



## **Child Development Services Parliamentary Enquiry Submission on behalf of FASD Collaboration for Assessment and Care, Research and Education (FASD C.A.R.E Inc.)**

FASD C.A.R.E Incorporated is a registered charity and non-government service-provider for individuals and their families affected by Fetal Alcohol Spectrum Disorder. In addition to providing some clinical services, FASD C.A.R.E Inc. is active in research, education and workforce training.

Fetal Alcohol Spectrum Disorder (FASD) describes the range of disabilities in children due to alcohol exposure in pregnancy. Affected children suffer alcohol-related permanent brain damage and show developmental delays, learning and behavioural difficulties. The prevalence of this largely invisible disability is estimated at 176/1000 (Hendricks G *et al* 2019). In Australia, FASD is underdiagnosed due in part to a lack of diagnostic clinics. The low reported prevalence rates in Australia are frequently attributed to under-diagnosis, under-reporting, lack of information regarding prenatal alcohol exposure, inconsistent diagnostic criteria, and under-representation of high-risk populations (Reid, N., 2018, Fitzpatrick, J *et al.*, 2015, p. 451; Fast & Conroy, 2004, p. 162).

It is well established in the literature that without early access to diagnosis and interventions for their disability, children are at high risk of poor academic performance and may experience early onset of mental health conditions including depression (Streissguth AP *et al* 2004, Pei J *et al* 2011). Without evidence-based support across the lifespan, adolescents and adults with FASD are at high risk of suicidal ideation, early mortality and may become dependent on welfare, engage in alcohol abuse or commit crimes (Streissguth AP *et al* 2004, Temple VK *et al* 2019, O'Connor MJ 2019, Bower *et al.*, 2018). The effects of prenatal alcohol exposure and unrecognised FASD are life limiting and adverse (Elliott *et al.*, 2006; Bower *et al.*, 2018; Mutch, Wray & Bower, 2012).

In response to the recommendations of the Coroner's Inquest into the deaths of 13 children and young people from suicide in the Kimberley Region 2019 (Fogliani 2019), WA Health Department commissioned Telethon Kids Institute (TKI) to undertake a study of the feasibility of screening for FASD in WA children. For screening to be successful, it needs to be embedded within a program which offers a pathway to diagnostic assessment for positive screens and intervention post-diagnosis, in order to change the course of illness and prevent adverse outcomes. The research report from TKI concluded that there is a lack of evidence-based screening tools for FASD which are appropriate and feasible for the Western Australian context. Therefore, at this time the research does not support universal screening for FASD in children in WA. However, there is a body of evidence which supports screening for alcohol use in pregnancy and for inclusion of alcohol exposure on the midwife's birth notification form, which significantly assists in later diagnosis of children affected by FASD. In addition, I would comment that the TKI study did not adequately investigate the feasibility of targeted screening of high-risk populations including children in out-of-home care and youth in juvenile justice settings (Bower, C *et al* 2018).

Children who have FASD will present to health services with developmental delays, difficulties adjusting to school, learning difficulties, ADHD symptoms and possible autism-like symptoms of poor social and adaptive functioning. The range of presenting complaints

requires assessment, diagnosis and management by a secondary tier health service and specialist doctors (Paediatrician or Psychiatrist) and therefore, this is **Core Business** for Child Development Services. Some children and families may require a tertiary service such as the Complex ADHD clinic at Perth Children's Hospital.

There is a current gap in service in the public sector in providing diagnostic assessments for FASD. Diagnostic assessment for FASD includes assessment of speech and language, motor coordination, learning, attention and behaviour. Best practice as recommended by the Australian Guide to the Diagnosis of FASD requires a coordinated multi-disciplinary approach (Bower C *et al* 2016). The multidisciplinary team should include a medical specialist (Paediatrician, Psychiatrist, Genetics specialist), Specialist Psychologist (Neuropsychologist, Clinical Psychologist), Speech pathologist, Occupational therapist and Social worker. Support for families during and post-diagnosis is essential, as mothers and kinship carers may experience shame and guilt knowing that their child has been harmed by prenatal alcohol exposure. Further, mainstream parenting programmes are not adequate to support families of children with FASD, and it is essential for all carers, including kinship carers to receive ongoing support and training in raising children with FASD (Williams & Badry, 2020).

Child Development Services (CDS) have community-based multi-disciplinary teams (with all disciplines except Neuropsychology), however, there is **NO identified pathway or program for children with possible FASD within CDS**. Instead, Paediatricians are obliged to refer school aged children over age 6 years requiring assessment and diagnosis to either the Neurosciences Unit, (Mental Health campus, Mount Claremont) or the Complex ADHD clinic. This involves another waitlist period for families which is burdensome and adds to anxiety, while delaying appropriate interventions. The waiting time for assessment through the Neurosciences Unit in 2021/ 2022 has been approximately 15 months. The cost of assessment for FASD in the private sector for a child over 6 years is upwards of \$2500 and there is no Medicare rebate for this service currently.

## Early Intervention

**There is NO government team-based FASD diagnostic and early intervention service for young children under 6 years old.**

There is substantial evidence to support establishing a program for children in this age group. (Hanlon-Dearman *et al*, 2020).

In addition, there is a lack of **Equity** for children with possible FASD within the CDS as they do not have the same access to multi-disciplinary assessment compared to young children with possible autism spectrum disorders.

Post-diagnosis, children and young people with FASD require an individualised intervention program and ongoing family support. Interventions need to be evidence-based and specific for FASD if possible (Ordenewitz LK *et al* 2021, Zarnegar Z *et al*, 2016; Paley, Blair & O'Connor, Mary J, 2009). For example, research indicates that therapies/ medication which may work for ADHD without prenatal alcohol exposure, may not work as effectively for ADHD associated with FASD (Peadon E & Elliott, E 2010, O'Malley & Storoz 2003).

A FASD-specific family support program is "Families Moving Forward". Families Moving Forward (FMF) is a positive parenting program designed for children from ages 3 to 13 (approximately). The program aims to support parents and give them an understanding of FASD and how it impacts on their child's behaviour and function (Petrenko CLM 2015). It gives parents new skills and strategies to enable them to care for the child with FASD. FMF

engages with teachers and healthcare providers, so that everyone in the child's world is "on board" and has an understanding of FASD.

Training in the FMF program is offered at the University of Washington, USA. In Australia there are two practitioners who are trained in FMF (Dr Natasha Reid, Child Health Research Centre, The University of Queensland and Dr Kerryn Bagley, La Trobe University).

Another established evidence-based intervention in supporting young mothers is the Parent Child Assistance Program (PCAP). The Parent Child Assistant Programme (PCAP) was developed in the United States over 20 years ago with now over 50 sites currently operating. PCAP supports pregnant and parenting women with complex life histories that have led to problematic alcohol and drug use. The PCAP has been piloted and successfully adapted in Canada for Indigenous women (Pei J *et al* 2019). The programme provides para professionals who support and advocate for young mothers and families over a three-year period (Grant, *et al* 2004; Grant *et al*, 2014). Dr Robyn Williams has extensive knowledge and experience on FASD workshop training and the PCAP programme.

Children diagnosed with FASD are eligible to receive support through NDIS funding. Therefore, the lack of a diagnostic pathway within CDS is delaying or in some cases preventing children from accessing NDIS-funded disability supports. NDIS funding provides an individualised approach based on functional need. It is superior to the allied health therapy offered through CDS because it is not defined by a service "contract" of a limited number of sessions and offers ongoing support throughout childhood. Child Development Services offer individual allied health therapies only in the first 6 years of life.

### **Children and Youth in Justice settings**

Children, aged between 10 and 17 years, who have developmental impairments and disorders are over-represented in youth justice (Bower, C *et al*, 2018; Blagg *et al*, 2020).

The landmark study by Telethon Kids Institute at Banksia Hill Juvenile Detention Centre, WA, considered the feasibility to screen and diagnose FASD, among sentenced young people (Bower C *et al* 2018). The TKI study examined a representative sample of sentenced young people of whom 73% were Aboriginal. Nearly two thirds (65%) of the participating young people had three or more developmental domains of impairment, the remaining third had five or more domains of impairment and 36% had FASD. The FASD prevalence rate of 36%, identified at Banksia Hill in Western Australia remains the highest reported rate in the world (Blagg *et al*, 2020).

**Only two of the participating 99 young people had their neurodevelopmental challenges diagnosed prior to participation in the study**, both were diagnosed with FASD not through routine health care services but through research. These findings of profound neurodevelopmental impairment and unmet need prior to participating in a research project demonstrates a failure of health, education, child protection and justice systems to consider or seek to determine these neurodevelopmental vulnerabilities during their prior involvement with each of these children. There were common histories of out-of-home care break down and early school failure, yet none of these behavioural difficulties prompted requests for a comprehensive health and neurodevelopmental assessment.

FASD C.A.R.E Inc. is under contract to the Department of Communities/Justice to provide neurodevelopmental assessment to children and youth who appear before the Courts. The assessments require the expertise of a neuropsychologist, paediatrician, speech pathologist and often forensic psychologist and/or Psychiatrist. Our organisation has limited capacity to undertake these assessments due to workforce shortages, particularly the lack of a permanent neuropsychologist. Our staff consists currently of three part-time Paediatricians

and one Speech pathologist. Unfortunately, the Neuropsychologist on our team left mid-year due to health issues and has not been replaced. We are able to continue this work in collaboration with the pool of neuropsychologists employed by Department of Communities/ Justice. However, our contract ends in December 2022. FASD C.A.R.E Inc. provided assessments for 20 clients referred by the Dept. of Justice between January 2021 and August 30, 2022. The young people ranged in age from 12 to 19 years.

In our opinion Child Development Services is not equipped to provide the comprehensive neurodevelopmental assessment of youth as required by the Court. The assessments are usually required to be completed within a defined timeframe from referral of about 6 weeks. Currently within CDS, adolescents will wait more than 12 months for a Paediatrician assessment. The Child Development Services does not employ a Neuropsychologist and the Child Development Services Speech pathologists lack experience in the assessment of adolescents. However, Child Development Services have a major role in providing assessments for children with neurodevelopmental impairments between ages birth to 16 years, **before** contact with the justice system.

Within CAHS, the Department of Adolescent Medicine provides a limited health service to youth in detention through partnership with Patches Paediatrics (private paediatric practice) and joint funding of an adolescent Advanced Trainee. In our opinion this service would be an appropriate service to undertake neurodevelopmental assessments of youth referred by Youth Justice, but additional funding would be required to meet the current needs and particularly to fund additional time for the Neuropsychologist. Ideally the Department of Adolescent Medicine would work together with Koorliny Moort to provide a culturally appropriate service for Aboriginal youth involved with Department of Justice. Following assessment the Department of Adolescent Medicine and Koorliny Moort could provide ongoing coordinated health care to the young person. There would be a role for ongoing medical care by a Paediatrician within CDS for younger children in the age range of 10 to 13 years following neurodevelopmental assessment.

### **Aboriginal children and services**

There is a great body of evidence which shows that health in adult life is influenced by factors (determinants) in early childhood and that early intervention changes the pathway towards positive physical and mental health outcomes. Early childhood is a critical period for brain development, which affects later educational progress and overall wellbeing (DiGiacomo, M *et al* 2013). Early intervention takes advantage of the plasticity of the brain in early childhood in order to accelerate development and ameliorate delays. While most Aboriginal children are developing normally, Aboriginal children are at higher risk of developmental and behavioural problems. In the Australian population overall, about 20% of children start school without the necessary developmental skills for success. This figure is estimated at 40% for Aboriginal and Torres Strait Islander children (Chando, S *et al* 2020). It is also known that there are higher rates of disability for Aboriginal children and adults (DiGiacomo, M *et al* 2013).

While there is a universal system in WA of developmental screening by Child health Nurses, the uptake of scheduled child health visits is poor after 12 months old (25%). When developmental concerns are identified either by screening or contact with health or educational professionals, families face long waiting lists to access public child development services. The limitation of mainstream public health services in meeting the cultural needs of Aboriginal families and their failure to provide services at the “point of need”, further disadvantages Aboriginal children.

FASD C.A.R.E Inc. was awarded a small grant in 2020 from Curtin University to pilot a project to improve the access to child development services for Aboriginal children in the metropolitan area in partnership with Derbarl Yerrigan Health Service. Dr Robyn Williams, Senior Research Fellow, School of Medicine, Curtin University is the project lead investigator.

This project aims to enhance child and maternal health services provided by Derbarl Yerrigan, the community-controlled Aboriginal medical service in metropolitan Perth. The child and maternal health program aims to improve the health of women before and during pregnancy and to improve health outcomes for children, focussing on early childhood. This aligns with the priorities of FASD C.A.R.E Inc. in promoting healthy pregnancies and improving health outcomes for children, although not specifically aimed at identifying FASD. The project will increase the capacity of child health nurses and GP's to assess children with a range of developmental delays and to support families in accessing early intervention.

The Curtin project seeks to lessen the disadvantage of Aboriginal children by enhancing the child and maternal program at Derbarl Yerrigan. The project team will provide education, training and mentoring to Child Health Nurses, Aboriginal health workers and GP's to equip them with the skills necessary to screen and assess children with possible developmental delays using evidence-based tools. Children who are identified with developmental delays will be eligible for referral directly to federal government-funded early intervention therapies (NDIS) and will be able to access ongoing family support through Derbarl Yerrigan. This should allow children to be "fast-tracked" to early intervention without waiting to see a Paediatrician in the over-burdened public health clinics.

In 2021, child health staff at Derbarl Yerrigan received a series of lectures on child development and in May 2022 four staff members (3 nurses and 1 GP) were trained in the administration of the Griffiths III Mental Development Scales (a standardised assessment tool for child development up to age 6 years). FASD C.A.R.E Inc. also provided funding to supplement the Medicare bulk-billed fees of a Developmental Paediatrician for two sessions per fortnight on a 12-month contract from March 2022. The Early Childhood Paediatric clinic is supported by a Child Health Nurse Coordinator. The Paediatrician caseload is comprised of children up to age 7 years. The pilot program will require evaluation and if successful, avenues for recurrent funding will need to be explored.

Derbarl Yerrigan also receives funding from Rural Health West to support a sessional Paediatrician (2 sessions per fortnight) in providing both general and developmental paediatric services to older children.

**Child Development Services** is currently running a pilot program in one geographic location (Armadale) to improve the access and timeliness of Paediatrician assessments for young Aboriginal children. Access is facilitated by the Aboriginal Child Health Team, CAHS.

**Koorliny Moort** (based at Perth Children's Hospital) provides high quality Paediatric care to Aboriginal children who are poorly engaged with mainstream paediatric health services. A significant proportion of their work involves the assessment and management of neurodevelopmental issues. Koorliny Moort has available medical and nursing staff, administrative support and clinical rooms. However, this service lacks a multi-disciplinary team of allied health professionals who could provide early intervention therapies. Koorliny Moort has experienced the same pressures as the Child Development Services in growing waitlists for new assessments and the demands of managing an increasing caseload of children with neurodevelopmental disorders.

## Models of Care

In order to achieve best outcomes, models of care should be integrated and collaborative e.g. collaborative case-management across government departments including Health, Mental health, Department of Communities and Justice and Department of Education.

FASD C.A.R.E Inc. is cognisant of the work which was done by the Child and Youth Health Networks, Health Department in producing the Fetal Alcohol Spectrum Disorder Model of Care for FASD (2010) and the Implementation report.

However, we are 12 years on from this report and very little was implemented in the proposed areas of Secondary and Tertiary prevention. A major recommendation from this report was to develop a diagnostic pathway for FASD based on the national diagnostic tool. The Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder was published in 2016. There is still no clear pathway to diagnosis for families within the Child Development Service.

Dr Wilkins has made enquiries in relation to the implementation of the FASD Model of Care. The following information was obtained in email correspondence from Marie Deverell, Acting Manager, Health Networks, Clinical Leadership and Reform/ Clinical Excellence Division on 16<sup>th</sup> May, 2022:

The MoC that you provided below is actually no longer an active document and was archived last year. Health Networks have no plans to update the document, however, there has been other work done in the space since then. Brief summary below.

- Department of Premier and Cabinet established a Senior Officers Working Group to review FASD resources across government agencies. One of the projects was to review screening options for FASD in WA ([Screening for Fetal Alcohol Spectrum Disorder \(FASD\) in Western Australia: Policy and Practice Recommendations \(health.wa.gov.au\)](#)).
- The Senior Officer's Working Group was dissolved and the Drug and Alcohol Strategic Senior Officer's Group at the Mental Health Commission are now responsible for monitoring the actions from the Senior Officer's Working Group.
- There was an inquiry undertaken in 2019 by the Standing Committee on Community Affairs of the Australian Senate into effective approaches to prevention, diagnosis and support for FASD. The final report was completed in March 2021, with 32 recommendations made - [Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder \(aph.gov.au\)](#)

The National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-2028, Commonwealth of Australia as represented by the Department of Health 2018, makes the following recommendation:

### **“Recommendation for Support and Management**

- Implement and evaluate multidisciplinary models of care which recognise that children diagnosed with FASD may have a range of comorbidities and social disadvantage, resulting in complex developmental and behavioural issues which require services across the lifespan. The models of care should reflect the principles that interventions must be evidence-based, individualised, accessible, coordinated, culturally appropriate and developed in consultation with families and communities.”

FASD C.A.R.E Inc. would like to ask the Parliamentary Select Committee to consider how Child Development Services could implement the recommendation of the National FASD Strategic Action Plan. Recognising the disadvantages that children with FASD have from early childhood through to adulthood and their complex developmental and behavioural issues, it is imperative that models of care be established which begin with diagnosis and lead to intervention plans and the delivery of effective supports to children and families.

### **Complimentary CAHS services**

**Koorliny Moort** (based at Perth Children's Hospital) provides high quality Paediatric care to Aboriginal children who are poorly engaged with mainstream paediatric health services. A significant proportion of their work involves the assessment and management of neurodevelopmental issues (including FASD) in Aboriginal children. Through strong relationships with Aboriginal health services, Koorliny Moort provides a sensitive and trusted avenue for families to seek advice and assessment for children potentially affected by alcohol exposure in utero. Koorliny Moort is staffed by medical and nursing staff, but lacks an allied health team and therefore, is not currently able to provide multi-disciplinary assessment for FASD. The service is not available to families who are non-Aboriginal and so this service would not meet the needs of all children with FASD.

### **Complex ADHD Clinic, Perth Children's Hospital**

The Complex ADHD clinic accepts referrals from Paediatricians and provides multi-disciplinary assessment for children and youth with diagnosed ADHD across the state. The team includes a Psychiatrist, Neuropsychiatrist, Speech Pathologist, Occupational therapist and Mental Health Nurse. The service is restricted to children who have already trialled stimulant medication and who have possible co-morbid mental health issues. However, this service has been reluctant to assess children for FASD, despite the known co-occurrence of FASD and ADHD (Peadon, E and Elliott, E 2010, O'Malley K & Storoz, L 2003).

I refer the Parliamentary Committee to the letter received by Dr Wilkins from the complex ADHD clinic (patient details redacted for confidentiality).

### **FASD Services around Australia**

**Goldcoast Health** offers a FASD diagnostic clinic within its public child development service. This is called The Neurodevelopment Exposure Disorder Service (FASD). It aims to provide a diagnostic service for families with children who may be affected by Fetal alcohol spectrum disorder (FASD). The service caters for children:

- from 0-10 years
- with confirmed exposure to alcohol when the mother was pregnant
- with delayed development, learning or behavioural concerns.

"The service is part of a multi-disciplinary clinic that provides effective models of care and early intervention to support families as well as education for health professionals" (information taken from the website):

<https://www.goldcoast.health.qld.gov.au/referrals/conditions/fetal-alcohol-spectrum-disorder-fasd>

The service has a priority classification system in order to respond to children with high needs in a timely manner. Recommended timeframes are Category 1 – 30 days, Category 2 – 90 days and Category 3 – 356 days.



### **Sunshine Coast Child Development Service – Coloundra Health Service**

The clinic was established in 2016 and uses Medicare bulk-billing. It provides a FASD assessment service for children from birth to 8 years. Older children can access the Sunshine Coast Hospital and Health Service in the 'School Aged Learning and Behaviour Clinic.

### **NSW FASD assessment service – CICADA**

THE NSW FASD Assessment Service provides a state-wide assessment service for children with confirmed prenatal alcohol exposure at the Children's Hospital at Westmead in Sydney within the Department of Adolescent Medicine. It provides a multi-disciplinary team for assessment and initial management of children from birth to 18 years.

<https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/cicada-centre-nsw>

### **Child Development Unit, Women's and Children's Hospital Adelaide**

This is a Tertiary child development service providing differential assessment for children and young people with complex developmental difficulties, including FASD. Clinical staff within the CDU have either completed face to face or online training in the assessment and diagnosis of FASD. It caters for children from birth to 18 years. It is funded by bulk-billing Medicare.

### **Victorian Fetal Alcohol Service (VicFAS)-Diagnostic Consultation Service – Monash Children's Hospital**

This service is part of public child development services at Monash Children's Hospital. The age range for service provision is birth to 18 years.

Information obtained via the FASD Hub website:

"The VicFAS FASD Diagnostic Consultation Service provides paediatricians with FASD diagnostic advice. Assessments already performed in the community form the foundation of the consultation. The VicFAS neuropsychologist, speech pathologist, occupational therapist, teacher and paediatrician review assessments performed to date against the Australian Guide to the Diagnosis of FASD. Advice is provided to the paediatrician as to what further information and local assessments could be obtained to progress the diagnosis. Telehealth feedback is provided to the child's paediatrician, and a written report with recommendations is provided to the paediatrician at the conclusion of the diagnostic consultation. Staff members have completed FASD diagnostic training."

### **Central Australian Aboriginal Congress**

Information taken from the FASD Hub website: "The Child and Youth Assessment and Treatment Service (CYATS) at Central Australian Aboriginal Congress commenced in April 2018. CYATS offers assessment and treatment to children suspected of FASD or other neurodevelopmental disorder. Children diagnosed with FASD are able to access speech and occupational therapy interventions from the CYATS team, post diagnosis."



The service caters for children from birth to 18 years and is an Aboriginal Controlled Community Health Service. It works in partnership with Paediatricians at Alice Springs Hospital.

The following recommendations are urgently required to begin addressing lengthy waitlists for young children requiring specialist developmental assessments and to improve therapeutic pathways for children with FASD.

### **Recommendations to improve Child Development Services**

1. Develop an identified pathway for children under 6 years to access multi-disciplinary assessment for FASD.
  - a. This could be done immediately with little additional investment by building on the multi-disciplinary early intervention program which already exists for autism and global developmental delay.
2. Provide training to staff of the Complex ADHD clinic in order to “Upskill” in diagnosis of FASD. This could be done within 3 months.
3. Develop an identified pathway for children over age 6 years to access multi-disciplinary assessment for FASD in a timely manner:
  - a. This would require additional funding for Neuropsychology. Potentially some of the CDS Clinical Psychology budget could be transferred to this program.
  - b. Additional funding for a Family support Worker or Clinical Nurse Specialist (0.2 FTE). The Clinical Nurse Specialist would triage referrals and coordinate the multi-disciplinary assessments. The role of the Family Support worker would be to guide the family through the assessment process, provide culturally appropriate social support and act as a “community navigator” to assist the family in accessing other service providers.
4. Provide professional development opportunities for CDS Social Work and Clinical Psychology staff for training in FASD and related interventions. E.g. Families Moving Forward program, Attachment-based interventions (e.g. Lighthouse Program).
5. Provide professional development opportunities for OT’s, Speech pathologists and other allied health within CDS for training in evidence-based interventions.
6. Evaluate and expand the Armadale catchment “fastrack” CDS pilot program for young Aboriginal children to access a Paediatrician across the metropolitan area.
7. Consider whether CDS could incorporate FASD assessment and management into a “School-age Learning and Behaviour” program which provides Paediatrician and allied health assessment and intervention. Recommend establishing a working party for clinical service redesign to report to management within 6 months.
8. Develop a youth justice neurodevelopmental assessment service within CAHS – e.g. within the Department of Adolescent Medicine and Koorliny Moort.
9. Recommend that CDS reviews its prioritization framework in comparison to other jurisdictions such as Goldcoast Health.
10. FASD C.A.R.E Inc. would like to ask the Parliamentary Select Committee to consider how Child Development Services could implement the recommendations of the National FASD Strategic Action Plan.



FASD C.A.R.E Inc.

Drs Robyn Williams, Raewyn Mutch and Amanda Wilkins

## References

Badry, D., Marcellus, L., & Choate, P. (2022). An Intersectionality-Based Policy Analysis of Canadian Child Advocate Reviews of Infants, Children and Youth with Prenatal Substance Exposure and Fetal Alcohol Spectrum Disorder in Child Welfare Care. *Journal of Fetal Alcohol Spectrum Disorder*, 4(SP1), e91-e115.

Blagg, H., Tulich, T., Williams, R., Mutch, R., May, S. E., Badry, D., & Stewart, M. (2020). *Decolonising Justice for Aboriginal Youth with Fetal Alcohol Spectrum Disorders*. Routledge.

Bower C, Elliott EJ 2016, 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)"

Bower C, Watkins RE, Mutch RC *et al*. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*. 2018 Feb 13;8(2):e019605. doi: 10.1136/bmjopen-2017-019605.

Chando, Shingisai; Jonathan C. Craig, Leonie Burgess, Simone Sherriff, Alison Purcell, Hasanthan Gunasekera, Sandra Banks, Natalie Smith, Emily Banks, Sue Woolfenden. Developmental risk among Aboriginal children living in urban areas in Australia: the Study of Environment on Aboriginal Resilience and Child Health (SEARCH) *BMC Pediatr*. 2020; 20: 13. Published online 2020 Jan 13. doi: 10.1186/s12887-019-1902-z

Department of Health, Western Australia. Fetal Alcohol Spectrum Disorder Model of Care. Perth: Health Networks Branch, Department of Health, Western Australia; 2010. Screening for FASD in Western Australia: Policy and Practice Recommendations; Department of Health, State of Western Australia (2021)

Falster, K., Jorm, L., Eades, S., Lynch, J., Banks, E., Brownell, M., ... & Randall, D. (2015). What factors contribute to positive early childhood health and development in Australian Aboriginal children? Protocol for a population-based cohort study using linked administrative data (The Seeding Success Study). *BMJ open*, 5(5).

Fast, D.K. & Conry, J. (2004). The Challenge of Fetal Alcohol Syndrome in the Criminal Legal System. *Addiction Biology* 9, 161–166.

Fitzpatrick, J. P., Latimer, J., Carter, M., et al., (2015). Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project. *Journal of Paediatrics and Child Health*, 51(4), 450–457

DiGiacomo,M; Patricia M Davidson , Penelope Abbott,, Patricia Delaney , Tessa Dharmendra , Sarah J McGrath , Joanne Delaney and Frank Vincent. Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review. *International Journal for Equity in Health* 2013, 12:7.

Elliott, E., et al., (2006). Diagnosis of foetal alcohol syndrome and alcohol use in pregnancy:a survey of paediatricians' knowledge, attitudes and practice. *Journal of Paediatrics and Child Health*, 42, 698–703.

Fogliani, R.V.C. (2019). Inquest into the deaths of thirteen children and young persons in the Kimberley region, Western Australia. Perth: Coroner's Court of Western Australia.

Garrison, L., Morley S., Chambers CD and Bakhireva, LN. Forty Years of Assessing Neurodevelopmental and Behavioral Effects of Prenatal Alcohol Exposure in Infants: What Have We Learned? *Alcohol Clin Exp Res* 2019 Aug;43(8):1632-1642.doi: 10.1111/acer.14127

Grant, T., Graham, J. C., Ernst, C. C., Peavy, K. M., & Brown, N. N. (2014). Improving pregnancy outcomes among high-risk mothers who abuse alcohol and drugs: Factors associated with subsequent exposed births. *Children and Youth Services Review*, 46, 11-18.

Hanlon-Dearman, A, Proven S. *et al* Ten years of evidence for the diagnostic assessment of preschoolers with prenatal alcohol exposure. *J Popul Ther Clin Pharmacol* Vol 27(3):e49–e68; 27 July 2020.

Hendricks G, Malcolm-Smith S, Adnams C et al. Effects of prenatal alcohol exposure on language, speech and communication outcomes: a review of longitudinal studies: *Acta Neuropsychiatr*. 2019 April; 31(2): 74–83. doi:10.1017/neu.2018.28

Kieran D O'Malley & Linda Storoz (2003) Fetal alcohol spectrum disorder and ADHD: diagnostic implications and therapeutic consequences, *Expert Review of Neurotherapeutics*, 3:4, 477-489, DOI: [10.1586/14737175.3.4.477](https://doi.org/10.1586/14737175.3.4.477)

May PA, Baete A, Russo J, *et al*. Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics* 2014;134:855-66.doi:10.1542/peds.2013-3319

Mutch, R., Wray, J., & Bower, C. (2012). Recording a history of alcohol use in pregnancy: and audit of knowledge, attitudes and practice at a child development service. *Journal of Population Therapeutics & Clinical Pharmacology*, 19(2), e227–33.

O'Connor MJ, Portnoff LC *et al*. Suicide risk in adolescents with fetal alcohol spectrum disorders. *Clinical Trial: Birth Defects Res*. 2019 Jul 15: 111(12):822-828. Doi: 10.1002/bdr2.1465. Epub 2019 Jan 24

O'Malley, KD & Storoz, L. (2003) Fetal alcohol spectrum disorder and ADHD: diagnostic implications and therapeutic consequences, *Expert Review of Neurotherapeutics*, 3:4, 477-489, DOI: [10.1586/14737175.3.4.477](https://doi.org/10.1586/14737175.3.4.477)

Ordenewitz LK, Weinmann, T. *et al.* Evidence-based interventions for children and adolescents with fetal alcohol spectrum disorders - A systematic review. *Eur J Paediatr Neurol* 2021 Jul;33:50-60. doi: 10.1016/j.ejpn.2021.02.001. Epub 2021 Feb 8.

Peadon, E and Elliott EJ. Distinguishing between attention-deficit hyperactivity and fetal alcohol spectrum disorders in children: clinical guidelines. *Neuropsychiatr Dis Treat.* 2010; 6: 509–515. Published online 2010 Sep 7. doi: [10.2147/ndt.s7256](https://doi.org/10.2147/ndt.s7256)

Pei J, Denys K, Hughes J, *et al*/ Mental health issues in fetal alcohol spectrum disorder. *J Ment Health* 2011;**20**:473–83.doi:10.3109/09638237.2011.577113.

Pei J, Carlson E., Tremblay, M & Poth,C. Exploring the contributions and suitability of relational and community-centered fetal alcohol spectrum disorder (FASD) prevention work in First Nation communities *Birth Defects Res* 2019 Jul 15;111(12):835-847.doi: 10.1002/bdr2.1480. Epub 2019 Feb 20

Petrenko, CLM. Positive Behavioral interventions and family support for Fetal Alcohol Spectrum Disorders *Curr Dev Disord Rep.* 2015 Sep; 2(3): 199–209.doi: [10.1007/s40474-015-0052-8](https://doi.org/10.1007/s40474-015-0052-8)

Pruner, M *et al*; The best possible start: a qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders. *Research in Developmental Disabilities*, 97 (2020) 103558

Reid, N. (2018). Fetal alcohol spectrum disorder in Australia: What is the current state of affairs?. *Drug and Alcohol Review*, 37(7), 827-830.

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*, 25(4), 228-238.

Temple VK, Cook JL, Kathy Unsworth K , *et al.* Mental Health and Affect Regulation Impairment in Fetal Alcohol Spectrum Disorder (FASD): Results from the Canadian National FASD Database. *Alcohol Alcohol* 2019 Jan 9;54(5):545-550.doi: 10.1093/alcalc/agz049.

Williams, R., & Badry, D. (2020). A decolonising and human rights approach to FASD training, knowledge, and case practice for justice involved youth in correctional contexts. In *Decolonising justice for Aboriginal youth with fetal alcohol spectrum disorders* (pp. 111-133). Routledge.

Zarnegar, Z *et al* : Clinical improvements in adopted children with fetal alcohol spectrum disorders through neurodevelopmentally informed clinical intervention. *Clin Child Psychol Psychiatry* 2016 Oct;21 (4): 551-567.

