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Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

FACTORS TO BE CONSIDERED AS PART OF A HOLISTIC ASSESSMENT: SCOPING REVIEW REPORT

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Authors and contributions

Natasha Reid	Shared responsibility for leading the design, conduct and reporting of the review. Contributed to writing of the report, study selection, data charting and review of qualitative synthesis. Oversight, guidance and communication and collaboration with the Project Steering Committee in the development of the protocol including the search strategy.
Nykola Kent	Contributed to study selection, data charting and significant contribution to the writing of the review report. Undertook the qualitative synthesis with input from NR.
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Nirosha Boaden	Contributed to data charting and commented and edited the report.
Nicole Hayes	Critical review of the protocol, review report, contributed to study selection and data charting and project oversight.

Declarations of interest

All authors declare they have no personal, financial, or professional interests that could be interpreted to have influenced conduct or results of this review.

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Summary: Factors to be considered as part of a holistic assessment for fetal alcohol spectrum disorder: A scoping review

What is the problem?

Individuals with prenatal alcohol exposure (PAE) and FASD can experience a wide range of complex factors. Focusing soley on impairments and diagnosis can over-look non-diagnostic personal and environmental factors that could support improved outcomes.

What is the importance?

The results of this review provide guidance for clinicians on the diverse factors that may influence long-term health, development, and wellbeing for individuals with PAE and FASD. This can be used to inform an individualised assessment process, facilitating tailored recommendations and supports that best meet the needs of individuals living with FASD and their families.

What are the key findings?

A total of 121 studies were included, spanning 12 key areas of interest: physical health, adverse postnatal experiences, substance use/other risk-taking behaviors, mental health, contact with the criminal justice system, First Nations cultural considerations, transition to adult roles, and strengths/interests/external resources.

Holistic assessment considered factors at the individual, family, and system levels. At the individual level, further characterisation of physical and mental health outcomes is needed. At the family level, deepening understanding of the interactions between adverse child experiences and PAE may prove beneficial. Finally, prioritising cultural connectedness, strengthening of cultural identities, and optimisation of the diagnostic process for First Nations individuals are critical.

1. Background and rationale

The Australian government funded a consortium of 12 organisations to review, update, and disseminate guidelines for assessment and diagnosis of FASD. This scoping review was undertaken as part of the evidence review supporting the revision process. An overview of the full evidence review is provided in the Administrative and Technical Report. The current review focused on identifying the factors outside of the diagnostic criteria (i.e., PAE, dysmorphology, neurodevelopmental impairments and growth restriction) that could be part of a holistic assessment process when considering a FASD diagnosis as one possible outcome. By performing an exploration of the available literature, this review aimed to aid further understanding of the wide range of potential factors that could be part of an assessment, informing the development of more individualised and holistic recommendations and support approaches to enable improved health and wellbeing for individuals with FASD and their families.

Whilst diagnosis of FASD is important, focusing on impairments and diagnosis alone can overlook non-diagnostic personal and environmental factors that could support an individual in researching their potential and maximizing their overall health and wellbeing across the lifespan (Allen et al., 2014). Taking a holistic approach to assessment aims to support the whole person, not just their medical condition. Further, holistic assessment aligns with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); and the prioritized equity principles embedded in the Declaration of the Rights of Indigenous Peoples (UNDRIP); and Leave No One Behind (LNOB). To comply with UNCRPD, UNDRIP and LNOB, impairments and activity limitations should not be the only considerations in diagnostic assessment processes. Assessments should also outline social determinants of health and wellbeing, environmental barriers, and support requirements of persons with disabilities. This approach also aligns with recent research in the field of FASD, highlighting the importance of holistic and integrated care approaches to enable targeted and meaningful supports for people with FASD (e.g., Himmelreich et al., 2020, Masotti et al., 2015, Pei et al., 2021, Reid et al., 2021).

2. Objectives

To undertake a scoping review to map the available evidence to inform the revision of the Australian Guide to Diagnosis of FASD. A scoping review methodology was selected for three key reasons: (1) to provide a broad overview of available evidence that explores health and wellbeing outcomes in individuals with FASD that are not currently covered by diagnostic criteria; (2) to be more inclusive of diverse types of evidence relating to health and wellbeing outcomes in individuals with FASD and; (3) to report on the types of evidence available and ascertain if further systematic reviews are appropriate in specific areas (Munn et al., 2018).

Research question

What broader factors (i.e., outside the components of the diagnostic criteria) should be considered for holistic care/support when undertaking an FASD diagnostic assessment?

3. Methods

3.1 Protocol and registration

A scoping review protocol was published on Open Science Framework (OSF) Registries (osf.io/7rcfs). The review was designed and reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for Scoping Reviews (PRISMAScR; Tricco et al., 2018).

3.2 Eligibility criteria

Published peer-reviewed articles were eligible for inclusion. This included both systematic reviews and original research, inclusive of quantitative, qualitative, and mixed methods designs. No restrictions were placed on publication dates. Studies were eligible for inclusion if they included a focus on any broader elements that could be considered as part of a holistic assessment process. This included: health, social, psychological, occupational, or other behavioural/mental health factors not typically considered as part of diagnostic criteria.

3.3 Information sources and search strategy

Six electronic databases were searched (PubMed, EMBASE, Web of Science, PsycInfo, Cochrane Library & CINAHL). Database searches were initially conducted on the 02/02/2021 and an updated search was conducted on 09/09/2022. Reference lists of included studies were hand searched and experts in the field were contacted to identify any additional studies for inclusion. See Appendix A for the full search strategies applied to each database.

3.4 Selection of sources of evidence

Search results were downloaded to Endnote and uploaded to Covidence for screening. Duplicate removal was undertaken by one reviewer. Title/abstract and full text screening was completed by two independent reviewers (NR & NHs), and a third reviewer (LA) resolved any conflicts.

Studies were eligible for inclusion if they reported on any broader elements that could be considered as part of a holistic assessment process (e.g., health, social, psychological, occupational, or other behavioural/mental health factors not typically considered in FASD diagnosis).

Studies were excluded if they did not focus on FASD; were exclusively preclinical studies, placenta studies or in utero studies, were not peer-reviewed or were conference abstracts, theses, government, or other reports, FASD guidelines, intervention or prevention studies, or studies that focused only on components of the diagnostic criteria (i.e., dysmorphology, growth impairments, neurodevelopmental impairments). Individual studies captured as part of included systematic reviews were excluded.

3.5 Data charting process and items

A standardised form was developed that included key study elements (i.e., study author, date, location, design, aims, and key findings). This was piloted by one author (NR) and then applied by multiple authors (NHa, NHe, KB, NB, SG, TT & NK) and checked by one author (NR). Studies were grouped by two authors (NR & NK) based on the key areas of interest covered by each of the included studies. The key areas of interest were first inductively derived from the broad elements outlined for study inclusion (health, social, psychological, occupational, or other behavioural/mental health factors not typically considered as part of diagnostic criteria). Additional key areas of interest were deductively created as the content analysis was undertaken to facilitate a detailed description of all included studies. All authors provided feedback and input to refine the key areas of interest based on the content analysis.

3.6 Synthesis of results

Content analysis was utilised to synthesise the results. Content analysis is a method for providing a systematic, yet simple way of condensing and describing data (Cavanagh, 1997; Downe-Wamboldt, 1992). The process involves coding and grouping the available text into similar groups and then counting the number of times each of the groupings occurs (Hsieh & Shannon, 2005). Coding was undertaken and the frequency of studies that addressed each key area of interest was calculated. Within each key area of interest, content analysis identified sub-areas of interest, and similarly, the frequency of studies that addressed each sub-area of interest was calculated. The content analysis was undertaken by one author (NK) and verified by another author (NR). Some studies were found to address multiple sub-areas and were included across multiple key areas/sub-areas of interest to accurately reflect this.

4. Results

4.1 Selection of sources of evidence

An initial search identified 5,897 records. After removal of 3,827 duplicates, 2,070 records underwent title and abstract screening. A further 1,883 articles were excluded, leaving 187 full-text articles for eligibility assessment. Of these, 116 articles were excluded (Figure 1). Reference list searches led to the inclusion of an additional 36 articles and an updated search before submission yielded 14 additional articles. See Appendix B for a summary table listing publications excluded at the full-text level with reasons for exclusion. In total, 121 studies were included in the review.

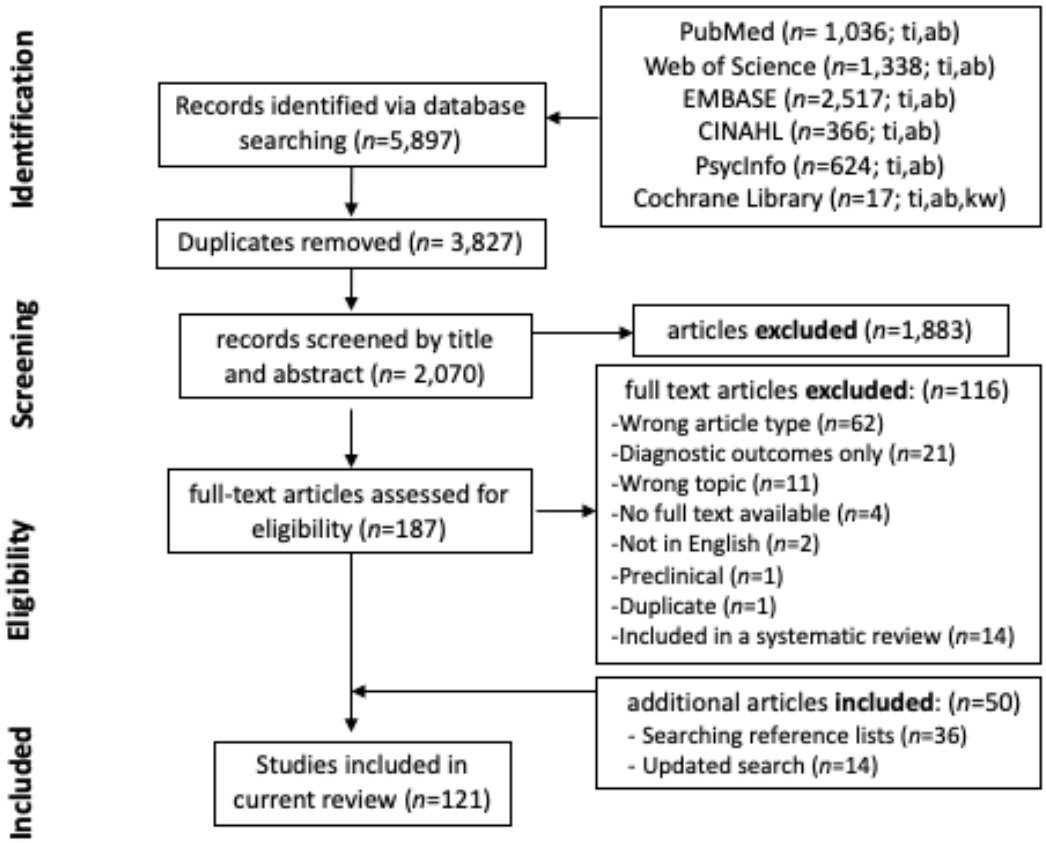

Figure 1. PRISMA Flowchart depicting number of articles identified, screened, assessed for eligibility and included in the scoping review. *Note.* only Cochrane reviews (17) included. Cochrane Protocols, Editorials and Special Collections were excluded from review. Trials were excluded as were all interventions. The search was repeated on the 27/09/2022. ti=title, ab=abstract, kw=keyword.

4.2 Characteristics of sources of evidence

Included studies originated from 12 countries, including 45 from the United States (U.S), 27 from Canada, 13 from Australia, five from the United Kingdom, four from South Africa, three each from Germany and Sweden, two each from the U.S/Canada and Poland, and one each from Chile, New Zealand, Norway, and Russia. The remaining studies were from international samples (*n*=2) or were systematic reviews. Of the 121 included studies, 60 were cohorts (49.5%), 32 were case-control studies (26.4%), 13 were qualitative studies (10.7%), 11 were systematic reviews (9%) and 5 were mixed-methods studies (4.1%). Appendix C provides an overview of the study characteristics.

4.3 Synthesis of results

Twelve key areas of interest were identified from the included studies: 1) physical health, 2) sleep, 3) adverse postnatal experiences, 4) substance use and other risk-taking behaviours, 5) mental health, 6) contact with the criminal justice system, 7) First Nations cultural considerations, 8) transition to adult roles, 9) out-of-home care (OOHC), 10) feeding/eating, 11) incontinence, and 12) strengths/interests/external resources. Figure 2 provides an overview of the synthesis of the findings.

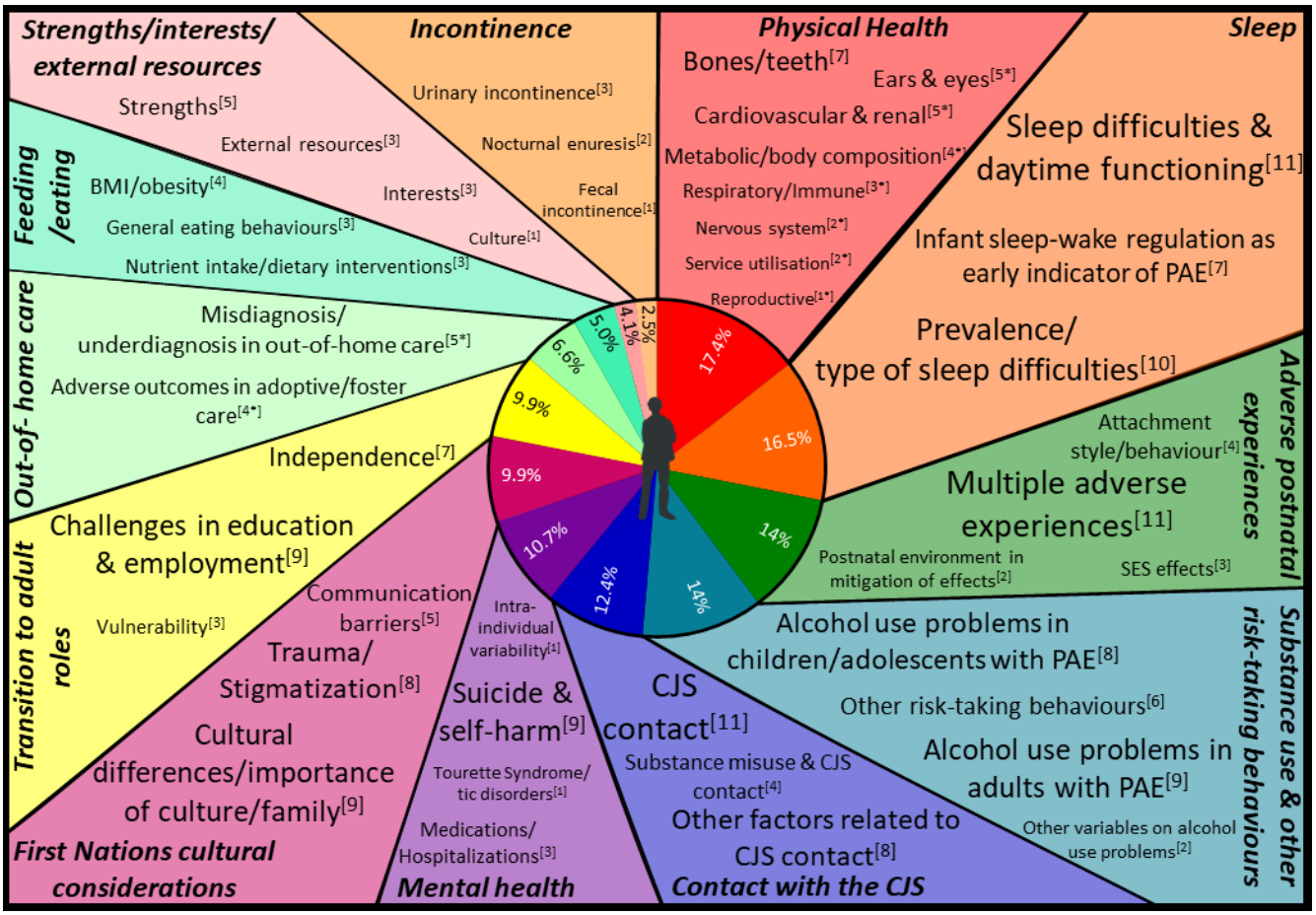

Figure 2. Summary of all key areas and sub-areas of interest identified from content analysis to be considered as part of a holistic assessment for FASD. The size of the font and number in superscript brackets depict the number of studies that addressed each sub-area. *=sub-areas that included systematic reviews, PAE=prenatal alcohol exposure, BMI=body mass index, CJS=criminal justice system, SES=socio-economic status. Note: some studies were included across 2-3 key areas of interest and therefore the sum of the percentages does not equal 100%.

4.4.1 Physical health (*n*=21 studies)

Sub-areas identified: bone/teeth health, eye/ear health, cardiovascular/renal health, metabolic health, nervous system development/function, respiratory/immune system health, reproductive health, and health service utilization.

Overall, studies highlighted that, there is some clinical evidence for altered metabolic (Akison et al., 2019b; Kable et al., 2021), cardiovascular and renal (Carter et al., 2007; Reid et al., 2021; Cook et al., 2019; Akison et al., 2019b), and reproductive function (Akison et al., 2019b) in individuals with PAE, much of the available research was preclinical and was therefore not included in the current review. PAE was associated with CNS damage (Avaria et al., 2004; Popova et al., 2016) and altered insulin sensitivity dependent on the body mass index (BMI) of the individual (Kable et al., 2021). Delayed skeletal maturation (Habbick et al., 1998), reduced bone mineral density (Young et al., 2022), and sex-specific dentofacial anomalies and tooth disturbances (Naidoo et al., 2005; Naidoo et al., 2006) were also reported.

Ophthalmic complications (Gummel & Ygge 2013; Tsang et al., 2022; Reid et al., 2021), structural and functional ear complications were associated with FASD (Cheung et al., 2022; Popova et al., 2016), increased infection risk, asthma and skin conditions (Reid et al., 2019; Reid et al., 2021) were all commonly reported in children with FASD/PAE. First Nations peoples in Canada with FASD (aged 20-42 years) reported complex physical needs such as respiratory diseases, cardiovascular complications, gastrointestinal issues, chronic pain, and dental issues (Flannigan et al., 2022a). Higher service utilization was reported in individuals with FASD compared to controls (aged 0-34 years), including health services, social services, and education services (Brownell et al., 2013; Loney et al., 1998).

4.4.2 Sleep (*n*=20 studies)

Sub-areas identified: prevalence/type of sleep difficulties in children with PAE, associations between sleep difficulties and daytime functioning, and infant sleep-wake regulation as an early indicator of PAE.

Persistent sleep problems were common in children with PAE/FASD (55-85%; Alvik et al., 2011; Chandler-Mather et al., 2021; Chen et al., 2012; Dylag et al., 2021; Goril et al., 2016; Hayes et al., 2020; Ipsiroglu et al., 2013; Mughal et al., 2020a; Mughal et al., 2020b; Rosett et al., 1979; Scher et al., 2000). Disrupted sleep patterns were attributed to challenging night behaviors (Chen et al., 2012; Dylag et al., 2021; Hayes et al., 2020; Ipsiroglu et al., 2013; Mughal et al., 2020b; Mughal et al., 2021; Spruyt et al., 2016; Wengel et al., 2011) in addition to behavioural, emotional and cognitive functioning difficulties (Akvik et al., 2011; Hayes et al., 2020; Mughal et al., 2020a; Mughal et al., 2021; Spruyt et al., 2016; Troese et al., 2008). Differences in processing auditory and multisensory stimuli during sleep may impact the ability to fall asleep and increase the incidence of night wakings (Wengel et al., 2011). Some predominately early research focused on the use of neonatal electroencephalogram to explore disruptions to sleep-wake state regulation as a possible early indicator of PAE (Chernick et al., 1983; Scher et al., 1988; Scher et al., 2000; Troese et al., 2008).

4.4.3 Adverse post-natal experiences (*n*=17 studies)

Sub-areas identified: risk of multiple adverse experiences, the postnatal environment in the mitigation of the effects of FASD, socioeconomic effects and how adverse postnatal experiences in children with FASD affect attachment style and behavior.

Experiences of inequitable access to health and wealth for all people globally drives social disadvantage and places children at greater risk of adversity (Allen et al., 2014). As such, FASD was reported to be more common among lower socioeconomic groups (Bingol et al., 1987). Estimates indicated 50-66% of children and adolescents with PAE were exposed to adverse child experiences (ACEs; Flannigan et al., 2021a; Kambeitz et al., 2019; Lebel et al., 2019). Individuals with PAE were more susceptible to negative effects of poor postnatal environments (Pfinder et al., 2012; Yumoto et al., 2008), possibly due to a greater prevalence of neurological deficits (Andre et al., 2020; Hemingway et al., 2020; Uban et al., 2020), and hypothalamic-pituitary-adrenal (HPA) axis disturbances (McLachlan et al., 2016). Environments lacking enrichment worsened outcomes (Jacobson et al., 2004), as did experience of trauma (Price et al., 2017; Pfinder et al., 2012). PAE was associated with insecure attachment in children and adults (Flannigan et al., 2022a; O'Connor et al. 1987; O'Connor et al., 1992; O'Connor et al., 2002). Intellectually stimulating and protective environments buffered further adverse outcomes (Jacobson et al., 2004; McLachlan et al., 2016).

4.4.4 Substance use and other risk-taking behaviors (n=17 studies)

Sub-areas identified: alcohol use in children/adolescents with PAE, alcohol use problems in adults with PAE, effects of other variables on alcohol use problems, and other risk-taking behavior excluding alcohol use in individuals with PAE.

PAE was associated with increased prevalence of alcohol and other drug (AOD) use in teenagers and adults (Cornelius et al., 2016a; Cornelius et al., 2016b; De Genna & Cornelius et al., 2014; Flannigan et al., 2022b; Goldschmidt et al., 2019; Lees et al., 2020; Lynch et al., 2017; McLachlan et al., 2020; O'Brien & Hill 2014; Yates et al., 1998). This may be due to a biological origin of early onset alcohol use disorders (Alati et al., 2006; Alati et al., 2008) and the reported increased hedonic value of alcohol odors (Hannigan et al., 2015). Children from higher socioeconomic groups and educated families more frequently reported alcohol experimentation by 9-10 years of age, while children from ethnically diverse families were less likely to experiment with alcohol (Lees et al., 2020).

Other variables reported to be associated with alcohol use in adolescence included parental laxity (less parental strictness, and involvement), greater maternal hostility during childhood, and greater exposure to child maltreatment and violence (Cornelius et al., 2016a). The number of substance dependence symptoms were higher in males than females (Yates et al., 1998). PAE was associated with an increased likelihood of adolescents engaging in risky sexual behaviors, defined as two or more sex partners in the past year. However, as this study did not assess sex education or access to contraception (De Genna & Cornelius 2014), future work should consider the role of kinship support, peer influences and contraceptive use.

4.4.5 Contact with the Criminal Justice System (*n*=15 studies)

Sub-areas identified: the effects of PAE on contact with the criminal justice system (CJS), interactions between risky AOD and CJS contact, and other factors related to CJS contact.

In children and adolescents, PAE was associated with lower overall moral maturity, which was secondary to lower verbal cognitive abilities. PAE was also associated with a higher number of conduct-related behaviours, which were related to specific abilities in moral judgement and reasoning (Schonfeld et al., 2005). Rates of offending were often higher in individuals with PAE and related to age, sex, geographic location, IQ, and degree of PAE-related dysmorphia (Streissguth et al., 2004; McLachlan et al., 2020; Lynch et al., 2017). Although this was not always the case with two studies from Sweden and one from the U.S. reporting no difference in rates of criminality in FASD populations compared to individuals without FASD (Lynch et al., 2003; Rangmar et al., 2015; Rangmar et al., 2017) Other factors that interacted with PAE to predict higher risk of offending behaviour and CJS involvement were AOD use, higher levels of stress and lower parental supervision (Currie et al., 2016; Lynch et al., 2003). While living with a caregiver as an adult and early diagnosis were reported to reduce risk of offending (Clark et al., 2004; Currie et al., 2016). One qualitative study (Pei et al., 2016) described how individuals with FASD experienced biological, psychological and social factors that placed them as increased risk of contact with the CJS and increased risk of experiencing barriers when interacting with the system.

The disproportionate involvement with the CJS for individuals with FASD is compounded for First Nations peoples as a consequence of the ongoing impacts of colonization and intergenerational trauma, in addition to barriers enforced by colonial policies and practices (Flannigan et al., 2022b). First Nations youth diagnosed with FASD often have high rates of involvement with child welfare and justice systems and were more likely to be charged with a crime than non-First Nations individuals (Brownell et al., 2019; Hamilton et al., 2020a) . Culture and family, cultural connections, belonging, resilience and overall ethnic identity were all associated with lower rates of offending (Rogers et al., 2013). Development of a “mobile-needs focused court”, a hybrid model involving the integration of First Nations perspectives, including Aboriginal Elders with the Victorian Neighborhood Justice Centre model, was suggested as a solution to reduce contact with the CJS for First Nations youth with FASD in Australia (Blagg et al., 2017).

4.4.6 Mental Health (*n*=13)

Sub-areas of interest identified: suicide/self-harm, medications/hospitalizations intra-individual variability and Tourette Syndrome/tic disorders.

Compared to controls, individuals with FASD had higher prevalence of Tourette Syndrome or tic disorders (Mathews et al., 2014), intra-individual variability (Ali et al., 2018), challenging behaviors towards others, and hallucinations (Rangmar et al., 2017). They also had higher prevalence for psychiatric care, hospitalizations and diagnosed psychiatric disorders, and higher rates of prescription psychotropic drugs (Rangmar et al., 2015; Streissguth et al., 2004).

High rates of suicidal ideation and suicide attempts have also been reported in individuals with FASD/PAE (Flannigan et al., 2022a; O’Connor et al., 2019). The high risk of suicide in First Nations peoples with FASD can in part be attributed to legacies of colonization and ongoing impacts of racism and discrimination (Brownell et al., 2019; Flannigan et al., 2022b).

In general, factors contributing to increased suicide risk included co-occurring health conditions, poor education and social outcomes, increased number of home placements for those in OOHC, sociodemographic characteristics, substance use, early life trauma, familial conflict, stigma, geographic region (rural vs urban), COVID-19, late/non-existent access to services, and affect regulation impairments (Harding et al., 2022; O’Connor et al., 2019; Rangmar et al., 2017; Temple et al., 2019). Protective factors relating to suicidality included pursuit of personal interests, physical activity, helpful interactions to improve wellbeing, and time in nature (Flannigan et al., 2022a; Harding et al., 2022).

4.4.7 First Nations cultural considerations (*n*=12)

Sub-areas identified: trauma/stigmatization, communication barriers, and cultural differences/the importance of culture and family.

FASD in First Nations populations was discussed as a direct consequence of colonization, intergenerational trauma, and ongoing systemic racism (Flannigan et al., 2022b; Gonzales et al., 2018; Miller et al., 2022). There can be a high-level of shame associated with FASD for individuals and families (Hamilton et al., 2019; Hamilton et al., 2020a) but it was discussed how shame was not a barrier for individuals when a culturally safe space is provided. Thus, there is great need for building a culturally responsive workforce as an antidote to the impacts of shame related to FASD diagnosis, colonization, intergenerational trauma, and systemic racism. It is also important to develop a collective sense of

understanding and compassion for those who use alcohol to alleviate and cope with trauma (Flannigan et al., 2022b; Miller et al., 2022).

Importance of connection to community, country, culture, and family were common across several studies from Australia, New Zealand, and Canada, and were reported to improve resilience, allow individuals to focus on strengths, and promote health and healing (Crawford et al., 2020; Gonzales et al., 2018; Hamilton et al., 2020a; Rogers et al., 2013) Barriers to effective communication were commonly cited to interfere with provision of effective services to First Nations individuals with FASD (Hamilton et al., 2019; Hamilton et al., 2020a; Miller et al., 2022). Poor communication and information access, inadequate resourcing and limited professional development of health practitioners were cited as barriers to service delivery (Hamilton et al., 2019) . Similarly understanding complex medical terminology in diagnostic reports and its implications for their child was difficult for Aboriginal caregivers due to inherent power imbalances that exist in a colonial controlled system (Hamilton et al., 2020b).

4.4.8 Transition to adult roles (*n*=12 studies)

Sub-areas identified vulnerability, independence and challenges in education and employment.

Individuals with PAE were more vulnerable to physical, sexual, or verbal assault, and exploitation or manipulation by those close to them (Clark et al., 2004; Freunscht & Feldmann 2011; McLachlan et al., 2020). Adults had challenges with living independently (Lynch et al., 2015; Lynch et al., 2017), and they often required moderate-high levels of care (Clark et al., 2004), lived in dependent circumstances (Freunscht & Feldmann 2011), accessed social welfare (Rangmar et al., 2015), experienced social problems (Freunscht & Feldmann 2011), and struggled with the transition into adult roles (Lynch et al., 2015; Temple et al., 2011).

Adults with FASD commonly experienced early life school disruptions (Freunscht & Feldmann 2011; McLachlan et al., 2020; Streissguth et al., 2004), and thus reported lower educational attainment and higher rates of unemployment (Rangmar et al., 2015), highlighting the need for further understanding of vocational opportunities for adults with FASD and education and support for their caregivers (Currie et al., 2016; Duquette et al., 2006; Duquette & Orders 2013).

First Nations adults with FASD identified concerns relating to finances, education, and employment (Flannigan et al., 2022b). However, there was also hope reported for future education experiences and pro-social community activities identified in their future goals (Hamilton et al., 2020a).

Delayed diagnosis was associated with poorer outcomes (Freunscht & Feldmann 2011; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). However, longer-term outcomes for adults could be improved through early diagnosis, and individually tailored long-term support provided in a stable and nurturing home environment (Currie et al., 2016; Duquette & Orders, 2013; McLachlan et al., 2020; Miller et al., 2022; Streissguth et al., 2004)

4.4.9 Out-of-home care (n=8 studies)

Sub-areas identified: misdiagnosed/undiagnosed children in adoptive/foster care, and adverse outcomes associated with children with PAE/FASD living in adoptive/foster care.

Youth with FASD in OOHC in rural and urban areas were commonly misdiagnosed with ADHD, and youth in rural OOHC also experienced higher rates of co-occurring mental health disorders relative to youth in urban populations (Chasnoff et al., 2015a; Chasnoff et al., 2015b). Of individuals with FASD living in foster/adoptive care, 78-80% had not received a diagnosis of FASD prior to the study (Chasnoff et al., 2015b; Patel et al., 2020). One hindrance to diagnosis may be underreporting of PAE to child protective services due to lack of staff awareness of FASD and/or lack of systematic PAE data collection processes (Richards et al., 2020). Inability to access specialized services for children and adolescents in adoptive/foster care meant that needs were often overlooked (Bakhireva et al., 2018; Chasnoff et al., 2015b) . Screening of all youth in care using an integrated community approach employing existing child protection and physician services and referral for appropriate follow-ups was proposed as a solution to missed diagnoses of children in OOHC (Patel et al., 2020) Foster care introduced additional risk factors for children with FASD, including increased risk of sexual or physical abuse and risk of involvement with the CJS (Burns et al., 2021). However, there was no difference reported in psychiatric conditions, medications, convictions, or cognitive, academic, and executive functioning in individuals with FASD who remained with their biological family or were placed in OOHC (Rangmar et al., 2016; Victor et al., 2008).

4.4.10 Feeding/Eating (*n*=6 studies)

Sub-areas identified: effects of PAE on general eating behaviors, nutrient intake in children with FASD and the opportunity for dietary intervention to improve outcomes, and sex-specific effects of PAE on BMI and obesity prevalence.

Caregivers reported disrupted eating behaviors among children with FASD including increased rates of oral aversion, food refusal, challenges using cutlery, not feeling full, poor appetite, and self-regulation (Amos-Kroohs et al., 2016). Children with FASD were reported to be "picky" eaters, which may affect nutrient density of their food intake (Nguyen et al., 2016; Werts et al., 2014). Accordingly, 50-100% of children with FASD often did not meet the recommended daily intake for several nutrients and minerals (Werts et al., 2014). Males with FASD were more likely to experience hyperphagia (i.e., excessive eating) without weight gain (Amos-Kroohs et al., 2016) and lower obesity prevalence (Werts et al., 2014), while females with FASD were more likely to experience overweight or obesity (Hayes et al., 2021; Werts et al., 2014). Finally, children and adolescents with partial FAS reported the highest prevalence of overweight/obesity, while FAS was associated with being underweight (Fuglestad et al., 2014).

4.4.12 Strengths, Interests and External Resources (*n*=5 studies)

Sub-areas identified: personal (internal strengths), personal (internal) interests and external supports (i.e., supportive environmental factors) and connection to culture.

Strengths of individuals with FASD included strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges/positive efforts/persistence or resilience, willingness to change, social motivation, individual aptitudes and skills, positive mood states and personality characteristics, and hopes for the future (Kautz-Turnbull et al., 2022, Pei et al., 2016, Flannigan et al., 2021b). A survey of 30 caregivers of children with FASD reported the four most common positive influences of their child on the family were that they: 1) tangibly contributed to the family (e.g., through assisting with household tasks), 2) provoked parental and personal growth (e.g., introducing caregivers to new experiences), 3) brought about social and/or family togetherness (e.g., increased time spent together, a sense of unity as a family), and 4) emotionally contributed to the family (i.e., showing affection and bringing joy/happiness into the home; Kautz-Turnbull et al., 2022). By leaning on external supports and resources, embracing assistance provided by caregivers and friends, and incorporating talents and interests into activities, individuals with FASD are better equipped to perform challenging activities (Skorka et al., 2022). The importance of having a unique identity was evident through interviews with young people with FASD, as it provided them with the opportunity to showcase their personality, characteristics, values and strengths (Skorka et al., 2022). A qualitative study by Hamilton et al., (2020b) described how young Aboriginal young people found and happiness through their culture and had a range of specific interests associated with this that could be fostered to further support their wellbeing.

4.4.11 Incontinence (n=3 studies)

Sub areas identified: urinary incontinent, fecal incontinence, and nocturnal enuresis.

Individuals with FASD aged 6-25 years experienced higher rates of incontinence (20-32%) compared to non-alcohol exposed individuals (<1-14.3%; Reid et al., 2021; Roozen et al, 2017; Roozen et al., 2020). Nocturnal enuresis was also reported in two studies, affecting 9.9-16.2% of individuals with FASD (Roozen et al., 2017; Roozen et al., 2020).

5. Discussion

5.1 Summary of main findings and comparison with previous studies

The intention of this scoping review was to identify broader factors outside the components of the diagnostic criteria that could be considered as part of a holistic assessment process when considering FASD as one possible outcome. Overall, the available literature highlighted that individuals with FASD experience a wide range of complex individual, family, and system level challenges, which can impact their health and wellbeing. The most researched areas were physical health problems, sleep problems, ACEs, and engagement in risky AOD use and other risk behaviors.

From a system-level perspective, studies noted high levels of involvement with OOHC and justice systems, which was magnified for individuals from First Nations backgrounds. First Nations peoples experience ongoing systemic racial discrimination, which has led to significant overrepresentation in child welfare and justice systems. For example, in child protection systems, systematic racism manifests through the privileging of colonial perceptions of superiority, western ways of parenting and norms of what 'family' is. These negative assumptions have contributed to the oppression of the rights of First Nations people to culture and to raise their own children (Choate & Tortorelli, 2022). In contemporary times in Australia, there continues to be poor compliance with adhering to the developed Aboriginal Child Placement Principle within child protection, resulting in more Aboriginal children not being placed in kinship care arrangements (Krakouer, Wise & Connolly, 2018). Cultural connections and developing a strong cultural identity was found to reduce recidivism and improve health and wellbeing (Rogers et al., 2013). Thus, gathering and prioritizing information about a person's culture and identity should be considered a critical component of a holistic assessment approach (Hewlett et al., 2023). This is also fundamental to the development of recommendations and support plans for all Australians, especially First Nations peoples and those from culturally and linguistically diverse backgrounds.

Evidence summarized in the current review also highlighted the high level and variability of mental health challenges individuals with FASD can experience. This brings attention to the inconsistencies in how mental health challenges are included or conceptualized as part of current FASD diagnostic criteria. The Australian Guide, which is based on Canadian diagnostic criteria, requires diagnosis of a psychiatric condition (i.e., anxiety or depression) to meet criteria for 'affect regulation' impairments, whereas other criteria consider the presence of self-regulation (Kable et al., 2016), or mood/behavioral regulation impairments (Astley 2013; Hoyme et al., 2016). The wide range of mental health challenges documented in the current scoping review (i.e., including suicidal ideation and attempts) supports a more generalized conceptualization of self-regulation impairments than the current Australian Guide. Requiring individuals to meet strict diagnostic criteria for anxiety and depression is likely to limit understanding of the self-regulatory challenges experienced by individuals with FASD (Reid & Petrenko 2018). Several external and personal factors were identified to be associated with mental health challenges for individuals with FASD. Further understanding of external and personal factors that place people at increased risk of mental health challenges, including suicide, and interplay of these factors for individuals with FASD is critical. Awareness and inclusion of these factors in a holistic assessment approach offers clinicians an opportunity to implement tailored supports to improve long-term mental health and wellbeing for individuals with FASD.

Current diagnostic criteria, including the Australian Guide, include assessment of SFFs, but also highlight the need for the collection of information on other dysmorphic features and major birth defects affecting the cardiac, renal, ocular, auditory and skeletal systems (Chudley et al., 2005; O'Leary et al., 2010). In line with current recommendations, this scoping review identified a high prevalence and wide range of physical health conditions. Therefore, interprofessional assessment should continue to include consideration of all physical health conditions. This scoping review also found that reproductive (Akison et al., 2019a), immune (Reid et al., 2019) and metabolic health (Akison et al., 2019b; Amos-Kroohs et al., 2016; Fuglestad et al., 2014; Hayes et al., 2021; Kable et al., 2021; Werts et al., 2014) may also be affected in individuals with FASD. However, further research is required to characterize the extent to which these systems may be affected by PAE.

Detrimental eating behaviors and poor nutrient intake has potential to compound poor metabolic outcomes for individuals with FASD. Improving nutrition may provide a window of opportunity during childhood to support various physical health concerns some individuals with FASD can experience. Gathering information regarding food intake and eating behaviors as part of a holistic assessment process could, therefore, inform recommendations and dietetic referrals to support individuals with FASD to achieve recommended daily intakes of key nutrients and optimize health and well-being. Additionally, the association of FASD with urinary and fecal incontinence issues were found to affect quality of life (Reid et al., 2021, Roozen et al., 2017, Roozen et al., 2020). Currently, the Guide does not consider incontinence issues. Overall, the current findings support wider consideration of physical health, feeding/eating behaviors, and toileting as part of a holistic assessment processes.

Finally, several studies identified disrupted sleep and challenging night-time behaviors in children with FASD (Alvik et al., 2011; Chen et al., 2012; Chandler-Mather et al., 2021; Dylag et al., 2021; Goril et al., 2016; Hayes et al., 2020, Mughal et al., 2020a; Mughal et al., 2020b; Mughal et al., 2021; Skorka et al., 2022; Spruyt et al., 2016; Troese et al., 2008; Wengel et al., 2011). As behavioral concerns are associated with sleep problems (Hayes et al., 2020), early interventions targeted towards improving sleep outcomes should be a therapeutic priority as it may lead to

improvements in cognitive outcomes (Mughal et al., 2020a, Mughal et al., 2020b). Some interventions proposed included a clinical health assessment (Chen et al., 2012), a multidisciplinary evaluation of the child's sleep, including an occupational therapy evaluation of sensory processing (Fjeldsted & Hanlon-Dearman, 2009; Wengel et al., 2011) and improving sleep awareness and educational initiatives for caregivers (Spruyt et al., 2016). Consequently, gathering information regarding sleep problems during the assessment and diagnostic process could help inform targeted supports to improve both sleep and daytime functioning for individuals with FASD.

5.3 Strengths and Limitations

The current scoping review has provided a comprehensive overview of a large number of studies across a diverse range of areas relating to FASD. The significant diversity of outcomes within key study areas currently limits the ability for future quantitative synthesis to be undertaken. As research increases across these key areas there may be more prominent, shared outcomes and measures that can inform more robust GRADE-based recommendations for future revisions of the Australian Guide for assessment and diagnosis of FASD. Notably, the Australian literature on FASD is constantly evolving, particularly with regards to First Nations peoples. As research approaches further integrate Western and Indigenous methodologies (Sharmil et al., 2021), future studies will undoubtedly expand our understanding of cultural considerations.

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Appendix A: Search strategy

Database	Search strategy
PubMed Title/Abstract	1. Prenatal alcohol 2. alcohol exposed 3. fetal alcohol 4. foetal alcohol 5. fetal alcohol spectrum disorder 6. foetal alcohol spectrum disorder 7. fetal alcohol syndrome 8. foetal alcohol syndrome 9. static encephalopathy 10. alcohol-related birth defect* 11. alcohol-related neurodevelopmental disorder 12. neurobehav* disorder AND alcohol exposed 13. neurobehav* disorder AND prenatal alcohol 14. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 ***[Alcohol related terms]*** 15. Trauma 16. Neglect 17. Abuse 18. Maltreatment 19. Culture 20. Cultural identity 21. Cultural considerations 22. Cultural connections 23. Culturally diverse 24. Culturally appropriate 25. Culturally responsive 26. Indigenous 27. First Nations 28. Aboriginal 29. Torres Strait Islander 30. Māori 31. American Indian/Alaska Native 32. Spiritual* 33. Community 34. Strengths-based 35. Holistic 36. Social determinants of health 37. Poverty 38. Social support 39. Social environment 40. Family context 41. Home environment 42. Wellbeing 43. Well-being 44. Physical health 45. Sleep 46. Eating 47. Feeding 48. Toileting 49. Incontinence 50. Enuresis

	51. Encopresis 52. 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 ***[holistic assessment-related terms]*** 53. #14 AND #52 Example syntax: cultural identity [Title/Abstract]
Web of Science Title/Abstract	Search terms as per above. Example syntax: (TI="cultural identity" OR AB="cultural identity")
EMBASE Title/Abstract	Search terms as per above. Example syntax: 'cultural identity':ab,ti
CINAHL Title/Abstract	Search terms as per above. Example syntax: TI "cultural identity" OR AB "cultural identity"
PsycInfo Title/Abstract	Search terms as per above. Example syntax: ti: ("cultural identity") OR ab: ("cultural identity")
Cochrane Library Title/Abstract/Key Words	Search terms as per above. Example syntax: (cultural identity):ti,ab,kw

Appendix B: Summary of publications excluded at the full-text level with rationale for exclusion

Title	Authors	Year	Rationale for exclusion
Oral findings of fetal alcohol syndrome patients	Riekman, GA.	1984	Full text not available
Steep corneal curvature: a fetal alcohol syndrome landmark	Garber JM.	1984	Full text not available
Corneal curvature in the fetal alcohol syndrome: preliminary report	Garber JM.	1982	Full text not available
Eating behaviors and fetal alcohol spectrum disorder	H, T.	2016	Full text not available
Neurobiology and neurodevelopmental impact of childhood traumatic stress and prenatal alcohol exposure	Henry et al.	2007	Included in a systematic review
A state of double jeopardy: Impact of prenatal alcohol exposure and adverse environments on the social communicative abilities of school-age children with fetal alcohol spectrum disorder	Coggins et al.	2007	Included in a systematic review
Effects of prenatal alcohol exposure on testosterone and pubertal development	Carter et al.	2014	Included in a systematic review
Prenatal alcohol exposure and childhood atopic disease: A mendelian randomization approach.	Shaheen et al.	2014	Included in a systematic review
Prospective study of maternal alcohol intake during pregnancy or lactation and risk of childhood asthma: The Norwegian mother and child cohort study	Magnus et al.	2014	Included in a systematic review
Maternal alcohol intake and offspring pulse wave velocity.	Morley et al.	2010	Included in a systematic review
Effects of alcohol and smoking during pregnancy on infant autonomic control	Fifer et al.	2009	Included in a systematic review
Prenatal alcohol exposure alters biobehavioral reactivity to pain in newborns	Oberlander et al.	2010	Included in a systematic review
Physiological self-regulation and mindfulness in children with a diagnosis of fetal alcohol spectrum disorder	Reid et al.	2018	Included in a systematic review
Dysregulation of cardiac autonomic function in offspring exposed to alcohol during antenatal period	Chandran et al.	2015	Included in a systematic review
Paediatric and opthalomologic observations in offspring of alcohol abusing mothers	Stromland et al.	1996	Included in a systematic review
Fetal alcohol syndrome--an ophthalmological and socioeducational prospective study	Stromland et al.	1996	Included in a systematic review
Hospitalizations of children who have fetal alcohol syndrome or incomplete fetal alcohol syndrome	Kvigne et al.	2009	Included in a systematic review
Maternal age, alcohol abuse history, and quality of parenting as moderators of the effects of prenatal alcohol exposure on 7.5-year intellectual function	Jacobson et al.	2004	Includes only diagnostic outcomes
Bone age and growth in fetal alcohol syndrome	Habbick et al.	1998	Includes only diagnostic outcomes
Fetal alcohol exposure, iron-deficiency anemia, and infant growth	Carter et al.	2007	Includes only diagnostic outcomes

Performance of American Indian children with fetal alcohol syndrome on the test of language development	Carney and Chermak	1991	Includes only diagnostic outcomes
The use of cardiac orienting responses as an early and scalable biomarker of alcohol-related neurodevelopmental impairment	Mesa et al.	2017	Includes only diagnostic outcomes
Meta-analyses of externalizing disorders: Genetics or prenatal alcohol exposure?	Wetherill et al.	2018	Includes only diagnostic outcomes
Development and psychopathology of children with the fetal alcohol syndrome	Steinhausen et al.	1983	Includes only diagnostic outcomes
Alcohol use, injuries, and prenatal visits during three successive pregnancies among American Indian women on the northern plains who have children with Fetal alcohol syndrome or incomplete fetal alcohol syndrome	Kvigne et al.	2008	Includes only diagnostic outcomes
Fetal alcohol spectrum disorders in Finland: Clinical delineation of 77 older children and adolescents	Autti-Ramo et al.	2006	Includes only diagnostic outcomes
Fetal alcohol syndrome: a prospective national surveillance study	Elliott et al.	2008	Includes only diagnostic outcomes
Fetal alcohol syndrome in adolescents and adults	Pytkowicz et al.	1991	Includes only diagnostic outcomes
Ten-year experience of fetal alcohol spectrum disorder; diagnostic and resource challenges in Indigenous children	Banerji et al.	2017	Includes only diagnostic outcomes
An examination of three key factors: Alcohol, trauma and child welfare: fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada	Badry and Felske	2013	Includes only diagnostic outcomes
An examination of the social determinants of health as factors related to health, healing and prevention of foetal alcohol spectrum disorder in a northern context--the Brightening Our Home Fires Project, Northwest Territories, Canada	Badry and Felske	2013	Includes only diagnostic outcomes
Seizures and electroencephalography findings in 61 patients with fetal alcohol spectrum disorders	Boronat et al.	2017	Includes only diagnostic outcomes
The remarkably high prevalence of epilepsy and seizure history in fetal alcohol spectrum disorders	Bell et al.	2010	Includes only diagnostic outcomes
Fetal alcohol spectrum disorders from childhood to adulthood: A Swedish population-based naturalistic cohort study of adoptees from Eastern Europe	Langdren et al.	2019	Includes only diagnostic outcomes
Behavior in Children with fetal alcohol spectrum disorders in remote Australia: A population-based study	Tsang et al.	2017	Includes only diagnostic outcomes
Neurocognitive function and fetal alcohol spectrum disorder in offenders with mental disorders	Mela et al.	2020	Includes only diagnostic outcomes
The demographic and neurocognitive profile of clients diagnosed with fetal alcohol spectrum disorder in PATCHES Paediatrics Clinics across Western Australia and the Northern Territory	Connor et al.	2020	Includes only diagnostic outcomes

Congenital defects of the limbs and alcohol exposure in pregnancy: data from a population based study	Froster and Baird	1992	Includes only diagnostic outcomes
Biopsychosocial effects of foetal alcohol syndrome among children from the Interventional Care Facility in Otwock	Sek et al.	2017	Not in English
Alcohol in pregnancy and toxic heart damage in the child	Loser et al.	1992	Not in English
Fetal alcohol spectrum disorder predisposes to metabolic abnormalities in adulthood	Weeks et al.	2020	Preclinical study
Developmental risk factors associated with incarceration in the juvenile justice system	Mutch R.	2016	Wrong article type
Diversionary pathways for Aboriginal youth with fetal alcohol spectrum disorder	Blagg and Tulich	2018	Wrong article type
Assessment and evaluation of fetal alcohol spectrum disorder (FASD) and its potential relevance for sentencing: A clarion call from Western Australia: LCM v The State of Western Australia [2016] WASCA	Freckelton	2017	Wrong article type
Socioeconomic wellbeing/impairment in a cohort of individuals prenatally exposed to alcohol: exploring parenting styles as a determinant of outcome	Ritfeld et al.	2020	Wrong article type
Sleep in children with fetal alcohol spectrum disorders (FASD)	Shada and Tangen	2020	Wrong article type
Reviewing the effects of prenatal alcohol exposure on sleep and circadian functioning in children: An emerging pathway to neurocognitive impairment	Kuhar et al.	2015	Wrong article type
Challenging/disruptive sleep/wake behaviours in adolescents with fetal alcohol spectrum disorders: Iatrogenic effects of prescription medications	Ipsiroglu et al.	2015	Wrong article type
Sleep in infants and children with prenatal alcohol exposure	Inkelis and Thomas	2018	Wrong article type
Fetal alcohol spectrum disorders and the criminal justice system	Fast and Conry	2009	Wrong article type
Prenatal alcohol exposure predicts greater alcohol use in young adulthood, after control for confounding variables	Dodge et al.	2009	Wrong article type
A systematic review of fetal alcohol spectrum disorder (FASD) federal case law: Implications for psychologists and competency to stand trial evaluators	Brown J	2018	Wrong article type
Sleep in fetal alcohol spectrum disorders	Chen et al.	2015	Wrong article type
Eating behavior in children with fetal alcohol spectrum disorders: A mixed methods study	Evans	2017	Wrong article type
Some implications of prenatal alcohol exposure for the treatment of adolescents with sexual offending behaviors	Baumbach J.	2002	Wrong article type
Fetal alcohol spectrum disorder and delinquency	Hassler et al.	2017	Wrong article type
Fetal alcohol spectrum disorders: Diagnostic considerations for children with a history of trauma	Shah et al.	2018	Wrong article type

Standing on one foot: FASD with and without early life stability	Hatcher et al.	2010	Wrong article type
Sleep, maladaptive behaviour and language acquisition in children with fetal alcohol spectrum disorders	Mughal et al.	2017	Wrong article type
Fetal alcohol spectrum disorder in aboriginal youth: A descriptive study of presentations to child and adolescent psychiatry emergency	Nugent et al.	2016	Wrong article type
Differential eating behavior patterns in children with moderate to heavy prenatal alcohol exposure	Chambers et al.	2015	Wrong article type
The relationship between sleep problems and behavioral functioning in 5-year-olds with prenatal alcohol exposure	Inkelis et al.	2017	Wrong article type
Restless leg syndrome (RLS) in children and youth with neuro developmental conditions - A clinically missed diagnosis aggravating the challenging behaviour of underlying conditions?	Ipsiroglu et al.	2011	Wrong article type
Prenatal alcohol exposure is a determinate of early teen alcohol use	Chiodo et al.	2010	Wrong article type
Prenatal alcohol exposure increases early adolescent alcohol use	Sokol et al.	2010	Wrong article type
Patterns of child abuse in children with fetal alcohol spectrum disorder (FASD)	Jimenez et al.	2010	Wrong article type
Sleep, self-regulation, and behaviour in children with fetal alcohol spectrum disorder (FASD)	Hanlon-Dearman A	2014	Wrong article type
Fetal alcohol syndrome: Long term effects in children, adolescent, and young adult patients	Feldmann R.	2010	Wrong article type
Ethical considerations when communicating a diagnosis of a fetal alcohol spectrum disorder to a child	Todorow et al.	2012	Wrong article type
Ethnic and cultural factors in identifying fetal alcohol spectrum disorders	Woods et al.	2011	Wrong article type
A pilot project on fetal alcohol syndrome among American Indians	May et al.	1982	Wrong article type
Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough	Morton et al.	2017	Wrong article type
Ethical aspects of diagnosis and interventions for children with fetal alcohol Spectrum disorder (FASD) and their families	Helgesson et al.	2018	Wrong article type
Fetal alcohol spectrum disorder as a marker for increased risk of involvement with correction systems	Burd et al.	2010	Wrong article type
Challenges and resiliency in Aboriginal adults with fetal alcohol spectrum disorder	Samaroden, M.	2018	Wrong article type
Alcohol-induced behavioural problems in fetal alcohol spectrum disorder versus confounding behavioural problems.	Malone et al.	2012	Wrong article type
Cardiac orienting response as an early indicator of impairment in fetal alcohol spectrum disorders	Jacobson and Jacobson	2017	Wrong article type

Genetic polymorphisms: impact on the risk of fetal alcohol spectrum disorders	Warren and Li	2005	Wrong article type
The patterns of sleep disorders and circadian rhythm disruptions in children and adolescents with fetal alcohol spectrum disorders	Goril and Shapiro	2011	Wrong article type
Healing colonial binaries: a "needs-based' approach to Aboriginal persons found unfit to stand trial on the basis of FASD	Bush Z.	2017	Wrong article type
Disruptions in nature, disruptions in society: Aboriginal peoples of Canada and the "Making" of fetal alcohol syndrome	Tait et al.	2009	Wrong article type
Ocular involvement in fetal alcohol spectrum disorder: a review	Brennan and Giles	2014	Wrong article type
Sleep disturbances in children with fetal alcohol spectrum disorder (FASD)	Keiver et al.	2013	Wrong article type
The lililwan project: neurodevelopmental outcomes and fetal alcohol spectrum disorders in remote australian aboriginal children	Fitzpatrick et al.	2015	Wrong article type
Disordered eating behaviors and nutritional issues in children with FASD	Amos-Kroohs et al.	2015	Wrong article type
Disordered eating behaviors and nutritional issues in children with fetal alcohol spectrum disorders (FASD)	Smith et al.	2015	Wrong article type
The Lililwan Project: Developing a culture-and language-appropriate fasd diagnostic questionnaire and assessing its reliability for history-taking in an Australian Aboriginal community	Fitzpatrick et al.	2011	Wrong article type
A review of sleep disturbances among infants and children with neurodevelopmental disorders	Kamara and Beauchaine	2020	Wrong article type
Let us talk night-time-related-quality-oflife for children and adolescents with neurodevelopmental disorders	Ipsiroglu et al.	2012	Wrong article type
Let us talk night time-related-quality-of-life for children and adolescents with FASD	Ipsiroglu et al	2012	Wrong article type
Fetal alcohol spectrum disorder standards: Supporting children in the care of children's services	Badry D	2009	Wrong article type
Children with FASD-related disabilities receiving services from child welfare agencies in manitoba	Fuchs et al.	2010	Wrong article type
Children with fetal alcohol spectrum disorders in the dependency court system: Challenges and recommendations	Paley and Auerbach	2010	Wrong article type
The nature of sleep in Canadian children with fetal alcohol spectrum disorder	Stade et al.	2010	Wrong article type
The prevalence and patterns of sleep disorders and circadian rhythm disruptions in children with fetal alcohol spectrums disorders (FASD)	Goril and Shapiro	2011	Wrong article type
The prevalence of fetal alcohol spectrum disorders and concomitant disorders among orphanage children in Lithuania	Kuzmenkoviene et al.	2012	Wrong article type

Improving outcomes in adolescents and adults with fetal alcohol spectrum disorders	DeJoseph et al.	2011	Wrong article type
Alcohol during pregnancy damages eye and vision development	Stromland	1992	Wrong article type
Parents with fetal alcohol spectrum disorders in the child protection systems: Issues for parenting capacity assessments	Choate	2013	Wrong article type
Sleep problems in infants with prenatal alcohol exposure	Chen et al.	2011	Wrong article type
Adolescents affected by fetal alcohol spectrum disorder (FASD) and behaviour	Clark E	2012	Wrong article type
A systematic review of the current literature investigating attachment and fetal alcohol spectrum disorders	Wray et al.	2012	Wrong article type
Prenatal alcohol exposure and hypothalamic pituitary-adrenal axis dysfunction: A systematic review	Rodriguez et al.	2012	Wrong article type
Alcohol and substance abuse identified during pregnancy: Maternal morbidity, child morbidity and welfare interventions	Sarkola et al.	2012	Wrong topic
Improving treatment and outcomes for young people with fetal alcohol spectrum disorder in the youth justice system: A social work led response and practice framework	Oatley and Gibbs	2020	Wrong topic
Health-related quality of life of Canadian children and youth prenatally exposed to alcohol	Stade et al.	2006	Wrong topic
The effects of prenatal alcohol and marijuana exposure: disturbances in neonatal sleep cycling and arousal	Scher et al	1988	Wrong topic
Feeling different: The experience of living with fetal alcohol spectrum disorder	Stade et al.	2011	Wrong topic
Integrating care for individuals with FASD: results from a multi-stakeholder symposium	Masotti et al.	2015	Wrong topic
Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions	Dossetor et al.	2019	Wrong topic
Disparities in Canadian indigenous health research on neurodevelopmental disorders	Di Pietro and Illes	2014	Wrong topic
Playfulness and prenatal alcohol exposure: a comparative study	Pearton et al	2014	Wrong topic
Who is most affected by prenatal alcohol exposure: Boys or girls?	May et al	2017	Wrong topic
Salivary cortisol levels are elevated in the afternoon and at bedtime in children with prenatal alcohol exposure	Keiver et al	2015	Wrong topic
A systematic review of the prevalence of foetal alcohol syndrome disorders among young people in the criminal justice system	Hughes et al	2016	Wrong topic

Mental health disorders among children within child welfare who have prenatal substance exposure: Rural vs. urban populations	Chasnoff et al.	2015	Duplicate

Appendix C: Summary of data charting of included studies

Author, date, location, setting	Study design and participants	Study aim	Key data collected	Key findings	Sub-area of interest addressed
Physical health (*n*=21)					
Akison et al. 2019a	Systematic review 3 clinical studies (2 case control, 1 cohort) *n* = 275 across the 3 studies 6 – 9yrs	Summarize the preclinical and clinical literature on non-neurological health outcomes in offspring following PAE.	Body composition (BMI, % body fat) Metabolism (glucose, insulin signalling, and/or lipid)	Out of the 32 studies, 3 were clinical. Two reported lower BMI or % body fat (BIA) than controls, or non-exposed or heavy exposed/non-syndromal. One small clinical study (from 1981) reported evidence of glucose intolerance and insulin resistance. More evidence was available from the preclinical studies.	1) Metabolic/body composition
Akison et al. 2019b	Systematic review 5 clinical studies (all cohorts) *n* = 4,106 14–21yrs	Evaluate all the clinical and preclinical studies reporting on reproductive outcomes of male and female offspring following PAE.	Puberty onset Serum/saliva hormone levels Semen analysis/sperm counts	Out of 23 studies, 5 were clinical. 1 reported older age at first menarche in heavy PAE (2 reported no difference cf non-exposed controls). 1 (of 1) study reported increased saliva T levels in PAE. 1 (of 1) study found reduced sperm concentration at highest PAE level, and semen volume in males. 1 of 2 found a "trend" towards delay in puberty onset (the other reported no change).	1) Reproductive
Avaria et al. 2004 Chile Population-based	Prospective cohort (Nested) *n* = 30 (17 heavy PAE, 13 no PAE)	Determine effect of PAE on the peripheral nervous system (nerve conduction velocity)	Tibial, ulnar, and median motor nerve velocity	PAE had slower velocities in the ulnar motor nerve, smaller proximal amplitude, and distal amplitude of the ulnar nerve. PAE had reduced proximal amplitude at the tibial nerve.	1) Nervous System

	Evaluation at 6 months and 12 months.			No significant differences were found between groups in the median nerve. No significant differences in those with early PAE vs PAE throughout pregnancy.	
Blanck-Lubarsch et al 2019 Germany Paediatric clinic	Case-control (Prospective) *n* = 60 (30 FAS, 30 controls) 5.8 – 11.9yrs	Identify dental anomalies or habits associated with FAS	Standardised orthodontic examination	Higher in children with FAS: mouth breathing, age at termination of oral habits, speech therapy, ergotherapy, physiotherapy, ratio permanent teeth with enamel defect: N permanent teeth, DDE index: N permanent teeth with enamel defect, DMFT index: N permanent and deciduous teeth, DMFT index, modified DDE index, N permanent teeth with enamel defect. Lower in FAS: breastfeeding and duration. No significant differences: exfoliation of teeth, swallowing pattern, N deciduous and permanent teeth, or otitis media.	1) Bones/teeth
Brownell et al. 2013 Canada Manitoba Clinic-based	Case-control (Retrospective) *n* = 3,577 (717 FASD, 1,434 controls, 1,426 with asthma) 6 – 34yrs	Describe health, education and social service use of individuals with FASD compared to the general population and asthma	Hospitalisations, prescription drug use, physician visit rate, involvement with Child & Family services, special education funding	Higher in FASD: N hospitalisations in most recent 3y, physician visit rate, overall prescription drug use, family receipt of income assistance, involvement with child & family services, special education funding (4-13x higher than controls and asthma).	1) Service utilisation
Carter et al. 2007 South Africa Population-based	Prospective cohort (Nested) *n* = 96 (42 heavy PAE, 54 abstained/ low PAE). Cape Coloured	Determine whether PAE is associated with iron-deficiency anaemia in infancy, and to compare effects of PAE and iron-deficiency anaemia on infant growth	Complete blood count: Iron-deficiency anaemia (IDA) defined as having Hgb <10.9 g/L & RDW ≥15% + MCV ≤70.0 fL or MCH ≤23.0 pg.	*n* =34 had IDA (38.3%; group not reported). Binge PAE associated with 3.6x increased risk of diagnosis of IDA at 12 mo. Difference was not significant at 6.5 mo.	1) Cardiovascular/ renal

	Assessed at birth, 6.5 mo, 12 mo.				
Cheung et al. 2022	Systematic review and meta-analysis 31 studies included; (25 in meta-analysis) n=843 children with PAE, 1653 children with FASD	Systematically review and conduct a meta-analysis on studies that report type and prevalence of functional and structural ear abnormalities among children with PAE and/or FASD	Frequency of functional or structural ear abnormalities	Highest pooled prevalence for functional abnormalities – chronic serous otitis media (88.5%), abnormal auditory filtering (80.1%), unspecified conductive hearing loss (68%), Highest pooled prevalence of structural abnormalities – microtia (42.9%), rail-road track ear (16.8%) and misplaced ear (12.3%)	1) Ears/eyes
Cook et al. 2019 U.S Atlanta, Georgia Clinic-based	Retrospective cohort with comparison to national prevalence data *n* = 625 (125 FAS/PFAS, 500 nationally representative sample) 8 – 17yrs	Examine the relationships between PAE (manifested through FAS and PFAS) and hypertension in children and adolescents.	Blood pressure	FASD significantly predicted hypertension status ($p<0.001$) after controlling for age, sex, race/ethnicity, medication use, and obesity status.	1) Cardiovascular/ renal
Flannigan et al. 2022a* Alberta, Canada Community-based	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD assessment, follow up interviews on average 9months later (5-17months)	Participants experienced complex physical needs reporting significant past or present concerns including, respiratory disease, cardiovascular problems, gastrointestinal issues, chronic pain, dental issues, and sleep problems.	1) Cardiovascular/ renal 2) Respiratory and immune 3) Bones/teeth

			Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program.		
Gummel et al. 2013 Russia Orphanages	Case control (Prospective) *n* = 100 (50 FAS, 50 Controls – all orphans) 10 – 16yrs	Study functional and anatomic characteristics of eyes of Russian children with FAS.	Visual acuity, refraction, FAS-related external ocular features, ocular alignment, biomicroscopy using a slit lamp.	In FAS vs Controls: poorer visual acuity and refraction, higher rates of external ocular anomalies and ocular misalignment.	1) Ears/eyes
Habbick et al 1998 Canada Saskatoon Child Development Program	Prospective cohort (Nested) *n* = 63 FAS >1 to <14yrs	Report skeletal maturation and longitudinal growth in FAS patients in Saskatchewan, Canada	Bone age (from radiograph of left hand and wrist).	60/63 were below the median reference value for bone age.	1) Bones/teeth
Kable et al 2021 U.S Atlanta Georgia	Case control (Nested) *n* = 61 (39 PAE, 22 controls)	Characterize the diabetes risk status of adult individuals with a history of PAE relative to non-exposed individuals.	Plasma glucose and hemoglobin Alc – measure of average glucose concentration over time.	Increased insulin sensitivity as indicated by lower insulin levels and lower insulin resistance in those with PAE and normal or low BMI. Those with overweight or higher BMI and PAE had increased	1) Metabolic/body composition

Clinic-based	Mean age 36yrs		Insulin and insulin resistance	insulin resistance compared to controls. No differences in glucose levels.	
Loney et al 1998 Canada Saskatoon Child Development Program	Retrospective cohort (Nested) *n* = 194 FAS 0 – 19yrs	Document hospital utilisation of Saskatchewan people with FAS between 1973 to 1992	Hospital separation (discharge) rates as indicator of burden of illness, N hospitalisations	Males: 92/101 (91%) hospitalised. Females: 77/93 (83%) hospitalised. Hospital separation rates were higher in FAS cf the general Saskatchewan child population and Saskatchewan Registered Indian children	1) Service utilisation
Naidoo et al 2005 South Africa Wellington	Case control (Prospective) *n* = 180 (90 FAS, 90 Controls) Mean age: 9 y	Analyse the anthropometric measures and oral health status of children with FAS compared to matched controls	Oral health, tooth and eruption disturbances, caries status	No significant differences between groups in DMFT score and its components. Some dentofacial anomalies were more frequent in FAS than Controls. Tooth disturbances were often more frequent in FAS than controls.	1) Bones/teeth
Naidoo et al 2006 South Africa Wellington	Case-control (Prospective) *n* = 180 (90 FAS, 90 Controls) Mean age: 9yrs	Assess if there dental or skeletal developmental differences between children with FASD and matched controls.	Dental maturity and skeletal age	Chronological age was higher than skeletal age in children with FAS cf controls. FAS boys' dental age was higher than chronological age (with the difference pronounced in controls), while in FAS girls, their dental age was lower than their chronological age.	1) Bones/teeth
Popova et al 2016	Systematic review and meta-analysis *n* = 1,728 with FAS across 33 studies.	Identify the comorbid conditions that co-occur in individuals with FASD, and estimate the pooled prevalence of comorbid conditions occurring in individuals with FAS	The comorbid disease conditions in FAS, classified according to ICD-10 and pooled prevalence	The most prevalent comorbid disease conditions were classified: congenital malformations, deformities and chromosomal abnormalities, mental and behavioural disorders. The 5 comorbid conditions with the highest pooled prevalence (50 – 91%)	1) Nervous system 2) Ears/eyes

				were: Abnormal results of functions studies of peripheral nervous system and special senses; Conduct disorder; Receptive language disorder; Chronic serous otitis media; Expressive language disorder.	
Reid et al. 2019a	Systematic review 9 clinical studies newborn – 14yrs	Synthesize all the available clinical and preclinical literature focused on cardiovascular and or renal outcomes associated with PAE.	Cardiovascular function Renal function	The few clinical studies found were typically of poor quality and/or had small sample sizes. 5 studies investigated cardiovascular outcomes (e.g., increased pulse wave velocity, reduced RSA/HRV, increased HR) and 4 on the same small cohort reported on renal outcomes (e.g., inability to concentrate urine and episodes of polyuria).	1) Cardiovascular/ renal
Reid et al. 2019b	Systematic review 12 clinical studies newborn – 17yrs	Synthesize the available clinical literature focused on immune-related outcomes associated with PAE.	Atopy outcomes (eczema, dermatitis, asthma and allergies) Infection outcomes (sepsis, newborn infections, immune cell assays)	8 included at least one atopy outcome with mixed findings –1/3 increased risk of eczema, 2/2 increased risk of dermatitis, 0/5 increased risk for asthma, 2/2 no association of PAE with hay fever. 6 included infection-based outcomes – 5/6 increased risk for infections.	1) Immune
Reid et al 2021a* International sample	Prospective cohort *n* =197 caregivers of children with FASD Median age of children: 12yrs	Compare rates of reported health conditions in children with FASD to prevalence data in the general population and investigate child and family predictors for adverse health outcomes.	Health and demographic data	The most commonly diagnosed health conditions: eye, asthma, heart, and skin – most were significantly higher in FASD than national prevalence data. Caregiver reported health conditions included problems with digestion and/or bowels, joint pain, and urinary incontinence. Predictors of greater number of health conditions were: older age at diagnosis, having a primary	1) Bones/teeth 2) Cardiovascular/ renal 3) Metabolic 4) Immune 5) Ears/eyes

				caregiver in paid work, and greater number of comorbid conditions.	
Tsang et al 2022	Systematic review 36 studies included FASD: 0-50.8yrs PAE: 0.02-48.1yrs Controls: 1month-21yrs	Document the range and prevalence of eye abnormalities reported in children with PAE and or FASD	Searched electronic databases for studies that reported quantitative or frequency data on functional/structural eye abnormalities. Calculated pooled prevalence, odds ratios and mean frequencies.	Most prevalent abnormalities: short palpebral fissures (66.1%), visual impairment (55.5%) epicanthus (53.5%), subnormal stereoacuity (53%), abnormal retinal tortuosity (50.5%), impaired fixation ability (33.3%), telecanthus (31.7%), optic nerve hypoplasia (30.2%), small optic discs (27%). Children with FASD had higher prevalence of strabismus, subnormal vision, ptosis, short palpebral fissure length, microphthalmos, smaller optic disc area, and retinal vessel tortuosity.	1) Ears/eyes
Young et al 2022 Australia Clinic-based	Case-control *n* = 19 at risk of or diagnosed with FASD, 56 in control group) 4-15yrs	Investigate associations between PAE (FASD or at risk of FASD) and bone and body composition parameters in children and adolescents using dual X-ray absorptiometry (DXA)	Body composition assessments at a single time point including height, weight, BMI and DXA (total body less head bone mineral density, bone mineral content, total body lean tissue mass and fat mass. Absolute values and Z-scores calculated.	Children aged 4-9yrs had similar growth trajectories to age-matched controls. By adolescence (≥10yrs) were shorter and had lower areal bone mineral density and lean tissue mass than typically developing peers. Overall, greater odds of impairments to bone and body composition in adolescents diagnosed with FASD.	1) Metabolic/body composition 2) Bones/teeth
Sleep (*n*=20)					
Alvik et al 2011 Norway Population-based	Prospective cohort *n* = 1,288 mother-infant dyads Assessed at 6 mo.	Study potential associations between early prenatal binge exposure and infant temperament and sleeping pattern	Prenatal binge (≥5 drinks per occasion) alcohol exposure: Collected prospectively via self-report. Infant outcomes via maternal	Prenatal binge once a week during pregnancy week 0–6 significantly predicted both difficult temperament and sleeping problems after adjusting for other confounding factors. Including binge drinking > once a week, further	1) Prevalence/type of sleep difficulties in children with PAE

			report: sleep problems (4 items related to falling asleep, night waking and sleep pattern). Temperament (11 items).	increased the odds of sleeping problems. Results were not explained by binge drinking later in pregnancy or higher consumption per occasion.	2) Associations between sleep difficulties and daytime functioning
Chandler-Mather et al 2021 Australia Population-based	Prospective cohort (Nested) *n* = 3,447 mother-child dyads 2 – 9 yrs	Investigate the association between dose and frequency of PAE and sleep problems in children, after controlling for established risk factors for sleep problems.	Prenatal alcohol exposure: collected retrospectively via maternal self-report Classified as abstinent, occasional, low, moderate and heavy (>70g per week) Sleep problems: Collected biennially from 2-9 years. Maternal report on 4 items related to getting to sleep, sleeping along, waking during the night and restless sleep.	Children with heavy PAE (>70g per week) had 1.13 more sleep problems across childhood (2- 9 years) relative to children without PAE. Heavy PAE increases the probability of having persistent sleep problems by 22.57 %. No negative associations between moderate or low PAE and sleep were observed.	1) Prevalence/type of sleep difficulties in children with PAE
Chen et al 2012 U.S. Clinic-based	Prospective cohort (Nested) *n* = 33 children with FASD 4 – 12 yrs	Assess sleep concerns in children with FASD using a caregiver-report survey; compare results with those of previously reported community sample; and describe pilot polysomnography findings in children with FASD.	Child Sleep Habits Questionnaire (CSHQ) Overnight polysomnography	85% of children scored above clinical cut-off on CSHQ. Elevated subdomain scores occurred primarily in areas of paediatric insomnia. Polysomnography (*n* = 5) revealed mild sleep disorders breathing and fragmented sleep with elevated non-respiratory arousal indices.	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning
Chernick et al 1983	Prospective cohort	Compare the electroencephalogram	Maternal self-report at admission to the labour	Infants with PAE had higher amplitude of electrical activity of the brain.	1) Infant sleep-wake

Canada Hospital-based	*n* = 70 mother-infant dyads (17 PAE, 18 nicotine and 17 and 18 matched control groups) Aged 3 days	power spectrum analysis and morphometric data of infants of alcoholic mothers with infants of smoking, nondrinking mothers carefully matched to their own control groups.	ward. Heavy (>2 ounces of AA per day); controls were occasional drinkers <1 ounce on any occasion/abstainers. EEG during sleep: recordings of 90-120ms immediately after feeding during the daytime.	Average integrated EEG power of infants was significantly higher in all 3 stages of sleep. This hypersynchrony was most pronounced during REM sleep.	regulation as an early indicator of PAE
Dylag et al 2021 Poland FASD diagnostic centre (hospital based)	Case-control (prospective) *n* = 80 children (40 with FASD and 40 typically developing, TD) 6-13 yrs (median FASD=8 yrs, median TD=10 yrs)	Investigate sleep problems related to FASD	1st phase - screening of sleep problems with Child Sleep Habits Questionnaire (CSHQ) 2nd phase – children who scored ≥41 points in CSHQ qualified for this phase, in-lab attended polysomnography (PSG) performed, compared to PSG laboratory reference data	55% of children in FASD group had sleep disturbances (compared to 20% in TD group) Age-adjusted odds ratio for positive result in CSHQ was 4.31 (95% CI: 1.54-12.11; p=0.005) compared to control group Significant differences observed for sleep onset delay, night wakings, parasomnias, sleep disordered breathing and daytime sleepiness between FASD and control group. More arousals during sleep in FASD group (PSG) compared to reference data, also higher respiratory indices for FASD group than previously published TD data.	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning
Fjeldsted et al 2009 Canada Manitoba Winnipeg	Cross-sectional cohort *n* = 20 children with confirmed PAE 0 – 36 months	Examine sleep and sensory processing in children with prenatal alcohol exposure.	Brief Infant Sleep Questionnaire Infant/Toddler Sensory Profile	Significant correlations between: total daytime sleep and sensation seeking, night wakefulness and sensation avoiding and oral sensory processing.	1) Associations between sleep difficulties and daytime functioning

Clinic-based					
Goril et al 2016 Canada Ontario Clinic-based	Prospective cohort *n* = 36 children and adolescents with FASD. Compared to normative data 6 – 18yrs	Detect both standard sleep parameters and features of melatonin secretion in children and adolescents.	Overnight polysomnography Dim light melatonin onset test Clinical interview including sleep history	58% had a sleep disorder. Most common sleep disorders were parasomnias (27.9%) and insomnia (16.8%). Sleep studies showed lower than normal sleep efficiency and high rates of sleep fragmentation. 79% had an abnormal melatonin profile.	1) Prevalence/type of sleep difficulties in children with PAE
Havlicek et al 1977 Canada Manitoba Winnipeg Hospital-based	Case-control *n* = 52 (26 PAE; 26 control) matched for gestational age.	Describe EEG and its power-spectrum characteristics of three sleep stages in infants born to alcoholic mothers and compares these data with similar information obtained from healthy babies born to non-drinking mothers.	NR how PAE collected EEG during sleep: Recording 90-120 mins duration immediately after a daytime feeding, during spontaneous sleep and wakefulness.	Infants with PAE showed prominent EEG hypersynchrony in all three stages of sleep: quiet sleep, indeterminate sleep and active-REM sleep.	1) Infant sleep-wake regulation as an early indicator of PAE
Hayes et al 2020 International sample	Prospective cohort *n* = 163 children with FASD. 5 – 17yrs	Examine the association of sleep problems with child behaviour problems, caregiver mental wellbeing, caregiver and family quality of life.	Sleep problems: 3 parent-reported items related to falling asleep, night waking and early morning waking Child behaviour: SDQ Caregiver mental health: DASS-21 Caregiver and family quality of life: PedsQL FIM	65.6% sleep problem (difficulty falling asleep 56.4%, night-waking 44.8%, early morning waking 29.4%). Medication associated with difficulty falling asleep and early morning waking. Younger age associated with early morning waking. Difficulty falling asleep associated with child conduct and caregiver worry. Night waking associated with child emotional problems, poorer caregiver physical and social functioning and family difficulties with daily activities	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning

			Adjusted for range of child and family covariates	Early morning waking associated with child conduct, caregiver anxiety, poorer caregiver physical, emotional, social functioning, poorer family functioning and family difficulties with daily activities.	
Ioffe et al 1988 Canada Manitoba Winnipeg Hospital-based	Prospective cohort *n* = 441 newborn infants with varying levels of PAE Assessed at 36-48 hrs of age	Compare the development of the neonatal EEG, as assessed by computer analysis, in infants from 30 to 40 weeks gestation who were exposed to varying quantities of alcohol in utero.	PAE categorised as: occasional (< 15ml per month), moderate (16 to 60ml, more than once/month); binge (>60ml alcohol, at least twice/month); and alcoholic (continued PAE throughout pregnancy). 90-120 min EEG during daytime sleep after feeding. Sleep state coded as REM (active) sleep, quiet sleep, indeterminate sleep and non-sleep states (crying, active awake, quite awake)	Infants with PAE demonstrated significant abnormality in the development of the EEG. Abnormality appeared to be more severe with binge PAE.	1) Infant sleep-wake regulation as an early indicator of PAE
Ipsiroglu et al 2013 Canada British Columbia Vancouver Paediatric sleep assessment clinic	Mixed methods *n* = 6 parents *n* = 7 health professionals *n* = 27 children with FASD and their caregivers.	Identify possible explanatory models to account for the children's restless day- and night-time behaviours.	Semi-structured interviews Comprehensive clinical sleep assessments	In the interviews parents and HCPs exhibited awareness of the significance of SPs and the effects on the daytime behaviours of the child and associated burdens on parents. HCPs' systemic inattention to the sequelae of SPs and the family's wellbeing appears due to insufficient understanding of various factors that contribute to night-time SPs	1) Associations between sleep difficulties and daytime functioning

				and their daytime sequelae. SPs were targeted with medications, without investigating the underlying problem.	
Mughal et al 2020b U.K. Nation-wide Online survey	Case-control (Prospective) *n* = 194 children (91 FASD, 103 controls) 6 – 16yrs	Examine a predictive association between anxiety and sleep in a large group of children with FASD, and to compare this to a cohort of TD children.	CSHQ Spence Children's Anxiety Scale Analyses adjusted for age and sex.	Children with FASD had significantly higher levels of bedtime resistance, sleep onset delay, sleep duration, sleep anxiety and night waking than their TD peers. In FASD group, sleep scores did not improve.	1) Prevalence/type of sleep difficulties in children with PAE
Mughal et al 2020a U.K. London Online recruitment	Case-control (Prospective) *n* = 96 children (29 FASD, 21 ASD, 46 typically developing) 6 – 12yrs	Examine the association between sleep and cognitive outcomes in FASD and autism in comparison to a TD control group.	Actigraphy Working memory: Digit Span; Nonverbal mental age: Ravens Standard Progressive Matrices; Receptive vocabulary: British Picture Vocabulary Scale; Choice Reaction Time.	Children with FASD presented with significantly shorter total sleep duration, lower sleep efficiency, and more nocturnal waking than their TD peers. Sleep was significantly associated with nonverbal mental age (RSPM) and receptive vocabulary (BPVS).	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning
Mughal et al 2021 U.K. London Online questionnaire	Case-control (Prospective) *n* = 277 caregivers of children (61 ASD, 112 FASD and 104 TD) 6-15 years old	Assess the content of nightmares and their associated outcomes, report on whether children with ASD and FASD were more likely to experience nightmares, and whether there is a correlation trend between nightmare content and psychometric outcomes of affect, behaviour, or executive control	Online caregiver questionnaires – Children's Sleep Habits Questionnaire (CSHQ), Child Behaviour Checklist (CBCL), the Spence Children's Anxiety Scale (SCAS) and the Behaviour Rating Inventory for Executive Functioning (BRIEF)	73.62% of caregivers reported nightmares in their children within FASD group (compared to 21.36% in the TD group). Significant correlations reported between anxiety and nightmares, maladaptive behaviour and nightmares, and executive function and nightmares in both the TD and FASD groups (not in ASD group).	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning

Rosett et al 1979 U.S. Boston Hospital-based	Prospective cohort *n* = 31 mother- infant dyads (4 heavy PAE throughout pregnancy, 8 heavy PAE that reduced, 9 without heavy PAE) Assessed at 3 days of age	Determine the extent to which high blood-alcohol concentrations in utero affect 24-hour distribution of sleep-awake states on the third day of life.	PAE via maternal self-report during pregnancy. Heavy PAE: ≥5/6 drinks on some occasions no less than 45 drinks per month. Without heavy PAE: abstainers or <once a month never ≥5/6 drinks on any occasion. State Regulation: Continuous non-intrusive bassinet sleep monitor recorded sleep-awake states over 24-hour period on third day of life.	No differences found in % time spent in active, quiet and indeterminate sleep. Infants with heavy PAE throughout pregnancy slept less during the 24-hour period of observation than infants with heavy PAE that reduced. Infants with heavy PAE throughout pregnancy, when compared with infants without heavy PAE, demonstrated a poorer quality of quiet sleep, with significantly more quiet episodes interrupted by awake or unclassified epochs. They were also more restless with more frequent major body movements.	1) Infant sleep-wake regulation as an early indicator of PAE
Scher et al 1988 U.S. Pennsylvania Pittsburgh Population-based	Prospective cohort (Nested) *n* = 55 mother-infant dyads Assessed 26 – 48hrs postpartum	Examine the effects of prenatal alcohol and marijuana exposure on neonatal sleep states.	PAE via maternal self-report for each trimester of pregnancy. Categorised as number of drinks/ week and drinks/day Sleep: 2-2 ½ hour EEG-sleep recording 24-36 hours after birth. Adjusted for a range of child and maternal covariates	Effect of alcohol was specific to 1st and 2nd trimester and in general was associated with an increase in the number of arousals. Other variables affected by PAE were low voltage irregular active sleep and trace alternant quiet sleep, both were decreased in relation to 1st trimester PAE, and indeterminate sleep which was increased by 1st trimester PAE.	1) Infant sleep-wake regulation as an early indicator of PAE
Scher et al 2000 U.S. Pennsylvania	Prospective cohort (Nested)	Investigate the effects of prenatal cocaine use on EEG sleep patterns, a	PAE: quantity, frequency and pattern of use obtained at three	At birth, PAE was a significant predictor of increased time awake, body movements during active and quiet sleep, cycle length and EEG band	1) Infant sleep-wake regulation as an early

Pittsburgh Population-based	*n* = 71 mother-infant dyads Assessed 24-36 hours postpartum and repeated at 1 year of age.	marker of central nervous system development. *Note:* prenatal alcohol was not the main variable of interest but was included as an independent variable in the analyses.	defined time points during pregnancy Infant EEG Sleep: 2-hour EEG sleep recording obtained Adjusted for a range of child and maternal covariates	frequencies. At 1 year of age, PAE associated with decreased indeterminate sleep, increased REM and spectral correlations, and EEG band frequencies.	indicator of PAE
Spruyt et al 2016 Canada	Qualitative study *n* = 59 caregivers of children with FASD. 4 – 12yrs	How and to what extent are sleep and wake behaviours described; and how are these behaviours associated with each other.	Semi-structured interviews with caregivers	Caregivers seldom interrelated 'sleep' but rather 'night' with challenging behaviours suggesting a wide range of night-related behavioural problems including problematic sleeping and waking. Although associations of routines, managing and planning with sleep underscores the challenges faced, they remain unexpressed in terms of specific sleep problems or disorders. Descriptors aligning with reported impairments of FASD such as behavior*, challenge*, hypersensitive*, impulsive* or repeat* were not associatively used with sleep, suggesting they were considered mainly as day-related by caregivers.	1) Associations between sleep difficulties and daytime functioning
Troese et al 2008 U.S. Maine Prenatal clinic	Prospective cohort *n* = 13 low-income mother-infant dyads 6 – 12 weeks	Examine the relationship between prenatal alcohol exposure, sleep, arousal and sleep-related spontaneous motor movements in early infancy.	PAE via maternal self-report 1-month post-birth using MAST, TWEAK, T-ACE. Categorised as low and high using median split	Pre-pregnancy alcohol consumption including binge drinking correlated with maternal report of poor infant alertness, and increased irritability. High exposure groups showed increased sleep fragmentation, e.g., frequency	1) Associations between sleep difficulties and daytime functioning 2) Infant sleep-wake

			and pre-pregnancy binge Infant outcomes: Sleep state organisation using EEG, EOG, actigraphy and infrared time-synchronized videography	and duration of wakefulness following sleep onset and decreased active sleep. Analysis of the temporal structure of sleep-related spontaneous movements showed significantly reduced duration associated with high maternal alcohol use.	regulation as an early indicator of PAE
Wengel et al 2011 Canada Manitoba Clinic-based	Case-control (Prospective) *n* = 31 children (19 with FASD, 12 age-matched typically developing controls). 3 – 6yrs	Describe sleep patterns in children with FASD and investigate the relationship between sleep and sensory processing in these children.	Actigraphy Sleep log CSHQ The Sensory Profile	Children with FASD had significantly more sleep disturbances: increased bedtime resistance, shortened sleep duration, increased sleep anxiety, and increased night awakenings and parasomnias. Actigraphy showed significant difference for sleep onset latency. Sensory processing: Children with FASD had significant sensory seeking behaviour and differences in registration of sensory information. Sleep and Sensory Processing: Night waking and prolonged wake times correlated with multiple sensory processing areas. Correlations between sensory processing and behavioural responses to bedtime.	1) Prevalence/type of sleep difficulties in children with PAE 2) Associations between sleep difficulties and daytime functioning
Adverse postnatal experiences (*n*=17)					
Andre et al 2020 Calgary, Alberta Canada Clinic-based	Case-control (Prospective) *n* = 33 with PAE (12 without postnatal exposures; 21 with postnatal exposures)	Determine how PAE in the presence or absence of postnatal adverse exposures (neglect, poverty, caregiver transitions, physical/verbal/sexual	Internalising and externalising behaviour, diffusion tensor imaging (DTI)	Children with PAE had more mental health symptoms than controls regardless of postnatal adversity. Children with PAE and no adverse postnatal exposures showed more widespread structural brain differences from controls than PAE and postnatal	1) Multiple adverse experiences

	n = 33 age and gender-matched controls. 7 – 17 yrs	abuse, witnessing violence, chronic substance abuse) is associated with brain structure and mental health symptoms in children.		exposures. PAE + postnatal exposures showed similar brain structure to controls. Authors proposed PAE + postnatal exposure may lead to accelerated brain development, which would be considered sub-optimal and likely to result in an earlier developmental plateau.	
Bingol et al 1987 U.S New York, New York City Substance abuse treatment centres	Prospective case-control *n* = 36 PAE + upper/middle SES (Group 1); *n* = 48 PAE and lower SES (Group 2); *n* = 330 no PAE and lower SES served as controls (Group 3)	Compare manifestations of FAS in the offspring of lower and upper middle SES and to compare these to offspring without PAE.	Maternal health behaviours during pregnancy and child birth and developmental outcomes.	Incidences of failure to thrive, developmental delay, and number of hospitalisations was higher in Group 2. FAS and FAE was 4.6% in Group 1 and 71% in Group 2. ADD was significantly higher in Group 2. Family history of alcoholism was threefold more common in lower SES groups. Although maternal weights were similar food intake was different – higher SES ate more regularly and with a more balanced diet.	1) SES effects
Flannigan et al 2021a Canada Clinic-based	Retrospective cohort *n* = 333 children and adolescents with PAE, 66% diagnosed with FASD. 1 – 17 yrs	Quantify and characterize experiences of adversity in a sample of children and adolescents with PAE assessed for FASD.	Adversity assessed using a 10-item ACEs questionnaire.	Average total ACE score of 3.4. Almost half had experienced 4 or more ACEs. Most common ACEs: not being raised by parents, caregiver disruption and exposure to household substance use.	1) Multiple adverse experiences
Flannigan et al 2022a* Alberta, Canada Community-based	Prospective cohort *n* = 16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better understand the diverse needs/factors that may	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD assessment, follow up interviews on average	T-scores above the normal range for a number of trauma-related symptoms including anxious arousal, depression, anger, intrusive experiences, defensive avoidance, dissociation, somatic preoccupations, sexual disturbance, suicidality, insecure attachment, impaired self-reference.	1) Multiple adverse experiences 2) Attachment style/behaviour

		be related to involvement in the justice system for clients in this program	9months later (5-17months) Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program. Trauma Symptom Inventory-Second Edition administered to assess impacts of past trauma and general emotional state of individuals in 6 months prior to assessment.		
Hemingway et al 2020 U.S WA FASDPN Clinic-based	Case-control (Retrospective) *n* = 84 (34 with FASD (11 FAS/pFAS, 12 SE, 11 NE, 16 controls)	Explore the proportion of variance in brain structural and functional abnormalities explained by PAE and other prenatal and postnatal risk factors.	MRI and comprehensive neuropsychology battery	PAE explained the largest proportion of variance across the greatest number of brain structural and functional measures. Other prenatal and postnatal risk factors explained a significant by smaller proportion of variance, however in combination rivalled PAE.	1) Multiple adverse experiences
Jacobson et al 2004	Prospective cohort	Examine the role of maternal age MAST (severity of alcohol-	WISC-III (intelligence scales)	PAE effects were seen in children with poorer HOME enrichment scores on Verbal IQ, Freedom from Distractibility	1) Multiple adverse experiences

U.S Detroit Population-based	*n* = 337 African American children (283 with PAE across pregnancy) 7.2-8.9 yrs	related psychosocial and physical problems) and quality of the caregiving in moderating the effects of PAE on the WISC.	Quality of caregiving: HOME (home observation for measurement of the environment) Inventory	and the Comprehensive, Picture Arrangement and Arithmetic subtests, whereas less effects were seen among those with more optimal HOME scores.	2) Postnatal environment in the mitigation of effects
Kambeitz et al 2019 U.S General developmental clinic	Case-control (Retrospective) *n* = 203 (98 with FASD and 105 without FASD)	Compare the prevalence of ACEs and disorders between those with FASD and without FASD	Chart review using a 10-item ACEs measure and record of diagnoses.	FASD group had a higher ACEs score (mean 5.3) compared to those without FASD (mean 1.69). Most common ACEs were neglect, parental substance abuse and parental separation. Increased ACEs were associated with increased risk of other diagnoses in the FASD group. Most common diagnoses were ADHD, oral comprehension deficits, sleep disturbance and cognitive impairment.	1) Multiple adverse experiences
Lebel et al 2019 Canada Clinic-based	Prospective cohort (Nested) *n* = 77 children and adolescents with confirmed PAE 2.8 – 15.9 yrs	Propose a method for characterization of prenatal and postnatal adverse exposures that may be useful for both future research and diagnostic practice.	Each child was scored on 7 exposure variables: prenatal alcohol exposure, other prenatal substance exposure, other prenatal toxic stress, early postnatal deprivation <24 months, late postnatal deprivation ≥24 months, early postnatal threat, late postnatal threat ≥24 months. Exposure was ranked as 1 confirmed absent, 2	PAE co-occurred with other prenatal exposures in 99% of cases. Co-occurring PAE and postnatal adversity was seen in two-thirds of the sample. High PAE predicted late postnatal exposure to threat or deprivation. The presence of one postnatal adversity was related to the presence of other postnatal adversities.	1) Multiple adverse experiences

			unknown, 3 confirmed, 4 confirmed high		
McLachlan et al 2016 Canada Clinic-based	Prospective cohort (Nested) with separate control sample *n* = 85 children and adolescents (confirmed PAE 42 which included 29 with FASD; 43 typically developing controls) 5 – 18 yrs	Evaluate HPA function through assessment of diurnal cortisol activity compared to typically developing controls as well as associations among specific adverse life experiences and protective factors.	Morning and evening saliva samples for 2 days to measure diurnal cortisol rhythm. Structured interview data was coded using an 8-item ACEs measure	Children with PAE + adversity had higher evening cortisol, a trend for lower morning cortisol and a flatter slope over the day. The flatter slope over the day and higher evening cortisol was found in both low/moderate and high PAE levels.	1) Multiple adverse experiences
Mukherjee et al 2019 U.K Clinic-based	Retrospective cohort *n* = 97 with FASD (38 no neglect; 44 prolonged neglect) 6 – 26 yrs	Assess the relationship between presence and length of neglect and neurobiological outcomes in children with PAE.	Adaptive behaviour (Vineland), autism spectrum disorder (ASD)/social communication disorder (SCD), ADHD, and short sensory profile (SSP)	In individuals with FASD, there was no difference in adaptive behaviour, ASD/SCD, ADHD, and SSP between the neglected and non-neglected groups.	1) Multiple adverse experiences
O'Connor et al 1987 U.S California, L.A Amniocentesis clinic	Prospective cohort *n* = 46 infants born to mothers > 30 yrs 26% reported moderate-heaving alcohol use.	Establish the relation between maternal drinking practices and infant attachment at 1 yr.	Strange Situation Procedure	Greater percentage of infants rated as insecure attachment in those exposed to alcohol prior to and during pregnancy. Majority of infants exposed to abstinent/light rated as secure and majority exposed to moderate/heavy rated as insecure.	1) Attachment style/temperament
O'Connor et al 1992 U.S California, L.A	Prospective cohort *n* = 44 infants born to mothers > 30 yrs	Investigate the relationship between PAE, mother-infant interaction and infant attachment behaviour.	Child and maternal behaviours: Mother-Child Rating Scales	Subtle behavioural changes in affect were observed in infants with PAE. These changes correlated with the mother's responses to the infants. Mothers of infants with more negative	1) Attachment style/temperament

Amniocentesis clinic	55% reported 2 or more drinks, 14% reported 4 or more drinks during pregnancy.			affect were less responsive and these infants displayed insecure attachment behaviour.	
O'Connor et al 2002 U.S California, L.A General medical centre	Prospective cohort *n* = 42 mother-child dyads ranged from abstinent to heavy use (ns in groups not reported)	Examine the association among PAE, mother-child interaction and child attachment behaviour.	Attachment Q-Set	PAE was related to attachment insecurity. 80% with PAE were classified as insecure and 36% unexposed classified as insecure. PAE also predicted negative child affect, which was related to lower levels of maternal emotional support of the child.	1) Attachment style/temperament
Pfinder et al 2012 Germany Population-based	Prospective nested cohort *n* = 996 children with PAE from a national cross-sectional survey 3 – 10 yrs	Test the hypothesis of a social gradient in hyperactivity/inattention in children with PAE.	German Health Interview and Examination Survey for Children and Adolescents which includes: Hyperactivity/inattention: SDQ, SES, Prenatal and perinatal, psychosocial, material-structural and cultural behavioural information.	The risk of hyperactivity/inattention was higher in children with PAE from low/middle SES compared to those with higher SES. Differences were explained by pre-and perinatal factors (smoking, low birth weight), cultural-behavioural (exercise, TV watching and fast food), material structural (exposure to smoke at home). Cultural-behavioural factors had the main explanatory effect.	1) SES effects
Price et al 2017	Systematic review *n* = 1,026 across all studies, 1 – 16 yrs.	Review all published research that sought to assess the interaction of both PAE and trauma or provided evidence of the likelihood of both presenting together.	Communication, motor, cognition, emotional and behavioural outcomes.	Five studies met inclusion criteria. Available evidence suggested problems with speech and language, attention, intelligence, memory and emotional and behavioural issues can occur to a greater extent when both exposures present together.	1) Multiple adverse experiences

Uban et al 2020 U.S CIFASD Clinic-based	Case-control *n* = 197 with PAE *n* = 197 age and sex-matched controls 6.5-17.7 yrs	Examine differences in associations between SES and subcortical brain volume in youth with PAE compared to non-exposed controls.	MRI scans, executive functioning, SES	Higher SES related to larger subcortical volumes in controls and larger volumes related to better executive functioning in both groups. There was an absence of typical SES-brain associations following PAE.	1) SES effects 2) Postnatal environment in the mitigation of effects
Yumoto et al 2008 U.S Detroit Population-based	Prospective cohort *n* = 337 African American children (110 non-exposed to prenatal substances; 227 exposed to prenatal substances Assessed at 7.5 yrs	Examine the degree to which cumulative risk and fetal substance exposure modify vulnerability to environmental risk.	Cumulative risk index computed from 8 factors (SES, *n* children at home, presence of father, parental stressful events, depression, parent-child interaction, parental violence, and substance use). Outcomes: WISC-III, TRF	Highest correlation among risk factors in both the exposed and unexposed group was maternal depression and stressful life events. Higher cumulative risk was associated with lower FSIQ in both groups. Cumulative risk was only associated with increased behaviour problems in the exposed group.	1) Multiple adverse experiences
Substance use and other risk-taking behaviours (*n*=17)					
Alati et al 2006 Australia, Queensland Mater University Study of Pregnancy (MUSP) Population-based	Prospective cohort (Nested) Mothers and children followed up at birth, 6 months and 5, 14 and 21 yrs. Subsample of 2,138 participants with complete 21-year data.	Examine the independent effect of maternal alcohol use during early (18 weeks) vs. late (last 3 months) periods in pregnancy on the time of onset of alcohol use disorders in offspring.	Prenatal exposures collected via prospective interview. Onset of an alcohol use disorder according to DSM-IV criteria.	Adjusted odds ratio of developing early onset alcohol use disorder was 2.95 for those exposed in early pregnancy and 1.35 for those exposed in late pregnancy. PAE of 3 or more glasses per occasion may play a role in the pathway that leads to alcohol use disorders in adulthood.	1) Alcohol misuse in children/adolescents 2) Alcohol misuse in adults

Alati et al 2008 Australia, Queensland Mater University Study of Pregnancy (MUSP) Population-based	Prospective cohort (Nested) Mothers and children followed up at birth, 6 months and 5, 14 and 21 yrs. Subsample of 4,363 participants with complete 14-year data.	Assess a potential association between maternal drinking in pregnancy and adolescent patterns of alcohol use.	Prenatal exposures collected via prospective interview. Offspring drinking patterns (i.e., never, 1 or 2 glasses vs 3+ glasses at 14 yrs.	Increased risk of adolescent alcohol use for those with PAE of 3 + glasses during pregnancy compared with no drinking or up to 2 glasses. Controlling for maternal alcohol use before pregnancy and at age 5 the odds ratio of PAE on risk of adolescent drinking of 3 and more glasses at 14 yrs was 2.74.	1) Alcohol misuse in children/adolescents
Baer et al 1998 U.S Seattle, Washington Population-based	Prospective cohort (Nested) *n* = 439 with complete data at the 14-year follow-up	Examine the relative importance of prenatal alcohol exposure and family history of alcohol problems for the prediction of adolescent alcohol problems.	PAE collected via prospective interview. Adolescent alcohol use assessed via questionnaire (Lifestyle Choices Survey)	PAE retained significant predictive effects on adolescent drinking after adjusting for family history and other prenatal and environmental covariates.	1) Alcohol misuse in children/adolescents
Baer et al 2003 U.S Seattle, Washington Population-based	Prospective cohort (Nested) *n* = 433 Assessed at 21yrs	To assess whether PAE affects alcohol-related problems in young adults (21 years of age).	PAE collected via prospective interview. Adult drinking habits and problems assessed via self-report including the Alcohol Dependence Scale.	Moderate and frequent drinking patterns in offspring may be associated with higher rates of PAE. Episodic heavy PAE tripled the odds that offspring reported mild alcohol dependence. No effect of nicotine exposure on 21-year-old drinking outcomes.	1) Alcohol misuse in adults
Cornelius et al 2016a U.S Pennsylvania	Prospective cohort (Nested) *n* = 917 mother-child dyads	Assess if youth with adverse gestational and environmental exposures have a greater risk of drinking during	PAE and other exposures collected via prospective interview each trimester.	Variables that predicted higher levels drinking: PAE, prenatal tobacco exposure, parental laxity (less parental strictness, less parental involvement), greater maternal hostility during	1) Alcohol misuse in children/adolescents

Pittsburgh Population-based	Assessed at 16yrs	adolescence. Assess if early adversity risk factors will predict greater adolescent drinking.	Adolescent substance use assessed via self-report interview	childhood, and greater exposure to child maltreatment and violence. Each drink/day increase in PAE increased the odds of being in a higher drinking group by 1.7 times. Heavier drinking during adolescence was predicted by PAE.	2) Effect of other variables on alcohol use problems
Cornelius et al 2016b U.S Pennsylvania Pittsburgh Population-based	Prospective cohort (Nested) *n* = 917 mother-child dyads Assessed at 16yrs	Determine characteristics of adolescents who drank before age 15 stopped vs. those who started drinking at the same age and persisted.	PAE and other exposures collected via prospective interview each trimester. Adolescent substance use assessed via self-report interview	34% of adolescents reported consuming a full drink prior to their 15th birthday, and 80% of these continued to drink at the 16-yrs. PAE was different between these groups where PAE levels ≥1 drink/day led to persistent drinkers among early alcohol users. 91% of the persistent offspring drinkers had PAE levels ≥1 drink/day.	1) Alcohol misuse in children/adolescents
De Genna et al 2015 U.S Pennsylvania Pittsburgh Population-based	Prospective cohort (Nested) *n* = 332 Interviews with mothers and children when offspring were 6, 10, 14, & 16 years old.	Determine if maternal substance use is associated with risky sexual behaviour & early pregnancy	PAE collected via prospective interview each trimester. Adolescents self-reported substance use and sexual behaviour.	Risky sexual first partner in offspring had an association with maternal prenatal tobacco and maternal alcohol use when offspring were 10yrs. Children with PAE were more likely to engage in risky sex as teens. Heavy PAE when offspring was 14 were 3x more likely to experience pregnancy by 16. Greater levels of maternal hostility during childhood were associated with offspring reporting 2 or more recent sex partners.	1) Effect of PAE on other risk-taking behaviours (excluding alcohol)
Flannigan et al 2022a* Alberta, Canada	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD	History of substance use challenges.	1) Alcohol misuse in adults

Community-based		understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	assessment, follow up interviews on average 9months later (5-17months) Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program.		
Goldschmidt et al 2019 U.S Pennsylvania Pittsburgh Population-based	Prospective cohort (Nested) *n* = 608 Assessment at 22yrs	Test whether offspring exposed to alcohol during gestation exhibit higher rates of alcohol use and abuse. Determine what level of PAE is associated with alcohol problems in adult offspring.	PAE collected via prospective interview each trimester. Adults self-reported substance use Lifetime alcohol abuse and dependence assessed using the DSM-IV	Offspring were more likely to drink if PAE ≥1 drink/day during first trimester Heavy PAE during the first trimester was associated with 84% increase in ≥2 symptoms for DSM-5 symptoms (Alcohol Use disorder). The association between PAE & DSM IV diagnosis of alcohol abuse/dependence was not significant.	1) Alcohol misuse in adults
Hannigan et al 2015 U.S Michigan Detroit Population-based	Prospective cohort (Nested) *n* = 75 African American adolescents 18 – 19yrs	Examine the odour responses to alcohol and other odours in a sample of young adults with detailed PAE histories.	PAE collected via prospective interview. Odour assessment via a 5-point scale rating the pleasantness of the odour.	After controlling for possible confounds, higher levels of PAE were related to higher relative ratings of pleasantness for alcohol odours.	1) Alcohol misuse in children/adolescents

Lees et al 2020 U.S ABCD Study 21 sites Population-based	Prospective cohort *n* = 11,875 9 – 10yrs	Assess association between low level PAE and alcohol experimentation in offspring.	PAE assessed via retrospective questionnaire. Children self-reported alcohol use (excluding religious ceremonies).	Any PAE exposure had an increased association with alcohol experimentation. Consistent, heavy PAE was associated with children participating in alcohol experimentation. Children from higher SES and highly educated families were more likely to report alcohol experimentation. Children from ethnically diverse families were less likely to experiment with alcohol compared to white children.	1) Alcohol misuse in children/adolescents 2) Effect of other variables on alcohol use problems
Lynch et al 2017* U.S Atlanta Georgia Population-based	Case control (Nested) *n* = 236 (123 PAE, 59 unexposed, 54 special education contrast) Mean age 22yrs	Examine the occurrence of problem behaviour at transition to adulthood, including mental health problems, substance use and difficulties with the legal system for those with PAE.	Neurocognitive evaluation, a medical evaluation, and an interview session on adaptive behaviour, problem behaviour, and background characteristics.	No differences in drugs tested between any of the groups. PAE + dysmorphic (DYSM) and PAE + cognitively affected (COG-AFF) associated with higher tobacco use compared to control (unexposed) and PAE + COG-cognitively unaffected (COG-UNAFF), higher marijuana use in DYSM and COG-UNAFF, males who were COG-UNAFF had highest GGT (indicator of high alcohol use) and self-reported alcohol use	1) Alcohol misuse in adults 2) Effect of PAE on other risk-taking behaviours (excluding alcohol)
McLachlan et al 2020* Canada National Clinic-based	Case-control (Retrospective) *n* = 726 individuals with PAE (443 adolescents -12 – 17 yrs, 135 transition aged youth 18-24 yrs	Profile difficulties in daily living experiences experienced by a large sample of adolescents, transition-aged youth and adults from the Canadian National FASD database.	9 current difficulties in daily living were reported at the time of diagnostic assessment.	Adults presented with high rates of difficulties: alcohol misuse (38%), other substance misuse (46%).	1) Alcohol misuse in adults

	and 148 adults – 25-60 yrs)				
O'Brien et al 2014 U.S Pennsylvania Pittsburgh	Prospective cohort *n* = 209 third generation offspring. Based on familial risk for substance dependence offspring defined as high risk (*n* = 99) or low risk (*n* = 110).	Examine the relative contribution of having a multiplex, familial history of alcohol dependence and prenatal exposure to alcohol and/or cigarettes on offspring smoking and drinking behaviour.	Prenatal exposures collected via retrospective interview. Offspring substance use and diagnosis of substance use disorder according to DMS-III (childhood) or DSM-IV (young adult)	After controlling for potential confounds across high and low-risk participants, prenatal exposure to either alcohol or cigarettes increased risk of offspring smoking, whereas prenatal alcohol increased risk of substance use disorder. Prenatal exposures increased the risk for offspring substance use and abuse above and beyond the effect of familial risk.	1) Effect of PAE on other risk-taking behaviours (excluding alcohol)
Rangmar et al 2015* Sweden Clinic-based	Retrospective cohort compared to population-based data *n* = 79 adults with FAS *n* = 3,130 comparison individuals matched on age, gender and place of birth. 18 – 47yrs	Investigate outcome variables such as education, employment, health and criminal acts in adults diagnosed with FAS.	Outcomes retrieved from National registries.	High prevalence of alcohol related disorders/illicit drug abuse (12.7% vs 3.4% in controls), Illicit drug abuse (6.3% vs 2.5% in controls), alcohol-related disorders (8.9% vs 1.6% in controls)	1) Alcohol misuse in adults 2) Effect of PAE on other risk-taking behaviours (excluding alcohol)
Streissguth et al 2004 U.S Washington Seattle	Prospective cohort (Nested) *n* = 415 with FAS or FAE 6 – 51yrs	Identify the rate of adverse life outcomes in FAS and FAE and the risk factors.	Life History Interview (LHI) with carers. Demographic information. Retrospective analysis of clinical data.	49% for Inappropriate Sexual Behaviours on repeated occasions; 35% of patients >12years reported alcohol and drug problems (29% adolescents and 46% of adults), alcohol problems more frequent than drug problems (33% vs 23%), 65% who abused alcohol went on to use street drugs	1) Alcohol misuse in children/adolescents 2) Alcohol misuse in adults 3) Effect of PAE on other risk-taking

					behaviours (excluding alcohol)
Yates et al 1998 U.S Iowa Adoption agencies	Prospective cohort *n* = 197 adults (21 PAE) 18 – 45yrs	Study the effect of PAE on later development of nicotine, alcohol, and drug dependence.	PAE assessed via adoption agency records, hospital, and prison records. Adult substance use behaviour assessed via comprehensive psychiatric and substance abuse interview diagnoses made using DSM-III-R criteria.	PAE was a significant factor in increasing the number of adult substance dependence symptoms. Males had higher number of symptoms than females. Difficult to tease out whether tobacco use confounded these findings.	1) Alcohol misuse in adults 2) Effect of PAE on other risk-taking behaviours (excluding alcohol)
Contact with the Justice System (*n*=15)					
Blagg et al 2017 Australia West Kimberley region (Broome, Fitzroy Crossing and Derby) Community-based	Mix of comparative legal analysis, review of policy and practice and place-based interviews and focus groups.	Map current state of FASD knowledge, describe ways one Aboriginal community has responded, discuss impact current legislation has and map out a reform agenda informed by a decolonizing approach (power transfer from settler mainstream to Indigenous structures/processes).	Consultation focused on 2 areas: indefinite detention (due to CLMIA Act regime) and the need for diversionary alternatives (movement away from community-based services that are "epistemologically white" towards community owned and managed structures and processes), beginning at the first point of contact with the system.	Proposed a "mobile needs-focused court" – hybrid model of Aboriginal courts (involvement of Elders) and Victoria Neighbourhood Justice Centre (single magistrate, comprehensive screening process for clients when they enter the court and rapid entry into on-country support). Proposed model combines techniques in 'problem-orientated courts,' with co-location of services, involvement of Elders and promotion of culturally appropriate options.	1) Effects of PAE on CJS contact 2) Factors other than PAE on CJS contact

Brownell et al 2019* Manitoba, Canada	Case-control (Retrospective) *n* = 743 First Nations young people with FASD; *n* = 315 non-First Nations diagnosed with FASD; *n* = 2,229 First Nations no FASD 1-25yrs	Examine health services, social services, education, and justice system outcomes among First Nations children and youth with FASD.	Administrative data from the Manitoba population research data repository linked to the health insurance registry. Captured health service utilization, social services, justice records and education records.	First Nations people with FASD had greater involvement with child welfare and the justice system and were more likely to be charged with a crime than non-First Nations individuals with FASD. There were no significant differences in education outcomes measured.	1) Effects of PAE on CJS contact 2) Factors other than PAE on CJS contact
Clark et al 2004* Canada British Columbia Okanogan Valley and West Kottenay Recruited from FAS Support Network	Prospective cohort (Nested) *n* = 62 adults with FAS or FAE 17 – 60yrs	Determine the prevalence of secondary disabilities amongst adults with FASD and factors that may affect the rates of secondary disability	Caregiver interview and questionnaire – functional assessment: Personal care, Daily living skills, Community access, social skills, Maladaptive behaviour, health and physical care demands.	Living with a caregiver was associated with not getting into trouble with the law.	1) Factors other than PAE on CJS contact
Currie et al 2016* Canada Ontario Community agencies	Qualitative study *n* = 14 adults with FASD and 11 support people. 18 – 41yrs	Examine services and supports experienced by adults with FASD in Ontario in light of a recommended best practice outlined in a position paper by the FASD-Ontario Network of	Interview questions included: age of diagnosis, experience of training and education in FASD, strengths, experience of collaborative services, Interdependent	Early diagnosis may have supported reduced contact with CJS. Drug and alcohol use were closely associated with CJS involvement.	1) Effects of PAE on CJS contact 2) Drugs/alcohol and CJS

		Expertise. Also, their reported contact with the Criminal Justice System (CJS).	supports, structure routine and supervision, Communication style and approach, Lifestyle factors, health professional access, Criminal justice involvement		
Flannigan et al 2022a* Alberta, Canada Community-based	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD assessment, follow up interviews on average 9months later (5-17months) Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program.	"Moderate" level of risk identified on the LSI-R subcomponents in terms of recommended service/supervision and likelihood of re-offending. Individuals identified that they wanted to live crime-free lives.	1) Factors other than PAE on CJS contact
Hamilton et al 2020b*	Qualitative study using a yarning approach.	To engage with the hopes, relationships and educational experiences	Yarning using thematic analysis, through the lens of the Recovery	Young people described having been affected by substance use, crime,	1) Factors other than PAE on CJS contact

Australia Western Australia Juvenile Justice	Detained youth *n*=38 (27 Aboriginal, 11 non-Aboriginal Australians) 24% had FASD, 34% had some severe neurodevelopmental impairment, 42% no diagnosis.	of a group of detained youth who had participated in a study for screening and diagnosis of FASD.	Capital model (i.e., personal, social and community recovery)	trauma, instability, and neurodevelopmental disability.	
Lynch et al 2003 U.S Atlanta Georgia Population-based	Prospective case control (Nested) *n* = 250 adolescent and primary carer dyads. (39 PAE + dysmorphic, 77 PAE + non-dysmorphic, 48 non-exposed controls, 84 special education contrast) Mean age 15.1yrs	Examine the relation between a range of levels of PAE and delinquent behaviour in a community sample and the effect of other current risk factors.	Measures of delinquency, life stress, substance use, behaviour problems, parenting practices, peer influences and current caregiver substance use.	The exposure groups did not differ from controls on measures of delinquent behaviour. Higher life stress, self-reported drug use and lower parental supervision were significantly related to delinquent behaviour.	1) Effect of PAE on CJS contact 2) Drug/alcohol and CJS 3) Factors other than PAE on CJS contact
Lynch et al 2017* U.S Atlanta Georgia Population-based	Case control (Nested) *n* = 236 (123 PAE, 59 unexposed, 54 special education contrast) Mean age 22yrs	Examine the occurrence of problem behaviour at transition to adulthood, including mental health problems, substance use and difficulties with the legal system for those with PAE.	Neurocognitive evaluation, a medical evaluation, and an interview session on adaptive behaviour, problem behaviour, and background characteristics.	COG-UNAFF group highest reports of being arrested and charged, males more likely than females, adults in COG-UNAFF group reported largest number of convictions (males also), longer incarcerations in COG-UNAFF group (again males longer than females, average number of months was 20.39)	1) Effect of PAE on CJS contact 2) Drug/alcohol and CJS 3) Factors other than PAE on CJS contact

McLachlan et al 2020* Canada National Clinic-based	Case-control (Retrospective) *n* = 726 individuals with PAE (443 adolescents -12 – 17 yrs, 135 transition aged youth 18-24 yrs and 148 adults – 25-60 yrs)	Profile difficulties in daily living experiences experienced by a large sample of adolescents, transition-aged youth and adults from the Canadian National FASD database.	9 current difficulties in daily living were reported at the time of diagnostic assessment.	Adults presented with high rates of difficulties: offending (30%), alcohol misuse (38%), other substance misuse (46%), legal problems with victimization (4%), and incarceration (3%).	1) Effect of PAE on CJS contact 2) Drug/alcohol and CJS
Pei et al 2016* Canada	Qualitative study *n* = 21 (9 people with FASD and 12 justice professionals)	Gain a deeper understanding of the experiences within the criminal justice system for people with FASD.	Semi-structured interviews and thematic analysis.	Major themes: primed to enter the system (biological, psychological and social factors); hindered within the system (biological, inability to self-advocate psychological and social issues, risks). Note also identified a theme on strengths included in subsequent section.	1) Effect of PAE on CJS contact
Rangmar et al 2015* Sweden Clinic-based	Retrospective cohort compared to population-based data *n* = 79 adults with FAS n = 3,130 comparison individuals matched on age, gender and place of birth. 18 – 47yrs	Investigate outcome variables such as education, employment, health and criminal acts in adults diagnosed with FAS.	Outcomes retrieved from National registries.	Rates of criminality did not differ.	1) Effects of PAE on CJS contact

Rangmar et al 2017* Sweden Clinic-based	Case control (Prospective) *n* = 40 adults (20 FAS, 20 control) 18 – 41yrs	Investigate self-reported physical and psychiatric problems, use of alcohol and illicit drugs, as well as conviction and being a victim of crime in adults with FAS.	Addiction Severity Index Interview: physical and psychiatric problems, use of alcohol and illicit drugs, criminal behaviour. Beck Anxiety and Depression Inventories	No differences reported in rates of offending.	1) Effect of PAE on CJS contact
Rogers et al 2013 Canada British Columbia and Manitoba,	Case-control (Prospective) *n* = 94 First Nations young people involved with justice (47 FASD and 47 without). 13 -23 yrs	Identify resources of resilience for young offenders and address questions regarding the association between enculturation and resilience, and whether offence histories differed between youth with and without a diagnosis of FASD.	*Enculturation/ethic identity:* Revised Multigroup Ethnic Identity Measure. *Characteristics and supports that enhance resilience:* The Child and Youth Resilience Measure. *Offence history:* Self-Report of Offending Questionnaire.	Youth who reported more resilience also endorsed more cultural connections, belonging and overall ethnic identity. Youth who had more resilience also had lower rates of offending. A diagnosis of FASD did not interact with the relationship between resilience and self-reported offending.	1) Factors other than PAE on CJS contact
Schonfeld et al 2005 U.S California San Diego Clinic-based	Case-control (Nested) *n* = 56 (27 PAE, 29 non-exposed controls) 10 – 18yrs	Investigate moral judgement and reasoning in children and adolescents with heavy PAE without a diagnosis of FAS	Sociomoral reflection measure-short form Conduct Disorder Questionnaire	PAE group demonstrated lower overall moral maturity compared with the control group. Delinquency was higher in the PAE group and specific sociomoral values were predictive of delinquent behaviour.	1) Effect of PAE on CJS contact

Streissguth et al 2004 U.S Washington Seattle	Prospective cohort (Nested) *n* = 415 with FAS or FAE 6 – 51yrs	Identify the rate of adverse life outcomes in FAS and FAE and the risk factors.	Life History Interview (LHI) with carers. Demographic information. Retrospective analysis of clinical data.	The life span prevalence for adverse life outcomes was: 60% for Trouble with the Law. Those with FAE had higher rates of all adverse outcomes compared to those with FAS.	1) Effect of PAE on CJS contact
Mental Health (*n*=13)					
Ali et al 2018 U.S Washington Seattle Clinic-based	Case-control (Nested) *n* = 81 (20 FAS/pFAS, 24 SE, 21 ND, 16 controls) Mean age 12yrs	Investigate Intra-individual variability (IIV) in children with FASD compared to controls. Investigate the relationship between IIV, attention and adaptive behaviour.	Continuous Performance Test Vineland IIV tasks – inhibitory control and sustained attention	Increased levels of IIV in FASD vs controls. IIV uniquely contributes to predicting adaptive behaviour, over attention. Attention partially mediates the relationship between IIV and adaptive behaviour.	1) Intra-individual variability
Baldwin 2007 U.S Alaska First Nations Clinic-based	Retrospective cohort and comparison with mental health service database 451 children with PAE 3 – 18yrs	To obtain a preliminary estimate of the prevalence of suicidality within a population of people with FASD.	Service access for self-harm-related consultations.	3.2% of individuals from the FASD clinic database had accessed a self-harm related service. Rates for adolescents only were 6%.	1) Suicide/self-harm

Brownell et al 2019* Manitoba, Canada	Case-control (Retrospective) *n* = 743 Canadian First Nations young people 1 – 25 yrs with FASD; *n* = 315 non-First Nations with FASD aged 1-25 yrs; *n* = 2,229 First Nations not diagnosed with FASD aged 1-25 yrs	To examine health services, social services, education, and justice system outcomes among First Nations children and youth with FASD.	There were significantly more suicides among First Nations individuals with FASD than non-First Nations individuals with FASD.	Young people with FASD are at risk for poor health, education, and social outcomes, but First Nations young people with FASD face comparably higher risks. No suicide attempts among non-First nations FASD individuals, crude rate/100 person-years of suicides among FN FASD individuals (0.22 for females and 1.06 for males) higher compared to FN non-FASD (0.08 for females and 0.32 for males)	1) Suicide/self-harm
Burns et al 2021* Canada Clinic-based	Retrospective cohort (Nested) *n* = 665 children and adolescents with FASD (mean 10.6 yrs)	Compare outcomes of children with FASD living in child welfare with those living in other settings (biological parents/family or adoptive)	Legal problems (as offender or victim), general difficulties with the law, sexual or physical abuse, mental health disorders, developmental conditions, PTSD, substance use and suicide attempts/ideation	Children in both groups (21.7% in foster care vs 17.8% in adoptive/ biological; 39% total) had experienced high rates of suicide attempts/ideation. No significant difference between the groups.	1) Suicide/self-harm
Flannigan et al 2022a* Alberta, Canada Community-based	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD assessment, follow up interviews on average 9months later (5-17months)	T-scores above the normal range for a number of trauma-related symptoms including anxious arousal, depression, anger, intrusive experiences, defensive avoidance, dissociation, somatic preoccupations, sexual disturbance, suicidality, insecure attachment, impaired self-reference.	1) Suicide/self-harm

			Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Trauma Symptom Inventory-Second Edition administered to assess impacts of past trauma and general emotional state of individuals in 6 months prior to assessment.		
Flannigan et al 2022b* Canada National FASD Database	Retrospective cohort *n*=796 individuals assessed for FASD with known PAE, 57.6% male Mean age 17.7ys (range 6-59yrs)	Determine rate of suicidal ideation/attempts in a large group of individuals with PAE who were assessed for FASD in Canada and investigate associations between suicidal ideation/attempts and select demographic and biopsychosocial variables and their associations with suicidality	Demographic data and biopsychosocial characteristics extracted from database and analysed using standard binomial logistic regression to explore factors contributing to suicidality	25.9% of sample reported to have experienced suicidal ideation/attempts. 55.4% of participants diagnosed with FASD. Highest rates reported in 18-24yrs (35.2%) and adolescents (34.7%). Odds of suicidality 6.7X higher in individuals with substance use challenges compared to those without, 2.8X higher in individuals with history of trauma/abuse and 1.9X higher in those with impaired affect regulation compared to those without.	1) Suicide/self-harm

Harding et al 2022 Alberta, Canada Community-based	Qualitative study *n*=5 caregivers of children and youth with FASD currently experiencing/history with suicidality 11-22yrs	Explore the lived experiences of caregivers of children/youth with FASD and suicidality, including perception of their child's/youth's suicidal experiences	Semi-structured interviews. Interpretative phenomenological analysis developed into composite vignette that was informed and organised by the social-ecological suicide prevention model (SESPM)	Individual factors relating to suicidality – socio-demographic characteristics, co-occurring health conditions, substance use, early life trauma and familial conflict. Individual protective factors relating to suicidality – pursuit of personal interests, physical activity and time in nature. Relational factors – feelings of belonging (or lack of), social disconnection, bullying, peer groups. Impacts on family unit – specific stressors, family dynamics and coping strategies. Community level influences – late/non-existent access to mental health support services, helpful interactions improve wellbeing Societal level factors – stigma, geographic region (urban vs rural) and COVID-19	1) Suicide/self-harm
Mathews et al 2014 U.K Population-based	Prospective cohort (Nested) *n* = 6,090	Examine the association between pre and perinatal exposures and Tourette/tic disorder in the Avon Longitudinal Study of Children.	Diagnosis based on DSM-IV-TR	Maternal alcohol and cannabis use, inadequate maternal weight gain and parity were associated with Tourette syndrome/Tic disorder. Birth weight and prenatal smoking were not associated.	1) Tourette syndrome/Tic disorder

O'Connor et al 2019 U.S California LA	Prospective cohort *n* = 54 adolescents with FASD 13 – 18yrs	Describe the prevalence of suicidal ideation and serious suicide attempts in a sample of adolescents with FASD.	Biological mother Health interviews Foster/adoptive parent questionnaire Kaufman brief intelligence test Children's Interview for Psychiatric Syndromes to assess suicidal risk	The prevalence of suicidal behaviours was high 35.2% of teens reported incidences of suicidal ideation vs. 17.2% in the general US adolescent population. 13.0% reported at least one serious suicide attempt in the past year vs. 2.4% in the general US population. 29.2% of males reported a serious suicide attempt -19½ times higher than national norms. No females reported attempts. Higher the psychosocial stressors (n home placements as a proxy), the more likely adolescents were to experience suicidal ideation. Presence of a depressive disorder increased risk of suicidal ideation and, in males, serious suicide attempts.	1) Suicide/self-harm
Rangmar et al 2015* Sweden Clinic-based	Retrospective cohort compared to population-based data *n* = 79 adults with FAS n = 3,130 comparison individuals matched on age, gender and place of birth. 18 – 47yrs	Investigate outcome variables such as education, employment, health and criminal acts in adults diagnosed with FAS.	Outcomes retrieved from National registries.	The FAS group had higher rates of mental health problems than peers - 33% diagnosed with psychiatric disorders (vs 5% in controls), 57% prescribed psychotropic drugs (vs 27% in controls) – sleep/anxiolytics, neuroleptics, and antidepressants. Higher prevalence at younger age for psychiatric care (0-17yrs 19% in FAS compared to 1.7% in controls), and >18yrs (13.9% in FAS compared to 3.0% in controls)	1) Suicide/self-harm 2) Medications/ hospitalisations

Rangmar et al 2017* Sweden Clinic-based	Case control (Prospective) *n* = 40 adults (20 FAS, 20 control) 18 – 41yrs	Investigate self-reported physical and psychiatric problems, use of alcohol and illicit drugs, as well as conviction and being a victim of crime in adults with FAS.	Addiction Severity Index Interview: physical and psychiatric problems, use of alcohol and illicit drugs, criminal behaviour. Beck Anxiety and Depression Inventories	FAS group reported higher levels of depression and anxiety, memory concerns, hallucinations, problems controlling violent behaviour and psychotropic drug use. Although there was no difference in physical health problems number of days with sickness leave were greater in the FAS group. Also reported lower age at first suicidal ideation. Non-significant trends for higher rates of lifetime suicidal ideation and attempts in the FAS group.	1) Medications/ hospitalisations
Streissguth et al 2004* U.S Washington Seattle	Prospective cohort (Nested) *n* = 415 with FAS or FAE 6 – 51yrs	Identify the rate of adverse life outcomes in FAS and FAE and the risk factors.	Life History Interview (LHI) with carers. Demographic information. Retrospective analysis of clinical data.	8% of children and 50% of adolescents and a adults reported confinement (psychiatric hospitalizations)	1) Medications/ hospitalisations
Temple et al 2019 Canada Ontario Clinic-based	Retrospective cohort *n* = 335 5 – 55yrs	Examine children and adults with FASD to investigate the relationship between Affect Regulation (AR) impairment and several mental health problems and diagnoses.	Data from the Canadian national FASD database was used for analysis.	Individuals with impairments in AR were more likely to have a history of suicidality. AR impairment most commonly found in those with greater overall neurodevelopmental impairment. Having AR impairment was associated with receiving a diagnosis of FASD at a later age, but was not related to gender, intellectual disability, or language disorder.	1) Suicide/self-harm
First Nations cultural considerations (*n*=12)					

Blagg et al 2017 Australia West Kimberley region (Broome, Fitzroy Crossing and Derby) Community-based	Mix of comparative legal analysis, review of policy and practice and place-based interviews and focus groups.	Map current state of FASD knowledge, describe ways one Aboriginal community has responded, discuss impact current legislation has and map out a reform agenda informed by a decolonizing approach (power transfer from settler mainstream to Indigenous structures/processes).	Consultation focused on 2 areas: indefinite detention (due to CLMIA Act regime) and the need for diversionary alternatives (movement away from community-based services that are "epistemologically white" towards community owned and managed structures and processes), beginning at the first point of contact with the system.	Proposed a "mobile needs-focused court" – hybrid model of Aboriginal courts (involvement of Elders) and Victoria Neighbourhood Justice Centre (single magistrate, comprehensive screening process for clients when they enter the court and rapid entry into on-country support). Proposed model combines techniques in 'problem-orientated courts,' with co-location of services, involvement of Elders and promotion of culturally appropriate options.	1) Cultural differences/importance of culture/family
Brownell et al 2019* Manitoba, Canada	Case-control (Retrospective) *n* = 743 First Nations young people with FASD; *n* = 315 non-First Nations diagnosed with FASD; *n* = 2,229 First Nations no FASD 1-25yrs	Examine health services, social services, education, and justice system outcomes among First Nations children and youth with FASD.	Administrative data from the Manitoba population research data repository linked to the health insurance registry. Captured health service utilization, social services, justice records and education records.	First Nations people with FASD had greater involvement with child welfare and the justice system and were more likely to be charged with a crime than non-First Nations individuals with FASD. There were no significant differences in education outcomes measured.	1) Cultural differences/importance of culture/family
Crawford et al 2020 New Zealand Clinic-based	Case control (Prospective) *n* = 68 (39 with FASD; 29 controls)	To better understand the important predictors of adaptive behaviour in children with FASD. And to consider the findings of this within the context	Neuropsychology assessment, collection of ACESs	Social cognition (specifically recognizing facial emotions) was the only significant predictor of teacher-rated adaptive functioning. Māori children descend from traditional societies where reliance of social connectedness and	1) Communication barriers 2) Cultural differences/importance of culture/family

	Māori were significantly over-represented in the sample. 8 – 12 yrs	of colonization and a te ao Māori (the Māori world) worldview.		strength of relationships were fundamental to survival. This impairment in social cognition in this study undermines one of the most important structures in Māori society.	
Flannigan et al 2022a* Alberta, Canada Community-based	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD assessment, follow up interviews on average 9months later (5-17months) Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program.	All participants received diagnosis of FASD. Often multiple diagnoses made in addition to FASD. Socio-environmental adversity common, beginning in early childhood and persisting throughout lives.	1) Trauma/stigmatization
Gonzales et al 2018 U.S	Qualitative study *n*=74 urban American Indian / Alaska Native	Explore knowledge and attitudes about FASD, perspectives on FASD risk factors, culturally	Community-based participatory research methods. Focus groups	Three inter-connected themes were identified from the data - knowledge of and experiences with FASD, the cycle of FASD risk, and culturally specific	1) Trauma/stigmatization 1) Cultural differences/im

	15 ys and older	relevant approaches to FASD prevention and healthcare		solutions to prevent FASD and support those affected by FASD. Addressing FASD in this urban AI/AN population should align with and emerge from community values; promote healing; incorporate wider contexts influencing behaviours. Must reflect community understanding that FASD risk behaviours are inextricably linked with historical and contemporary trauma. Participants described a complex cycle through which FASD is cultivated and perpetuated. Including using alcohol for coping, trauma and historical events, family impact and influence, mistrust with the healthcare system. We must draw on community and cultural strengths to reduce the occurrence of substance-exposed pregnancies and encourage transformational change in systems where Indigenous people are, to promote a healthy and thriving community now and for future generations.	portance of family/culture
Hamilton et al 2019 Australia Western Australia Juvenile justice	Qualitative study Case study using thematic network analysis. Focus groups: case managers (*n*=6), psychologists (*n*=5), first educators (*n*=18), follow-up educator	To undertake qualitative inquiry to identify and describe the perspectives of non-custodial staff detention staff regarding the value of an FASD prevalence study.	Focus groups of non-custodial staff to capture their perspectives on FASD assessment in juvenile justice setting.	Many participants undertaking diagnosis became 'tired', 'exhausted' and 'needing quiet time'. Some of the young people felt they were involved in the research 'because they are stupid' or because 'the courts think they are idiots'. Other participants were concerned about trauma. "He has problems, he is not the problem. We must be part of the solutions for him."	2) Trauma/stigmatization 3) Communication barriers

	focus group (*n*=14) with overlap of some participants. Individual meetings with staff members from the health service (*n*=1) and Aboriginal welfare officers (*n*=2).			Barriers to service delivery included: poor communication and information access, inadequate resourcing and limited professionals development.	
Hamilton et al 2020a Australia Western Australia Juvenile Justice	Qualitative study Case studies using thematic network analysis *n* = 17 caregivers (12 Aboriginal, 5 five non-Aboriginal)	Explore the experiences of diagnostic assessment among detained young people and their caregivers.	Interviews undertaken using yarning approach.	Regardless of cultural background, there was a shared absence of the use of medical terms. Aboriginal participants used the term 'that thing in his head/brain' to refer to FASD. Neither of the non-Aboriginal participants used the terms FASD or neurodevelopmental impairments, but they did refer to their child's 'problems'. Aboriginal caregivers conceptualised their children's diagnosis and ongoing management in the context of their family networks and community. In contrast, non-Aboriginal caregivers focused on how the diagnosis would affect their child and interactions with various institutions including healthcare systems and schools. Diagnostic reports were not as easily understood by the Aboriginal participants.	1) Trauma/stigmatization 2) Communication barriers 3) Cultural differences/importance of family/culture
Hamilton et al 2020b* Australia Western Australia	Qualitative study using a yarning approach Detained youth *n*=38 (27 Aboriginal, 11 non-Aboriginal Australians)	To engage with the hopes, relationships and educational experiences of a group of detained youth who had participated in a study for	Yarning using thematic analysis, through the lens of the Recovery Capital model (i.e., personal, social and community recovery)	Young people described having been affected by substance use, crime, trauma, instability, and neurodevelopmental disability.	1) Trauma/stigmatization 2) Communication barriers 3) Cultural differences/im

Juvenile Justice	24% had FASD, 34% had some severe neurodevelopmental impairment, 42% no diagnosis.	screening and diagnosis of FASD.			portance of family/culture
Hayes 2012 Australia	Perspective piece using a narrative framework Aboriginal Australians	Examine the role history, politics and culture play in Aboriginal communities.		Aboriginal respondents concept of health status is grounded in terms of historical, cultural and systemic impediments. At age 11-13 years, while perceived as young teenagers by mainstream society, services and law, they often perceived as true adults by themselves and accepted as such by community.	1) Trauma/stigmatization 2) Cultural differences/importance of family/culture
Miller et al 2022 Western Australia	Two-phase multi-method approach *n* = 47 attendees (41 were women) of first community consultation workshop and other stakeholders recruited by local Elders and respected community members	Quantitatively assess gains in workshop attendee knowledge about FASD and neurodevelopmental assessments, confidence in assessment prototype and perceived competence to implement assessment post-workshop. Also aimed to gain qualitative feedback on implementation of assessment prototype within local community.	First phase – collection of quantitative pre-post attendee surveys and qualitative attendee discussions throughout workshop. Second phase – qualitative collection of facilitator data post-workshop. Equal weighting given to the qualitative and quantitative components of analysis.	Attendee knowledge, confidence and perception of competence increased post-workshop compared to pre-workshop. Key themes that emerged were: 1) ensuring awareness of ongoing impacts of colonisation, intergenerational trauma and systemic racism is acknowledged by practitioners engaging with First Nation's People's health; 2) collective sense of compassion for those who use alcohol to cope but exhaustion due to cyclical and enduring impact of alcohol use/FASD on community; 3) frustration at westernised approach of professionals working within silos instead of embracing collaborative, holistic, community-centred approach; 4) importance of ensuring prominent	1) Trauma/stigmatization 2) Cultural differences/importance of family/culture

				role for Aboriginal health workers in assessment process, given their standing in community and knowledge of connection as integral to stronger system.	
Reid et al 2021b Australia North Queensland Community-based	Mixed methods evaluation – use of Narrative analysis *n* = 87 participants (41 Aboriginal and/or Torres Strait Islander)	Record experiences from staff, service-users and family members to inform evidence-based community design process for a novel FASD assessment.	Pre-post workshop questionnaires and narrative analysis of the discussions during the workshop.	Common theme of ongoing impacts of colonisation on the community today, in terms of intergenerational trauma and alcohol use. Use of alcohol to 'counteract' racism/discrimination. Participants reported increases in knowledge about assessment and prevention, attitudes regarding alcohol use during pregnancy and FASD, however not in intentions to engage in clinical activities related to prevention and diagnosis of FASD.	1) Trauma/stigmatization 2) Communication barriers
Rogers et al 2013* Canada British Columbia and Manitoba,	Case-control (Prospective) *n* = 94 First Nations young people involved in youth justice (47 with FASD and 47 without). 13 -23 yrs	Identify resources of resilience for young offenders and address questions regarding the association between enculturation and resilience, and whether offence histories differed between youth with and without a diagnosis of FASD.	*Enculturation/ethic identity:* Revised Multigroup Ethnic Identity Measure. *Characteristics and supports that enhance resilience:* The Child and Youth Resilience Measure. *Offence history:* Self-Report of Offending Questionnaire.	Youth who reported more resilience also endorsed more cultural connections, belonging and overall ethnic identity. Youth who had more resilience also had lower rates of offending. A diagnosis of FASD did not interact with the relationship between resilience and self-reported offending.	1) Cultural differences/importance of family/culture
Transition to Adult Roles (*n*=12)					

Brownell et al 2019* Manitoba, Canada	Case-control (Retrospective) *n* = 743 Canadian First Nations young people 1 – 25 yrs with FASD; *n* = 315 non-First Nations with FASD aged 1-25 yrs; *n* = 2,229 First Nations not diagnosed with FASD aged 1-25 yrs	To examine health services, social services, education, and justice system outcomes among First Nations children and youth with FASD.	Administrative data from the Manitoba population research data repository linked to the health insurance registry. Captured health service utilization, social services, justice records and education records.	No significant differences reported in education outcomes measured between First Nations with FASD and First Nations individuals without FASD. First Nations FASD children were more likely to not be ready for school in at least 1 domain of developmental health and had to receive special education funding, and were less likely to graduate from high school.	1) Challenges in education/ employment
Clark et al 2004* Canada British Columbia Okanogan Valley and West Kottenay Recruited from FAS Support Network	Prospective cohort (Nested) *n* = 62 adults with FAS or FAE 17 – 60yrs	Determine the prevalence of secondary disabilities amongst adults with FASD and factors that may affect the rates of secondary disability	Caregiver interview and questionnaire – functional assessment: Personal care, Daily living skills, Community access, social skills, Maladaptive behaviour, health and physical care demands.	Most had experienced physical, sexual or verbal violence (87%). Only 34% had an IQ below 70, but 81% required moderate-high care, indicating deficits in adaptive skills. 92% were described as vulnerable to manipulation.	1) Independence 2) Vulnerability
Currie et al 2016* Canada Ontario Community agencies	Qualitative study *n* = 14 adults with FASD and 11 support people. 18 – 41yrs	Examine services and supports experienced by adults with FASD in Ontario in light of a recommended best practice outlined in a position paper by the FASD-Ontario Network of	Interview questions included: age of diagnosis, experience of training and education in FASD, strengths, experience of collaborative services, Interdependent	An early diagnosis of FASD was associated with more positive adult outcomes. Low numbers of participants (parents and individuals with FASD) received FASD education or training. Defining what structure, routine and supervision mean for people with FASD is challenging. More research on	1) Challenges in education/ employment 2) Independence

		Expertise. Also, their reported contact with the Criminal Justice System (CJS).	supports, structure routine and supervision, Communication style and approach, Lifestyle factors, health professional access, Criminal justice involvement	vocational placement opportunities for adults with FASD is needed.	
Duquette et al 2006 Canada & U.S Recruitment through FASD agency/website	Qualitative study *n* = 8 adolescents with FASD and their adoptive parents. 15 – 20yrs	Examine persistence among high school students with FASD from the perspective of the students themselves.	Interviews regarding school experiences	When asked about barriers to achieving their goals, 3 cited deficits caused by FASD, namely ADHD, inability to regulate feelings of anger and making the wrong friends. Parents also reported that their child was easily frustrated by failure and was inclined to give up when a problem appeared.	1) Challenges in education/ employment
Duquette et al 2013 Canada & U.S	Qualitative *n* = 13 adults with FASD 19 – 44yrs	Examine the employment outcomes of individuals with FASD who had undertaken post-secondary studies.	Open-ended survey questions (*n* = 13) and individual interviews (*n* = 4)	More than half of the adults were employed, albeit mostly in the service sector and on a part-time basis. Six had completed their college programs were working at the time of the research. For those individuals who did not graduate or were not employed, symptoms of FASD and other disabilities (e.g., substance abuse and mental health problems) were related to negative outcomes.	1) Challenges in education/ employment
Flannigan et al 2022a* Alberta, Canada	Prospective cohort *n*=16 adults Mean age 27.6yrs (20-42yrs, 75% male)	To explore the impacts of blending a restorative justice system program with FASD clinical services in the Alexis Nakota Sioux Nation, and better	Interview data collected through two in-person visits with clients, baseline interviews on average 6months (1-14months) after FASD	All participants received diagnosis of FASD. There was a wide range of functioning across participants and domains, pronounced difficulty with mathematical skills, and several relative strengths, including inhibition.	1) Challenges in education/ employment

Community-based		understand the diverse needs/factors that may be related to involvement in the justice system for clients in this program	assessment, follow up interviews on average 9months later (5-17months) Assessment measures included: intellectual ability, academic skills, language, verbal memory, motor skills, executive function, attention, adaptive skills. Level of Service Inventory (LSI-R) data also collected but did not form part of FASD assessment or justice program.	Females had higher LSI-R risk scores compared to males. Prominent concerns identified relating to financial situation, education, and employment.	
Freunscht et al 2011 Germany Clinic-based	Qualitative study *n* = 60 adults with FAS 18 – 39yrs	Examine biographical development and living situation in adults diagnosed with FAS as children.	Interview: patient characteristics, living situation, education/ occupation, social contacts, health diagnoses, social problems, alcohol and other drugs.	Most adults lived in dependent circumstances. Occupational development (education and employment) characterized by disruption and failure. Social problems were common. 3/4 were victims of physical and sexual abuse. Manipulation and exploitation by friends and partners was common.	1) Challenges in education/ employment 2) Independence 3) Vulnerability
Lynch et al 2015 U.S Atlanta Georgia Population-based	Case-control (Nested) *n* = 236 (123 PAE, 59 unexposed, 54 special education contrast) Mean age 22yrs	Determine effects of PAE on adaptive functioning in adulthood.	A series of questionnaires and interviews on adaptive function and problem behaviour. (Community Integration Survey, Addiction severity index, ABAS-II)	Adults who were dysmorphic and/or cognitively affected by PAE had difficulty with adaptive function and entry into adult roles. Males showing cognitive effects with no physical effects were the most severely affected. PAE exposed adults not showing physical or cognitive effects were	1) Independence

				similar to or more positive than those of the control group for most outcomes.	
McLachlan et al 2020* Canada National Clinic-based	Case-control (Retrospective) *n* = 726 individuals with PAE (443 adolescents -12 – 17 yrs, 135 transition aged youth 18-24 yrs and 148 adults – 25-60 yrs)	Profile difficulties in daily living experiences experienced by a large sample of adolescents, transition-aged youth and adults from the Canadian National FASD database.	9 current difficulties in daily living were reported at the time of diagnostic assessment.	Adults presented with high rates of difficulties: independent living support needs (63%), employment problems (37%), assisted or sheltered housing (21%), school disruption (18%), rates greater for adults and those with low overall intellectual functioning.	1) Challenges in education/ employment 2) Independence
Rangmar et al 2015* Sweden Clinic-based	Retrospective cohort compared to population-based data *n* = 79 adults with FAS n = 3,130 comparison individuals matched on age, gender and place of birth. 18 – 47yrs	Investigate outcome variables such as education, employment, health and criminal acts in adults diagnosed with FAS.	Outcomes retrieved from National registries.	The FAS group had lower education and higher rates of unemployment, social welfare and mental health problems than peers.	1) Challenges in education/ employment 2) Independence
Streissguth et al 2004* U.S Washington Seattle	Prospective cohort (Nested) *n* = 415 with FAS or FAE 6 – 51yrs	Identify the rate of adverse life outcomes in FAS and FAE and the risk factors.	Life History Interview (LHI) with carers. Demographic information. Retrospective analysis of clinical data.	14% of school children and 61% of adolescents/adults reported disrupted School Experiences; 53% of adolescents with FAS/FAE suspended from school, 29% expelled and 25% dropped out Those with FAE had higher rates of all adverse outcomes compared to those with FAS.	1) Challenges in education/ employment 2) Vulnerability

Temple et al 2011 Canada Ontario Toronto Clinic-based	Case control (Prospective) *n* = 30 (15 FASD, 15 IQ matched controls)	Examine adaptive living skills in adults with FASD and compare them to a group of clinic-referred individuals with similar IQ scores.	Wechsler IQ ABAS-II	Compared with IQ matched controls adults with FASD had significantly lower adaptive living skills. One area of particular difficulty was Conceptual skills (e.g., managing money, ability to express complex thoughts or ideas, ability to plan for the future and control emotions/impulses).	1) Independence
Out-of-home care (*n*=8)					
Bakhireva et al 2017 U.S Northwest Texas Developmental clinic	Retrospective cohort *n* = 681 (97 FAS/pFAS, 135 SE/ND, 449 some features/PAE unknown) 5 months – 17 yrs	Evaluate the association between patient characteristics and FASD diagnostic outcome and identify the role of unknown PAE in children living with biological parents/relatives vs adopted/foster.	FASD diagnostic assessment Guardianship status	Adopted/foster children were more likely to have unknown PAE and not receive a FASD diagnosis, potentially denying them access to specialized services and treatment.	1) Undiagnosed children in adoptive/foster care
Burns et al 2021* Canada Clinic-based	Retrospective cohort (Nested) *n* = 665 children and adolescents (mean 10.6 yrs)	Compare outcomes of children with FASD living in child welfare with those living in other settings (biological parents/family or adoptive)	Legal problems (as offender or victim), general difficulties with the law, sexual or physical abuse, mental health disorders, developmental conditions, PTSD, substance use and suicide attempts/ideation	Children in foster care had greater rates of sexual or physical abuse and legal problems as an offender. Children in other care arrangements had greater rates of mood disorders.	1) Adverse outcomes associated with adoptive/foster care
Chasnoff et al 2015a U.S	Case-control (Retrospective)	Assess the presence of mental health disorders in rural vs urban populations of children with PAE in the child	Neurological and dysmorphology examination, full neuropsychological assessment.	Youth from rural areas had significantly higher rates of co-occurring mental health disorders. The driving factor for increased rates was neglect (not access to services). ADHD was the most	1) Undiagnosed children in adoptive/foster care

Southern Illinois and Chicago Behavioural health clinics	Rural clinic: *n* = 95 children with confirmed PAE Urban clinic: *n* = 175 children with confirmed PAE 4 – 18 yrs	welfare system and understand the factors that may differentiate risk in the two groups.		common diagnosis for both groups. Rural children exhibited higher rates of anxiety and mood disorders.	2) Adverse outcomes associated with adoptive/foster care
Chasnoff et al 2015b U.S Illinois Children's mental health centre for high-risk children	Retrospective cohort (Nested) *n* = 547 charts reviewed *n* = 156 diagnosed with FASD 4 – 18 yrs	Assess the rate of misdiagnosis and missed diagnoses of FASD among foster and adopted youth referred to a children's mental health centre.	Neurological and dysmorphology examination, Neurodevelopmental assessment.	80.1% with FASD had never been previously diagnosed. Most common diagnosis at referral was ADHD, followed by PTSD, conduct, ODD, RAD. Majority of children once diagnosed with FASD required significant alteration of therapeutic services. Need for specialised educational services and dental care had often been overlooked.	1) Undiagnosed children in adoptive/foster care
Patel et al 2020 Canada Toronto Clinic-based	Retrospective cohort *n* = 18 (14 diagnosed with FASD) 3 – 15yrs	Describe their three-phase multidisciplinary approach to diagnosing FASD for youth in care.	Neurobehavioural Screening Tool (NST), paediatric assessment, psychiatric assessment	To address the challenge of limited access to specialist diagnostic teams, the current model of care tied together pre-existing services offered by a community welfare agency to help facilitate the process of diagnosis and treatment. 78% who screened positive on NST were diagnosed with FASD.	1) Undiagnosed children in adoptive/foster care
Rangmar et al 2016 Sweden	Retrospective cohort 51 adults with FAS (8 not placed in out-of-home care, 31	Investigate placements in out-of-home care and number of early separations from caregivers, related to	Data on education, living arrangements, criminal history collected from hospital and linked data. Current	Psychiatric disorders, medications and convictions were equally common regardless of whether they were placed in care early or late and whether they had experienced few or many early separations.	1) Adverse outcomes associated with adoptive/foster care

Gothenburg Children's Hospital	placed < 3 yrs, 9 placed > 3 yrs) 20 – 47 yrs	psychosocial outcomes in adults with FAS.	assessment of mental health.		
Richards et al 2022	Systematic review of 16 research/evaluation and 16 policy/practice papers	Search for literature that addresses child welfare information sources, policies, and practices	Articles categorized by primary tasks of child welfare agencies, improvement efforts and broader systemic issues.	Identifying children prenatally exposed to alcohol typically occurs after newborn period. High rate of children going undiagnosed in contact with child welfare but not identified by case workers meaning that these children/families are not able to receive much needed services and increased risk of maltreatment due to poor parental coping skills combined with difficult child behaviours due to prenatal brain damage. PAE does not induce vigorous response from child welfare systems compared to drug exposure. Lack of staff knowledge of importance of FASD interfered with early child identification services. Gap identified in inability to accurately assess prevalence of FASD.	1) Undiagnosed children in adoptive/foster care
Victor et al 2008 U.S Clinic-based	Retrospective cohort (Nested) *n* = 136 children who completed FASD evaluations. 6-12 yrs	Examines the relationship between out-of-home placement and neurocognitive and behavioural status.	Placement history, cognitive, academic, executive and behavioural functioning	Children placed with biological families had lower Verbal IQ Math, TOVA Commission errors and increased CBCL internalizing scores compared to children placed in foster care.	1) Adverse outcomes associated with adoptive/foster care
Feeding/Eating (*n*=6)					

Amos-Khoohs et al 2016 U.S Minnesota and Wisconsin Clinic-based	Case-control (Prospective) *n* = 155 (74 with FASD, 81 controls)	Compare eating behaviours in children with FASD to typically developing children.	BMI Eating behaviours collected via parental questionnaire.	Lower median BMI in males with FASD. BMI may increase more with age in children with FASD. Caregivers reported increased rates of concerns regarding eating behaviours compared to controls (e.g., oral aversion, food refusal, challenges with using cutlery, not feeling full or poor appetite, poor self-regulation with food)	1) General eating behaviours 2) BMI/obesity
Fuglestad et al 2013 U.S Minnesota Clinic-based	Prospective cohort (Nested) Part of a treatment study *n* = 31 children with FASD 2.5 – 4.9yrs	Evaluate the dietary intake of a representative sample of children with FASD in the age range where supplementation might be beneficial in order to determine the adequacy of intake of nutrients critical to brain development.	Dietary intake data collected three times during nine months via interview administered 24hr recall	Although children with FASD had similar caloric intakes to population data, they had lower saturated fats, vitamin D and calcium – indicating likely lower dairy product consumption. Children with FASD did not meet recommended intakes for several nutrients. Most did not meet requirements for fibre, n-3 fatty acids, vitamin K, choline, Vitamin D, E or calcium.	1) Nutrient intake/dietary interventions
Fuglestad et al 2014 U.S Minnesota Clinic-based	Retrospective cohort *n* = 616 (445 FASD, 171 no FASD diagnosis) 2 – 19yrs	Determine the prevalence of overweight and obesity in a large sample of children and adolescents with FASD and identify characteristics of individuals with FASD who are overweight or obese.	BMI Dietary intake collected 3 times across 9-months via parent interview using 24hr recall.	34% were either overweight (18%) or obese (16%) and 7% were underweight. There was no difference between overweight/obesity and national data. Overweight/obese children had higher intakes of most macronutrients than non-overweight children. The highest prevalence of overweight/obesity was in pFAS and lowest was in FAS. Underweight most prevalent in those with FAS.	1) BMI/obesity
Hayes et al 2021 Australia	Prospective cohort (Nested)	Examine association between heavy PAE and	BMI z-scores Waist-to-height ratios	Female adolescents with heavy PAE during late pregnancy had significantly higher BMI z-scores (M = 0.75) and	1) BMI/obesity

Population-based	*n* = 828 adolescents aged 12-13 years (782 controls with no PAE; 46 with heavy PAE [defined as ≥70g per week]; matched on sex, ethnicity and socio-economic position)	indirect measures of adiposity in adolescence.	Proportion overweight/obese	were more likely to be overweight/obese (38.5%) than female adolescents without any PAE (M = 0.29 and 23.8%). No differences in female waist-to-height ratios. No differences in BMI, waist-to-height ratio and overweight/obesity for male adolescents with heavy PAE.	
Nguyen et al 2016 U.S San Diego and Toledo Clinic-based	Prospective cohort FASD *n* = 55 (6 FAS, 31 FASD, confirmed heavy PAE 18) Comparison *n* = 1,047 5 – 10yrs	Assess dietary intake among school-aged children with FASD	Automated self-administered 24hr dietary recall (web-based)	FASD group consumed sig. lower levels of protein, Ω-3 fatty acids, magnesium, potassium, zinc, Vitamin B6, Vitamin C, Vitamin K, niacin, and choline. FASD group did not meet dietary recommendations for fibre, potassium, vitamins E, K, Ω-3 fatty acids, and choline. Calcium intake was sig. lower in 9-10-year-olds (not 5- to 8yrs). FASD group consumed less nutrient dense foods than typically developing group.	1) General eating behaviours 2) Nutrient intake/dietary interventions
Werts et al 2014 U.S Wisconsin Clinic-based	Prospective cohort *n* = 19 (2 FAS, 4 pFAS, 9 ARND, 1 possible ARND, 3 suspected FASD)	Assess the relationship between PAE and eating behaviours, and nutritional status.	BMI Dietary Behaviours Questionnaire - caregiver report 24hr diet recall Nutritional interview by a dietitian. Nutritional adequacy: assessed by comparing average intake of selected nutrients in study population to the	31.6% picky eaters/poor appetites, 36.8% constant snacking, 26.3% never seems full or satisfied. 64% did not consume recommended intake of dietary fibre, >50% of children obtained 25% of their total calories as simple sugars and exceeded recommendations, 50% did not consume sufficient Ω-6 fatty acid, 71% did not consume sufficient Ω-3 fatty acid, sodium intake was excessive in 85.7% of the participants. Low micronutrient intake: Vitamin D (100%); Vitamin E (85.7%);	1) General eating behaviours 2) Nutrient intake/dietary interventions 3) BMI/obesity

			general U.S. population (same age groups)	Vitamin K (57.1%); Potassium (85.7%); Choline (71.4%); B-carotene (64.3%)	
Strengths/interests/external resources (*n*=5)					
Flannigan et al 2021b	Systematic review with narrative synthesis 19 studies	Understand state of strengths-based research related to individuals with FASD across the lifespan and describe positive characteristics, talents, and abilities of individuals with FASD that may be cultivated to promote fulfillment and well-being. Also determine how this can be integrated into research, practice and policy to advance the field of FASD.	Targeted studies that identified positive characteristics, talents, or abilities that my contribute to, and be cultivated to promote fulfillment and well-being for individuals with FASD.	Intrinsic strengths of individuals with FASD include – strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges and hope for future.	1) Strengths
Hamilton et al 2020b* Australia Western Australia Juvenile Justice	Qualitative study using a yarning approach Detained youth *n*=38 (27 Aboriginal, 11 non-Aboriginal Australians) 24% had FASD, 34% had some severe neurodevelopmental impairment, 42% no diagnosis.	To engage with the hopes, relationships and educational experiences of a group of detained youth who had participated in a study for screening and diagnosis of FASD.	Yarning using thematic analysis, through the lens of the Recovery Capital model (i.e., personal, social and community recovery)	Young people described strong connections to country and community and had hopes for future education experiences and pro-social community activities in their future goals. Aboriginal voices shared factors important to them – some of which were similar to non-Aboriginal but many of which were different. Those with and without FASD overwhelmingly found happiness in their family. Aboriginal participants also found hope and happiness in cultural activities. Many with and without FASD saw education or taking up a trade as a	1) Strengths 2) Interests 3) External resources 4) Connection to culture

				support for not getting into trouble in the future. Most Aboriginal participants from remote and regional WA wanted to join an Indigenous rangers program, be a station hand, or be involved at some level in community programmes and looking after country.	
Kautz-Turnball et al 2022 U.S Recruited as part of a small-scale pilot randomized control trial of multicomponent intervention trial	Mixed-methods approach 30 caregivers of children with FASD or PAE (mean age 6.5yrs)	Characterise adoptive and relative caregivers' perceptions of strengths and positive influences of young children with FASD	Strengths and positive influence interview, Eyberg Child Behaviour Inventory (ECBI), Parenting Sense of Competence (PSOC), Parenting Stress Index, Fourth Edition, Short Form (PSI-4-SF), Emotion Regulation Checklist (ERC)	Strengths fell into four categories: Social motivation Positive effort/persistence Individual aptitudes and skills Positive mood states and personality characteristics Positive influence fell into five categories: i) Tangibly contributed to the family ii) Parental growth iii) Social/family togetherness iv) Emotional contribution v) Repeat of strengths without connection to broader family Positive correlation between adaptive strengths and child and caregiver function in medium to large range, strengths and positivity scale not significantly related to any of the child and caregiver functioning variables	1) Strengths 2) Interests 3) External resources
Pei et al 2016* Canada	Qualitative study *n* = 21 (9 people with FASD and 12 justice professionals)	Gain a deeper understanding of the experiences within the criminal justice system for people with FASD.	Semi-structured interviews and thematic analysis.	Key theme identified: Strengthened to move beyond the system – which included personal strengths of hope, willingness to change and resilience.	1) Strengths

Skorka et al 2021 Australia Neurodevelopmental assessment clinic and Australian FASD support organisations	Qualitative study 4 adolescents (1 non-binary, 1 male and 2 females) 13-15yrs	Explore lived experiences of adolescents with FASD to understand: i) The ways in which their challenges influence daily functioning and; ii) The personal assets and external resources that facilitate participation	Photo elicitation and semi-structured interviews. Adolescents took photographs of their daily activities and environments, photographs used to generate discussion during interviews, data analysis involved interpretative phenomenological analysis to generate themes	Themes that emerged from interview related to participants' lived experiences: i) Anxiety challenges participation (subthemes - i) need for external support, ii) power of positive relationships, and iii) talents and interests facilitate participation) ii) Importance of unique identity Incorporation of strengths into daily activities reduced anxiety and improved participation, adolescents desired unique characteristics to be recognized and appreciated.	1) Strengths 2) Interests 3) External resources
Incontinence (*n*=3)					
Reid et al 2021a* International sample	Prospective cohort *n* =197 caregivers of children with FASD Median age 11 years (11-25 years)	Compare rates of health conditions in children with FASD to prevalence data in the general population.	Health and demographic data	Caregivers reported high rates of urinary incontinence (32%) and this was higher than available national prevalence comparisons.	1) Urinary incontinence
Roozen et al 2017 South Africa Random selection from a prevalence study	Prospective cohort *n* = 99 children with FASD. 6 – 10 years	Investigate the possible presence of incontinence among children with FASD	Caregiver questionnaires assessing enuresis, encopresis and lower urinary tract symptoms	Overall incontinence rate of 20.2% was reported. The most common sub-type was nocturnal enuresis (16.2%)	1) Urinary incontinence 2) Nocturnal enuresis

Roozen et al 2020 Poland Krakow Outpatient and inpatient centre at St Louis Children's Hospital	Case-control (Prospective) *n* = 119 (24 FAS, 19 pFAS, 28 ARND, 34 undergoing therapy for pollen allergy, 14 celiac disease – both control groups) 8.3-11.1 years	Investigate incontinence among people with FASD.	Caregiver questionnaires assessing enuresis/urinary incontinence, encopresis and lower urinary tract symptoms	Overall incontinence rate estimated to be 24%. Fecal incontinence was the most common (12.7%), followed by daytime urinary incontinence (11.3%) and nocturnal enuresis (9.9%). Highest rates were observed in pFAS and ARND.	1) Urinary incontinence 2) Fecal incontinence 3) Nocturnal enuresis