system have been pursued through amending the Criminal Code, although no bills have been successfully passed to date.
- The most recent, Bill C-235, was introduced in 2016 to establish FASD as a mitigating factor in sentencing and grant power to judges, through expedited processes, to order assessments of cases with a suspected diagnosis of FASD.
- The Truth and Reconciliation Commission of Canada (2015) released calls to action concerning the ongoing impacts of colonialism and residential schools on Indigenous populations. Two focused specifically on FASD including justice reform and prevention
- Although FASD seems overrepresented in the criminal justice system, there is no singular profile differentiating FASD cases from those without, particularly pertaining to risk. FASD is not the only disability with high prevalence in the justice system.
- Examination of best practices in justice services may not be diagnostically derived but rather individually informed, based on risk factors indicative of complex needs.
- Developing intervention programs for offenders with “cognitive diversity,” incorporating a high degree of tailored flexibility, could be preferable.
- Expanding frameworks for considering FASD and criminality could improve outcomes. Alternative justice measures such as *mental health and wellness courts* may be appropriate in some cases in pursuing best practice
- As societies move towards embedding FASD into legislation, and serving as a mitigating factor in sentencing, there is a need to clarify that FASD does not necessarily result in criminality.
- The link between FASD, early delinquency, other potential risk factors and later legal involvement could be explored to identify mechanisms to divert youth away from a pathway into the justice system (Flannigan et al 2018)

4. Review of FASD in Australia

Recommendation 4 The following international evidence to be considered in context of Australian reforms to improve the prevention, diagnosis, and interventions for FASD

Prevention

Reid (2018) recommends improvements in preventing FASD in Australia through broader implementation of the Canadian four-part framework tailored for individual community needs:

- Level 1: public awareness and broad health promotion
- Level 2: conversations about alcohol use, pregnancy planning and contraceptive use with females of reproductive age and their support networks
- Level 3: specialised holistic support for pregnant women and their support networks, including addressing relevant social and environmental factors
- Level 4: postpartum support for new families to maintain changes and support for child assessment and development
- All these initiatives could be provided in conjunction with supportive alcohol policies. (Poole et al 2016)
- Some FASD prevention projects in Australia are based on the four-part model in WA, NSW, and NT. In WA, drinking rates in a high-risk community decreased from over fifty percent to less than one-fifth of females (Reid, 2018).

Diagnosis and intervention

- The ‘Australian guide to the diagnosis of FASD’ dated February 2020 should be updated as a high priority given new evidence published from 2016 to 2020 is not included in the 2020 Guide (Antioch 2020)

- The ‘gold standard’ FASD assessment involves multiple assessment days and a multidisciplinary case-conference. It is labour intensive, not cost effective nor feasible in remote or high-risk areas. A promising method is the American Emory Neurodevelopment and Exposure clinic involving a tiered approach to assessment (Coles et al 2016) streamlining clinical services and triage (Reid 2018)
- increase availability of diagnostic and intervention services for high-risk populations such out-of-home care and justice systems to facilitate early access to support. (Reid 2018)
- Promising early interventions in Australia for neurodevelopmental problems could be more effective if adapted to suit the needs of children with FASD. Several for school-aged children identified by Reid, et al (2015) could be considered.

ATTACHMENT 1: Interventions for the prevention and management of FASD in Indigenous communities

Table 2 General characteristics of included studies

| Study | Country | Target Population | Study Population | Design | Brief Description of the Intervention | Outcome Types | Results |
|------------------------------|-------------|---|---|--|--|---|---|
| Indicated Strategies | | | | | | | |
| KB Masis & PA May, 1991 [29] | US, Arizona | American Indian women from Tuba City | Women referred to an Indian Medical centre at 'high risk' for producing alcohol affected children | Single cohort with surveys conducted post-intervention | Primary prevention included: community media, posters, and pamphlets; training of school and health personnel Secondary prevention included: screening of prenatal patients for alcohol use with education about FAS and alcohol; referral of women with high risk drinking or a child with FAS to tertiary prevention Tertiary prevention evaluated in this study: case management; counselling; detoxification; individual and group alcohol treatment, follow-up and after care; voluntary birth control or sterilisation | Number of children born with FAS-FAE Alcohol consumption: Screening tool assessment of risky drinking; self-reported frequency and quantity verified by family members at 18 months (n = 32) Contraceptive Use (n = 32) | See brief summary in text |
| PA May et al., 2008 [30] | US | American Indian women from four communities in Northern Plains States | Women at extremely high risk for PAE (substantial history of alcohol abuse, drinking during pregnancy or previous birth of a child with FASD) | Pre-post cohort study with data collected at baseline then at six month periods through to 72 months | Training of a prevention site manager and case manager at each of the four sites who provided three levels of FASD prevention activities: Community, education and policy strategies High risk groups: Screening, targeted messages, referral for alcohol abuse Women identified through screening: Case management enhanced by brief intervention based on MI | Number of children born with FASD Alcohol consumption: Frequency, Times 'high' or drunk, binge drinking (Three drinks or more per occasion per day) Birth control status | Overall, 69.5% of the time (n = 105) fetuses were protected from PAE either by using birth control while drinking (39%), not drinking and using birth control (18.1%), or not drinking and not using birth control (12.4%) Further results are not reported due to high loss to follow-up from baseline (n = 115) to 6 months (n = 39) and 12 months (n = 37). |
| JD Hanson et al., 2017 [31] | US | American Indian women from two reservation sites and one urban site ≥18 years old, sexually active and fertile | Non-pregnant women All participants were at risk of AEP (4 or more drinks per occasion or 8 or more drinks per week and not using any contraception or using a method incorrectly or | Single cohort study with surveys at baseline, and three and six months post-intervention | Oglala Sioux Tribe (OST) CHOICES Program was delivered to all participants (2–4 sessions) The intervention included MI techniques delivered by trained interventionists to encourage participants to decrease binge drinking and increase birth control use to reduce the risk of AEP | Proportion of women at risk of AEP (defined as per the inclusion criteria, along with the proportion of participants pregnant at follow-up) Alcohol consumption: Volume, frequency, binge episodes Contraceptive use: Use | Significant reduction in AEP risk from baseline (100%) to three months (exact value not provided, p value not stated), and six months (exact value not provided, p value not stated) |

Table 2 General characteristics of included studies (Continued)

| Study | Country | Target Population | Study Population | Design | Brief Description of the Intervention | Outcome Types | Results |
|---|-------------------------|---|--|---|---|--|---|
| AC Montag et al, 2015 [34] | US, Southern California | American Indian/Alaskan Native women | Women of childbearing age recruited at three AIAN health clinics | Randomised control trial of an intervention compared with treatment as usual with surveys at baseline and one, three and six months post-intervention | ~20-min web-based brief assessment and intervention tool tailored to the population consisting of an anonymous survey followed by individualised risk feedback for AEP, including impact of alcohol exposure on a fetus, physical and financial costs of alcohol consumption and comparison of drinking levels with other Native women. Information on additional resources was provided at the end of the web session and could be printed. Treatment as usual control: Assessment of alcohol use and access to displayed health education brochures that did not include FASD specific information. | Birth control use ($n = 162$) in past 90 days: sexual activity, contraception method, frequency Proportion of women at high risk of AEP Alcohol Consumption: number of drinks per week and per occasion, episodes ($> = 3$ drinks) in past 2 weeks. Birth control use (only reported at baseline). Awareness of FASD and knowledge regarding the risks of alcohol consumption for women and their pregnancy (baseline only) | All outcomes showed a significant time effect but no intervention effect. The proportion of women at high risk of AEP (%) for the intervention and control groups respectively was 36.4/33.6% at baseline, 18.8/21.9% at one month, 16.7/21.7% at three months and 18.9/22.1% at six months. Drinks per week were 4.40 ± 0.94 , 0.89 ± 0.21 , 0.98 ± 0.26 , and 1.64 ± 0.55 for the intervention group and 3.38 ± 0.50 , 1.34 ± 0.24 , 1.94 ± 0.38 , and 1.99 ± 0.46 for the control group at baseline, one month, three months and six months respectively. Binge episodes (over two weeks) were 1.47 ± 0.40 , 0.36 ± 0.08 , 0.49 ± 0.17 , 0.50 ± 0.12 for the intervention group and 1.06 ± 0.16 , 0.49 ± 0.09 , 0.62 ± 0.13 , 0.72 ± 0.14 for the control group at baseline, one month, three months and six months respectively. |
| Universal Strategies PA May & KJ Hymnbaugh, 1999[26] | US-wide | Native American and Alaskan Native communities serviced by 92 Indian Health Services across 48 USA states | Prenatal groups, school children, Indian Health Service (IHS) workers and community groups | Pre-post intervention surveys with multiple disparate cohorts and limited follow-up | The National Indian FAS Prevention Program was developed to provide knowledge, skills and educational resources for communities to carry out | Five questionnaires were used to assess prevention education. Four consisted of fact identification and fixed response items and one | Four of eight school classes (from Grade 5 through to high school) had significant improvements ($p < .05$) in knowledge pre- to |

Table 2 General characteristics of included studies (Continued)

| Study | Country | Target Population | Study Population | Design | Brief Description of the Intervention | Outcome Types | Results |
|------------------------|--------------------------------|--|--|--|--|---|--|
| KJ Plasier, 1989 [33] | US, Michigan's Upper Peninsula | American Indian Communities | Women of childbearing age who were pregnant or had delivered an infant in last 12 months were recruited at clinics or by Indian health workers | Cohort intervention with post-intervention survey | Indian health workers were educated using previously developed culturally sensitive materials, and helped to plan and deliver FAS education programs. Programs aimed to encourage women to participate in sponsored community-wide workshops, including school and senior citizen programs. Individual counselling was provided at clinics | FAS Knowledge | post-test Eleven of 14 adult groups had significant improvements in knowledge ($p < .01$) pre- to post-test Two out of three groups (two high school and one community health group) had significant knowledge gain ($p < .01$) from pre- to post-test after receiving the education materials alone Of the six groups assessed at follow-up at least two months later (four school classes and two community groups), four had significant ($p < .01$) knowledge gain post-education and three were still significantly ($p < .01$) higher at follow-up compared with pre-test See brief summary in text |
| RJ Bowerman, 1997 [25] | US, Alaska | American Indian and Alaskan Native populations | Pregnant women from six remote villages in Barrow in Arctic Alaska | Cross-sectional pre- and post-intervention surveys with different groups | 1994 ban on alcohol possession in the town of Barrow | Alcohol consumption: reported by trimester as percentage engaged in "alcohol abuse" (not defined) | The proportion of women engaged in alcohol abuse was reported as 42% for the pre-intervention sample and 9% for the post-intervention sample (RR = 0.21, 95% CI = 0.08, 0.55) |

Table 2 General characteristics of included studies (Continued)

| Study | Country | Target Population | Study Population | Design | Brief Description of the Intervention | Outcome Types | Results |
|-----------------------------|---------|---|--|------------------------------|---|---|--|
| JD Hanson et al., 2012 [32] | US | Three tribal American Indian communities located 400–600 miles apart in the Northern Plains | American Indian Women of child bearing age (18–44 years) self-enrolled by calling a 1–800 phone line | Post-intervention evaluation | <p>A culturally and linguistically tailored media campaign included:</p> <ul style="list-style-type: none"> posters displayed in community settings and local newspapers; radio advertisements; pens; brochures; and t-shirts. The campaign was delivered through: information booths set up at local fairs or community events, community centres, health clinics and local tribal colleges; community presentations at local schools and treatment facilities; and Public Service Announcements and live interviews broadcast on local radio stations | <p>Post-campaign telephone surveys assessed participants attitudes regarding the effects of the campaign including:</p> <ul style="list-style-type: none"> Alcohol consumption FASD knowledge Cultural appropriateness of the campaign | <p>Alcohol abuse in the 1st Trimester was reported as 43% pre-intervention and 11% post-intervention (RR = 0.25, 95% CI = 0.07, 0.94)</p> <p>Differences in pre- and post-intervention groups for Trimester 2 (17% and 7%) and Trimester 3 (14% and 5%) were not significant (RR, p value, and CI not reported)</p> <p>See brief summary in text</p> |

ATTACHMENT 2: Systematic Review - Justice System and FASD

Table 1
Summary of reviewed studies.

| Author(s) & date | Country | Study years | Sample size/population | Method | Key findings |
|---|---------|-------------------|---|---|--|
| <i>Prevalence, screening, and cost</i> Streissguth, Barr, Kogan, and Bookstein (1996) ^a | USA | 1992–96 | 415 individuals with FASD (6–51 years) | Caregiver report | - Trouble with the law was reported in 14% of children and 60% of adolescents/adults - Eligibility for disability services was the strongest protective factor for positive outcomes |
| Rangmar et al. (2015) | Sweden | 2011 | 79 adults with FAS (18–47 years), 3160 controls | Record-linkage | - No differences in criminal offending were found between FAS and control groups - Conviction rates were lower in the FAS group than in a subgroup of controls placed in state care |
| Fast, Conry, and Look (1999) | Canada | 1995–96 | 287 remanded youth (12–18 years) | Inpatient assessment | - 23.3% of youth were diagnosed with alcohol-related disorders |
| Burd, Selfridge, Klug, and Juelson (2003) | Canada | 2001–02 | Directors of Corrections from 8 provinces, 3 territories (population estimate of 148,797 inmates) | Survey | - 0.87% of inmates reported to have an FAS diagnosis - No screening programs were identified - Staff reported limited FASD training but strong willingness to learn |
| Burd, Selfridge, Klug, and Bakko (2004) | USA | 2001–02 | Directors of Corrections from 42 entities (population estimate of 3.08 million inmates) | Survey | - One inmate reported to have FAS - Very few screening programs and limited access to diagnostic services were reported |
| Rojas and Gretton (2007) | Canada | 1985–2004 | 359 youth court-ordered for offender treatment (12–18 years) | Client record review | - 11% of youth had confirmed or suspected FASD - Higher rates of FASD were reported in Aboriginal (27%) compared to non-Aboriginal (4%) youth |
| Popova, Lange, Bekmuradov, Mihic, and Rehm (2011) | Global | 2010 | 6 prevalence studies in youth and adult | Systematic literature review | - Research was limited to Canada/US - Prevalence rates were estimated at 0.9 to 23.3% - Canadian data suggested youth with FASD are 19 times more likely than youth without FASD to be incarcerated |
| Hughes, Clasby, Chitsabesan, and Williams (2016) | Global | 2015 | 4 prevalence studies in youth settings | Systematic literature review | - Research was limited to Canada - Prevalence rates were estimated at 0.9 to 23.3% |
| Momino et al. (2012) | Brazil | 2003–04 | 262 incarcerated youth, 145 controls (12–21 years) | Medical assessment and maternal questionnaire | - Features of FASD were more common in institutionalized youth than controls, but clinical diagnosis was not possible |
| Streissguth, Bookstein, Barr, Press, and Sampson (1998) | USA | 1994 | 81 male inmates (12–51 years) | Survey | - Inmates scored lower than an FASD reference group on a screening tool - Higher scores on the tool were associated with higher reported maternal alcohol consumption |
| Popova, Lange, Burd, and Rehm (2015) | Canada | 2011–12 | N/A | Cost estimate | - Annual cost of correctional services for youth and adults with FASD in Canada was estimated at \$374 million |
| Thanh and Jonsson (2015) | Canada | 2014 | N/A | Literature review and expenditure analysis | - Annual cost of criminal justice in Canada (police, court, and corrections) was estimated at \$1.2 billion - Criminal justice accounted for the greatest proportion of total cost (40%) of FASD |
| <i>Offender profiles and perspectives</i> Streissguth et al. (1996) ^a | USA | 1992–96 | 415 individuals with FASD (6–51 years) | Caregiver report | - Most common offense type was crimes against persons - First offense type among participants 12 years and older was shoplifting/theft - Age at first offense was most often 9 to 14 years |
| Stinson and Robbins (2014) | USA | 2014 ^b | 235 adult inpatient forensic patients with intellectual disabilities (18–67 years) | Client record review | - Offenders were identified with intellectual disability (cause unknown) (55%), traumatic brain injury (22%), pervasive developmental disability (15%), and FAS (8%) - The FAS group had earlier onset of behaviour problems, and higher rates of impairment, abuse, trauma, and parental substance abuse |
| McLachlan, Roesch, Viljoen, and Douglas (2014) | Canada | 2012 | 100 young offenders (50 with FASD, 50 without PAE) (12–23 years) | Clinical assessment and database review | - Youth with FASD had significantly higher rates of psychological impairment than those in the comparison group |
| Rogers, McLachlan, and Roesch (2013) | Canada | 2012 | 96 young offenders (47 with FASD, 49 without PAE) (13–23 years) | Survey | - Resilience correlated positively with enculturation and negatively with self-reported offending - No group differences were found in ethnic identity or resilience between youth with and without FASD |
| Brown, Gudjonsson, and Connor (2011) | USA | 2008–09 | 7 male offenders with FASD (17–53 years) | Forensic assessment | - Participants showed higher suggestibility compared to general population norms - They showed no differences in suggestibility compared to |

(continued on next page)

Table 1 (continued)

| Author(s) & date | Country | Study years | Sample size/population | Method | Key findings |
|---|-----------|-------------------|---|--|--|
| Currie, Hoy, Legge, Temple, and Tahir (2016) | Canada | 2016 ^b | 14 adults with FASD (18–41 years), 11 support workers | Semi-structured interview | non-forensic FASD - 8/14 of adults reported criminal history - Justice-involved adults were more likely to use substances and receive diagnosis at later age, and less likely to have FASD-trained support workers and report regular routine, structure, and supervision |
| Pei, Leung, Jampolsky, and Alsbury (2016) | Canada | 2011 | 9 adults with FASD and criminal justice involvement (24–59 years), 12 justice professionals | Semi-structured interview | - Participants identified risk factors that primed them to enter, and hindered them once involved in justice system - Factors that helped to move participants out of the system were also identified |
| Tait, Mela, Boothman, and Stoops (2017) | Canada | 2017 ^b | 2 paroled male offenders with FASD (61 and 66 years) | Case study (interview and photo-voice) | - Participants' lives were characterized by early adversity, trauma, social isolation, instability, and mental illness, but also strength and resilience - A period of stability post-incarceration was followed by gradual withdrawal of supports and eventual deterioration |
| <i>FASD knowledge and awareness among justice professionals</i> | | | | | |
| Cox, Clairmont, and Cox (2008) | Canada | 2005–06 | 39 justice professionals | Survey | - Participants reported some awareness of FASD, but a desire for more FASD information and training, and access to services |
| Douglas, Hammill, Russell, and Hall (2012) | Australia | 2011 | 49 members of the judiciary | Survey | - Participants showed some awareness of FASD - They also showed uncertainty about the characteristics and diagnosis of FASD and its relevant to their work, and called for more resources |
| Mutch, Jones, Bower, and Watkins (2016) | Australia | 2012 | 427 justice professionals | Survey | - Many participants had heard of FASD but were unfamiliar with key features - Most considered FASD to be relevant to their work - Almost all desired more information and resources |
| Stewart and Glowatski (2014) | Canada | 2013 | 34 police officers | Semi-structured interview | - Participants showed a solid baseline understanding of the causes/consequences of FASD, and some strategies for working with the population - There was also interest in more opportunities for FASD training, education, and information |
| <i>Impact of FASD in the courtroom</i> | | | | | |
| Douds, Stevens, and Sumner (2013) | USA | Prior to 2011 | 108 court cases involving evidence related to FASD and PAE | Systematic case law review | - All courts accepted FASD as a relevant issue, particularly in terms of offender capacity - Since 2002, FASD evidence has tended to be considered more heavily, but with more strict and inconsistent interpretation |
| Chandler (2015) | Canada | 2008–12 | 133 court cases involving neuroscientific evidence | Database review | - FASD and PAE were the most common types of neuroscientific evidence - FASD was framed in some cases as a mitigating factor, but in others as an aggravating factor |

^a This article is summarized under two categories.^b Date of data collection was not specified in this article.