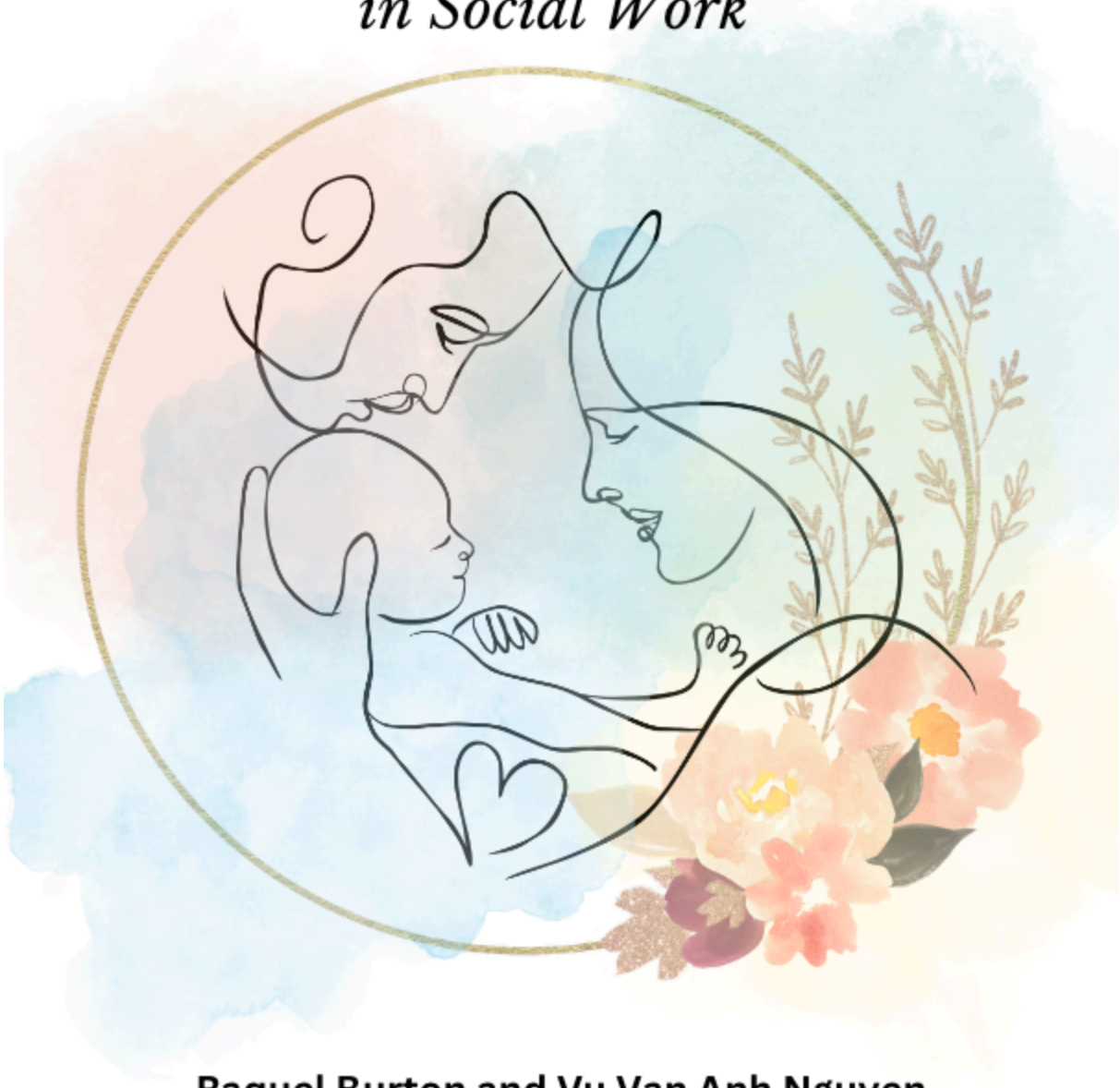
Raising Awareness of Fetal Alcohol Spectrum Disorder in Social Work



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2024

SANDAS South Australian Network of Drug & Alcohol Services

University of South Australia

Acknowledgement of country

The South Australian Network of Drugs and Alcohol Services (SANDAS) and The University of South Australia (UniSA) Community Outreach Centre (COC) acknowledge this land that we meet on today is the traditional lands of the Kaurna people and that we respect their spiritual relationship with their country. We also acknowledge the Kaurna people as the custodians of the Adelaide region and that their cultural and heritage beliefs are still as important to the living Kaurna people today. We acknowledge that Aboriginal peoples have endured past injustice and dispossession of their traditional lands and waters. We also pay respects to the cultural authority of Aboriginal people visiting/attending from other areas of South Australia/Australia. This is, was and always will be Aboriginal Land.

Artist: Philip (Phil) Allen

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About the team

Our research officially began on August 5th, 2024, and was completed on December 18th, 2024. This project was conducted and written by UniSA Social Work students - Raquel Burton and Vu Van Anh Nguyen, both of whom were contributing to this project as part of their social work student placement at UniSA COC. Each member has brought unique skills and perspectives to the table, and their seamless efforts and collaboration have been instrumental in making this project successful.

About SANDAS

SANDAS, established in 2004, aims to reduce harm from Alcohol and Other Drug (AOD) use in South Australia (SA) by supporting the community sector through advocacy, workforce development, and continuous improvement. As a leading non-profit, SANDAS provides statewide representation, networking, and policy support to non-government AOD services. SANDAS is funded by The Australian Government Department of Health, Drug and Alcohol Services SA, and project-based funding.

Executive summary

Fetal Alcohol Spectrum Disorder (FASD) refers to a range of physical and cognitive impairments caused by Prenatal Alcohol Exposure (PAE). It is a lifelong condition that affects motor skills, learning, memory, attention, communication, emotional regulation, and social skills. The severity of FASD varies based on factors like alcohol use, the mother's health, and environmental influences (NOFASD, 2020). FASD in Australia is thoroughly examined in this research, with a focus on the disorder's prevalence, difficulties, and profound effects on individuals, families, and communities. The report covers many facets of FASD, including its diagnosis, the strain it places on parents and caregivers, and the structural and social elements that contribute to its enduring nature. This paper highlights the challenges in diagnosing FASD, due to its overlap with other neurodevelopmental disorders, as well as the developmental difficulties faced by children and the social, emotional, and financial stressors experienced by parents and caregivers. Despite national guidelines and public health campaigns recommending abstinence from alcohol during pregnancy, significant gaps remain in knowledge, early intervention, and access to essential resources and support systems.

Research rationale

Despite the high prevalence of FASD and its socioeconomic burden, education and training for health professionals—especially social workers who are at the forefront of interacting with individuals affected by FASD—are limited. This lack of training results in a significant gap in professional knowledge, further exacerbating the challenges faced by individuals with FASD and their caregivers. This report aims to address this gap by providing social workers and other health professionals with insights into current patterns of alcohol consumption in Australia, the interplay of social and contextual factors that influence individuals' drinking choices, the responses of federal and state governments to FASD, and the systemic issues that perpetuate the difficulties faced by individuals and families affected by FASD.

Purpose/aim

This report is directed towards social workers and other health professionals who are interested in learning more about FASD. The purpose of this report is to provide a deeper understanding of FASD, offering valuable insights into the challenges and realities of individuals who have been diagnosed with FASD and the families affected by FASD. By exploring the medical, social, and emotional aspects of FASD, this report aims to provide health professionals with comprehensive knowledge about the causes, symptoms, and long-term impacts of PAE and FASD. Additionally, it seeks to highlight the experiences of parents and caregivers, shedding light on the unique struggles they encounter in navigating support systems, accessing resources, and advocating for their children. The report aims to foster greater awareness, empathy, and informed action within the community and among policymakers, contributing to more effective strategies for prevention, intervention, and support.

Methodology

This report provides a comprehensive literature review of FASD, with a focus on the challenges faced by individuals with the condition and the parents and caregivers who support them. The methodology includes a two-phase approach. The first phase involves a review of existing literature and data to explore the prevalence of FASD, the socioeconomic impacts, and the pathophysiology of the disorder. This phase also considers the social drivers of alcohol consumption and its correlation with FASD, as well as key systemic issues pertaining to the challenges faced by individuals and families affected by FASD. References for this phase included peer-reviewed journal articles, government reports, and research reports from non-profit organisations such as The National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia. The reviewed articles were sourced from search databases such as the UniSA Library and Google Scholar.

The second phase critically evaluates the current policies, legislation, and support services available to parents of children with FASD, as well as advocacy efforts in this space. This phase focuses on the effectiveness of national and local strategies, such as public health campaigns and specific interventions aimed at supporting individuals and families living with FASD. Documents reviewed in this phase included policy papers, government documents, and reports from organisations that provide direct services and support to those affected by FASD. In addition to the review of data, the report incorporates insights from various advocacy groups, focusing on their role in supporting individuals with FASD and the challenges they face. The evaluation of policies and interventions aims to highlight both the strengths and limitations of current strategies, ultimately offering recommendations to improve awareness, support, and prevention efforts for FASD across Australia.

Research findings

Our findings highlight a significant need for more comprehensive information and resources to assist parents raising children with FASD. Many parents face considerable challenges, including understanding the condition, navigating support systems, and addressing their child's unique developmental, behavioural, and emotional needs. These challenges often leave families feeling isolated and underprepared. Enhanced support, with better access to services, can empower parents to manage these complexities more effectively and improve outcomes for their children. To meet the requirements of children with FASD by supporting the family, the report emphasises the significance of a multidisciplinary approach involving medical specialists such as, a General Practitioner (GP), occupational therapist, physiotherapist, speech therapist, psychologist, and paediatrician. Better regulations and programs are recommended, including increased access to healthcare, and specialised support services. The main goals of the recommendations are to strengthen the social and healthcare systems, raise public awareness, and improve preventative education. Australia can lower FASD's prevalence and long-term effects by strengthening early diagnosis and intervention, empowering families, and tackling larger socioeconomic causes.

Introduction to FASD in Australia

FASD is a neurodevelopmental disorder describing a wide range of symptoms, including prenatal or postnatal growth restrictions, congenital anomalies, characteristic dysmorphic facial features, and deficits in cognitive, behavioural, emotional, and adaptive functioning (Rahman et al., 2023). The varying individual capacities and challenges associated with FASD, distinguishes children and adults with FASD from others with special needs, such as those with disabilities, severe behavioural problems, and serious medical conditions (Brown et al., 2007; Mukherjee et al., 2013). FASD, a result of PAE, occurs when alcohol consumed during pregnancy affects the developing fetus, leading to a range of physical, cognitive, and behavioral challenges.

Alcohol, a teratogenic substance, can cause developmental abnormalities in the fetus's brain and body, resulting in lifelong impairments (Uban et al., 2010). Subsequently, individuals affected by FASD face a higher risk of secondary conditions, including mental health issues, substance use, poor health, and involvement with the criminal justice system (Streissguth et al., 2004). Previous research indicates that alcohol entering the mother’s system can diffuse through the placenta and reach the fetus, resulting in the fetus receiving the same level of alcohol exposure as the mother (McBride, 2014; see Appendix A). PAE poses significant direct and indirect (maternal mediated) detrimental to the developing fetus as the fetal liver is not fully developed and cannot metabolise alcohol as effectively as an adult (Chung et al., 2021; Uban et al., 2010). The timing and duration of alcohol exposure are critical factors influencing the severity of FASD outcomes. If alcohol is consumed during the first trimester, specifically the first 13 weeks, the child is 12 times more likely to be affected by FASD, with major impacts on the brain, spinal cord, heart, and facial features. The risk escalates dramatically if alcohol is consumed during both the first and second trimesters, with a staggering 61 times increased likelihood of FASD, affecting the brain, spinal cord, and immune system. Additionally, if alcohol is consumed throughout all three trimesters, the risk increases to 65 times, leading to serious effects on the brain, spinal cord, and bones (May et al., 2013). To predict PAE it is critical to understand alcohol use patterns among women, as it occurs in an estimated 10% of all pregnancies globally. Among

these patterns, binge drinking during pregnancy stands one of the most detrimental, posing the highest risk of fetal harm. Although binge drinking is deemed to be the most dangerous pattern, potential risks linked with low to moderate levels of alcohol consumption cannot be underestimated.

Reid (2018) explains that Fetal Alcohol Syndrome (FAS) and FASD are terms used to describe effects of PAE. FAS, introduced in 1973 by Drs. Smith and Jones, refers to a specific set of symptoms including distinct facial features (e.g. small eye openings, a thin upper lip, and a smooth area between the nose and mouth), growth restrictions, and severe developmental issues. It is important to note that although some individuals with FASD have sentinel facial features, most do not. As a result, FASD often goes undetected, and is sometimes referred to as a 'hidden disability' (NOFASD, 2024). The term FAS or FASD was adopted by the Australian guide to the diagnosis of FASD in 2016 to recognise the overarching array of complications associated with alcohol exposure, not just being limited to facial features of FAS (Bower et al., 2017; see Appendix B). Thus, FASD is a broader term that covers a range of other conditions caused by PAE. This includes partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorders (ARND). This change helps provide a more comprehensive understanding and diagnosis by covering a broad spectrum of symptoms manifestation in individuals with FASD, allowing for better-targeted interventions and support.

Alcohol-related harm and FASD

Alcohol-related harm during pregnancy, specifically ARBD and FASD, is a significant public health concern in Australia. Recent statistics indicate that FASD affects approximately 1 in 20 Australian children, underscoring the need for heightened awareness and prevention strategies (NOFASD, 2020c). This highlights the importance of addressing alcohol consumption during pregnancy. The Australian Institute of Health and Welfare (AIHW) provides data indicating that many women continue to consume alcohol during pregnancy, despite public health campaigns and the National Health and Medical Research Council (NHMRC) recommends that no alcohol level is safe during

pregnancy (Stanesby et al., 2018). The link between alcohol consumption and FASD is crucial: Alcohol consumption increases the risk of FASD, and awareness campaigns aim to reduce alcohol use among pregnant women to mitigate these risks. Continued education and support for pregnant women and family are essential in preventing FASD and ensuring healthier outcomes for children.

Prevalence of FASD

Figure 1 highlights the prevalence of FASD among children, indicating that FASD affects more children than several well-known conditions, including Autism Spectrum Disorder (ASD), Cerebral Palsy, Down Syndrome, Spina Bifida, and Sudden Infant Death Syndrome (SIDS) combined. This finding underscores the urgent need for increased awareness, prevention strategies, and support systems for affected families, as FASD is often overlooked in discussions about childhood health despite its significant impact on cognitive and behavioural development. Addressing this issue is essential to improve outcomes for children and their parents and families and reduce the long-term societal costs associated with these disorders.

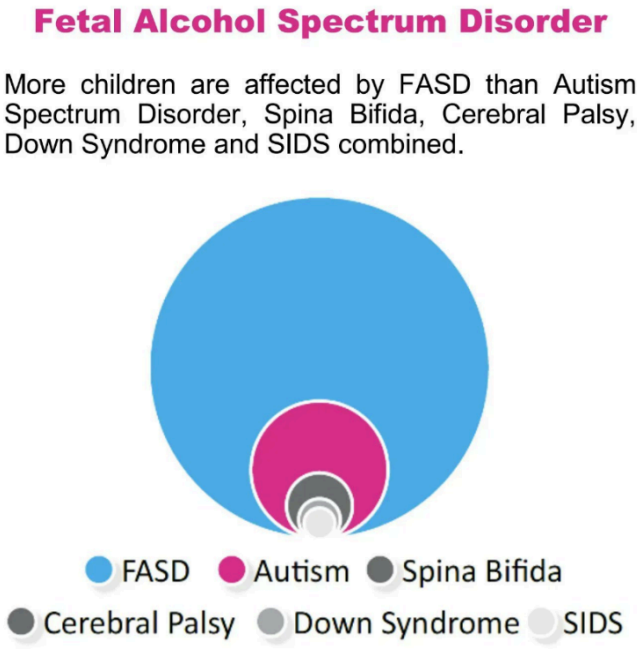

Figure 1: More children are affected by FASD than ASD, Spina Bifida, Cerebral Palsy, Down Syndrome and SIDS combined *(*NOFASD, 2020b*).*

Women living in remote (4.3%) or very remote (7.2%) areas, as well as teenage mothers under 20 (4.7%), were more likely to report consuming alcohol during the first 20 weeks of pregnancy. Factors contributing to this include delayed recognition of pregnancy and limited access to health services such as chemists, doctors, nurses, and health workers for early testing. Some women may unknowingly consume alcohol before realising they are pregnant but often stop once aware. According to the National Drug Strategy Household Survey 2022–2023, two-thirds of women (64%) who were unknowingly pregnant in the past year reported drinking alcohol before knowing, but this figure dropped significantly to 15% after they became aware of their pregnancy (AIHW, 2022; AIHW, 2024a). Compared to regional and remote areas, major cities exhibit a higher rate of alcohol consumption during pregnancy at 38%, compared to 24% in remote regions (AIHW, 2022). Research by Stanesby et al. (2018) suggests that highly educated and high socioeconomic status (SES) women are more likely to drink while pregnant, as shown in Figure 2. Although it does not directly indicate FASD prevalence, this data implies that FASD affects families across all education and SES levels, not exclusively those with lower education and SES, and those residing in remote areas. It is also worth noticing that people with higher SES, despite consuming similar or greater amounts of alcohol to those with lower SES, the latter group often experience stigma associated with their lower SES status (Potter et al., 2019).

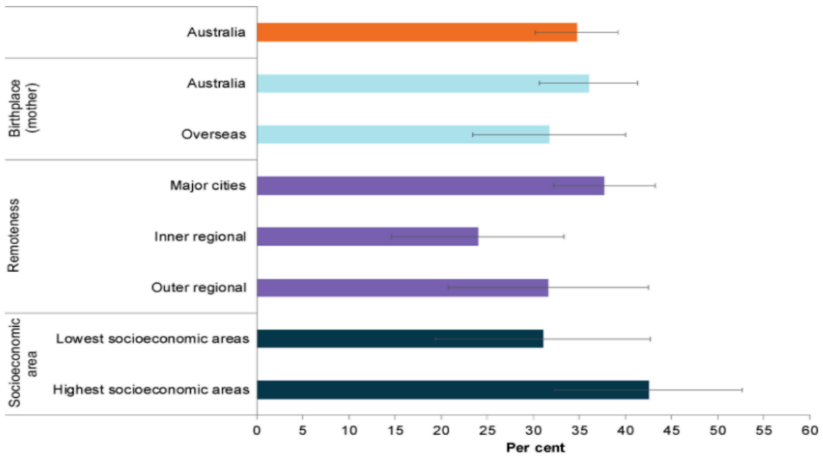

Figure 2: Drinking patterns in pregnancy associated with remoteness and socioeconomic status in the general Australian population in 2016 (AIHW, 2022).

A prevalence study of children living in remote Australia (*N*=108) found that 13 children were diagnosed with either FASD or pFAS, resulting in a prevalence rate of 120 per 1000 children. These children are less likely to access comprehensive support and interventions due to the challenges of remote living (Fitzpatrick et al., 2015). In a subsequent study among First Nations communities in remote Western Australia (WA; *N*=108), Fitzpatrick et al. (2017) reported that 34 children (314.8 per 1000) met the criteria for neurodevelopmental disorders, with 21 children (194.4 per 1000) specifically diagnosed with FASD. More recently, a study conducted in youth detention centers in WA (*N*=99) revealed that over a third (36%) of the young people were diagnosed with FASD (Bower et al., 2018). However, the above findings may still underestimate FASD prevalence due to researchers unable to measure all key domains required for FASD diagnosis such as affect regulation, adaptive functioning/social skills/social communication, and identify PAE (Curtis et al., 2022). It is also important to note that these are small studies within specific groups and may not be generalisable across the general population.

Figure 3 highlights a trend between 2013-2016 showing a decrease in alcohol consumption after women learned of their pregnancies, indicating that increased awareness may lead to behavioural changes. Additionally, it provides insight into how public health messaging and education may have influenced drinking patterns and behaviours over the years. By analysing these communications, we can understand how they have influenced public perceptions of alcohol consumption, promoted healthier drinking habits, and addressed the risks associated with excessive drinking. Over time, evolving strategies—such as warnings about the dangers of alcohol, targeted campaigns, and educational programs—have contributed to shifting societal norms and attitudes toward drinking. This in turn has affected individuals' choices, awareness of alcohol-related harms, and the overall prevalence of drinking in various demographic groups. As it is now 2024, we unfortunately lack recent data to assess any further changes beyond 2016 (AIHW, 2022).

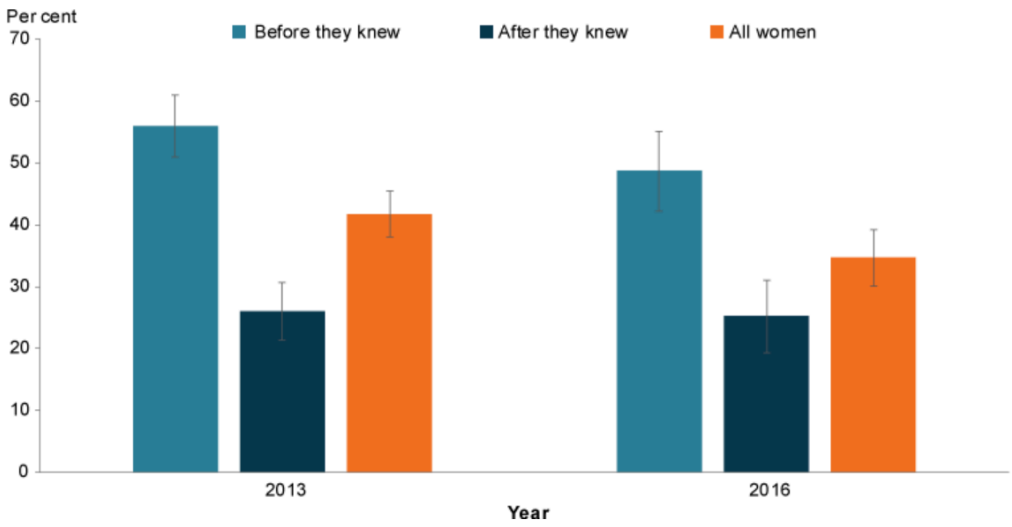

Chart: AIHW. *Source:* NDSHS.

Figure 3: Drinking patterns of women aged 14–49 before and after they became aware of their pregnancies, comparing data from 2013 and 2016 (AIHW, 2022).

Social drivers of drinking

Alcohol is a significant element in Australian culture, intertwined with various social and cultural activities (AIHW, 2022). The Australian drinking culture encompasses a range of activities and social norms related to drinking behaviours and patterns observed across the country (Savic et al., 2016). When alcohol is a regular component of social interactions or cultural expression, alcohol-related risks are often overlooked (Sudhinaraset et al., 2016). For pregnant women, conflicting social norms between drinking culture and traditional motherhood roles can make it challenging for them to decide whether to continue or abstain from alcohol use (Laborde & Mair, 2012; Meurk et al., 2014). Furthermore, some women do not consider moderate or occasional drinking as harmful to the developing fetus, but heavy drinking is widely recognised as detrimental (Holland et al., 2015). Recognising these factors is crucial for developing effective education and prevention strategies to promote healthier behaviours and protect at-risk groups. To effectively reduce the risks of FASD occurring, it is important to understand that Australia's drinking culture is multi-dimensional and continuously shifting, creating a dynamic landscape of drinking patterns.

Presumptions and misconceptions amongst medical and other health professionals

Research indicates that health practitioners often assume pregnant women are aware of and actively avoiding alcohol consumption during pregnancy. This presumption may result in a lack of direct inquiry or thorough discussion about their alcohol use, potentially overlooking instances where women continue to consume alcohol (Elek et al., 2013; Crawford-Williams et al., 2015). The NHMRC guidelines recommend abstaining from alcohol, making it clear that ‘no amount of alcohol is considered safe during pregnancy’ due to the uncertainty and lack of evidence-based research surrounding the impacts of low-to-moderate alcohol consumption on pregnancy (NHMRC, 2020). Doctors, midwives, peer groups, and partners play significant roles in influencing a woman's decisions regarding alcohol consumption during pregnancy by offering reassurance and reinforcing behaviours (Holland et al., 2015). Research indicates that while midwives often feel comfortable discussing alcohol consumption with their clients (Muerk et al., 2014), they often receive limited education and training about the harms associated with alcohol use during pregnancy (Jones et al., 2012).

Family and peer pressure

The fear of losing social connections can make it difficult for individuals to maintain their commitment to abstain from alcohol (Popova et al., 2022). This issue is compounded when family, friends, or partners encourage alcohol consumption, creating a more conflicting environment for pregnant women. This is a significant research gap and is something that should be rectified. Studies also show that contextual and structural factors impacting pregnant women, including SES, histories of trauma and violence, and involvement in child welfare, play a role in alcohol use during pregnancy (Hubberstey et al., 2019). Other risk factors include limited access to antenatal care, pre-pregnancy drinking patterns, or history of mental health issues or substance use disorders (Popova et al., 2022).

Diagnosing FASD

According to Astley (2011), diagnosing FASD can be complex due to the disorder's invisible nature and its overlap with other neurodevelopmental conditions. Diagnosis can only be given from a multidisciplinary team that involves evaluating multiple factors. This team typically involves a GP, occupational therapist, physiotherapist, speech therapist, psychologist, and paediatrician, each bringing their specialised expertise to the assessment.

The diagnosis primarily links to understanding the specifics of PAE, including the timing, the amount consumed, and the duration of use. These details are crucial, as they directly influence the severity and range of potential impairments in the child. The assessment process itself involves three critical components. The first is confirming that alcohol was consumed during pregnancy. This can be challenging, as it often relies on self-reported information or medical records. The second component is the identification of neurodevelopmental impairments such as cognition, language, and social skills. These impairments can lead to misdiagnoses or co-diagnoses with disorders like ASD, Attention-Deficit/Hyperactivity Disorder (ADHD), Reactive Attachment Disorder (RAD), Conduct Disorder (CD), and Oppositional Defiant Disorder (ODD). These may present in various forms, including difficulties with language and speech, memory deficits, lower Intelligence Quotient (IQ), and challenges in social skills. These impairments can significantly impact the child's ability to function in daily life and often require targeted interventions. The third component involves identifying physical features associated with FASD. These can include defects such as heart or skeletal abnormalities, as well as kidney problems. The presence of these physical signs, combined with neurodevelopmental impairments and confirmed PAE, strengthens the diagnosis of FASD. If FASD is suspected, it is crucial to consult with a doctor or healthcare professional immediately as early diagnosis and treatment may help mitigate some of the issues.

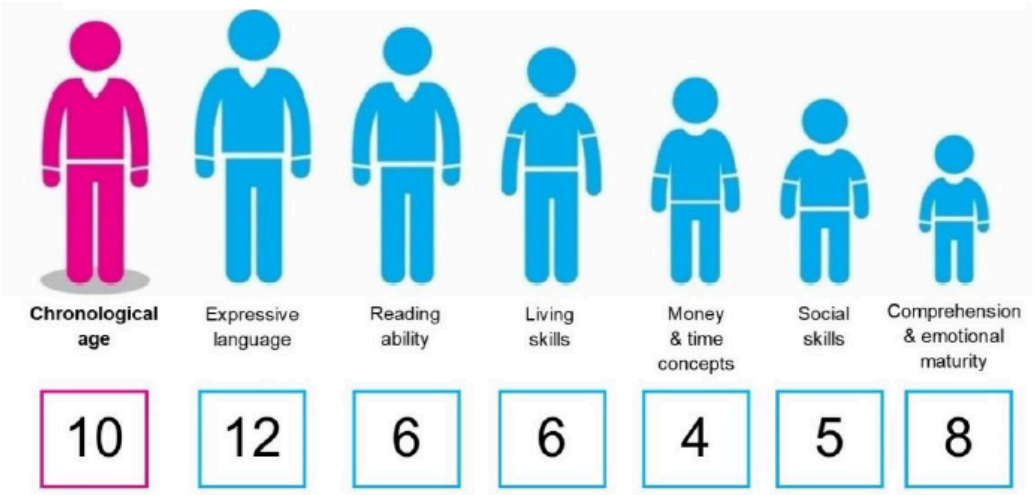

***Figure 4**:* An example of developmental dysmaturity for a child with FASD (NOFASD, 2020b).

When a diagnosis of FASD is considered the team evaluates the young person in regards to age dysmaturity. Age dysmaturity refers to the developmental gap that can exist between a child's chronological age and their functional or emotional maturity. Children with FASD may exhibit behaviours and skills that align more closely with those of younger children, despite being older. This mismatch can create significant challenges in social interactions, academic performance, and daily living skills, as their developmental milestones may not coincide with those of their peers. For instance, a 10-year-old with FASD might demonstrate their expressive language as a 12-year-old, but their living skills may be as a 6-year-old. Recognising age dysmaturity is crucial for parents, educators, and healthcare professionals as it underscores the need for support and interventions that reflect the child's actual developmental level rather than their chronological age. This understanding can lead to more effective communication, realistic expectations, and compassionate guidance, enhancing the outcomes for children with FASD as they navigate their growth and development (NOFASD, 2020b).

Identifying systemic issues

Transitioning into motherhood

Pregnancy is a transformative period that impacts women's identities, daily routines, responsibilities, and relationships (Hubberstey et al., 2019; Milligan et al., 2017). While this may result in decreased alcohol consumption (Gomez et al., 2022), some women continue to drink after pregnancy (AIHW, 2022). This decision is often influenced by an interplay of factors, including cultural norms and social pressures that may obscure the clear guidelines provided by health authorities. Pregnancy can be a time of significant stress for many women, which is exacerbated among First Nations women, women of colour, and women of lower SES due to heightened scrutiny, stigma, and intergenerational trauma (Wolfson et al., 2019). Stressors might include financial difficulties, relationship problems, work-related pressures, or lack of social support (Mckinlay, 1996). Pregnant women who lack a supportive network may experience heightened feelings of isolation and helplessness. Without adequate support, the temptation to use alcohol as a form of escapism, self-medication, and coping mechanisms can increase (Orr, 2004). Consequently, some women may continue drinking as they navigate the shift into motherhood, viewing it as a familiar activity that aligns with their positive, feminine identity (Killingsworth, 2006) and serves as a coping mechanism for isolation and stress (Elek et al., 2013; Gomez et al., 2022).

In situations like Alcohol Dependence (AD) and depression, women may resort to drinking as a form of self-medication (Brown & Stewart, 2008). Many individuals believe that alcohol provides temporary relief from mental health symptoms, but it can worsen these issues over time. The link between mental health and substance use is significant - individuals may turn to alcohol to cope with anxiety and depression, creating a relationship where one condition exacerbates the other. For some, the prospect of seeking help for mental health concerns during pregnancy can feel overwhelming, often compounded by community-wide barriers to accessing mental health services. Additionally, physical health is at risk; alcohol can disrupt sleep, which may exacerbate mental health symptoms, poor nutrition and lack of exercise further contribute to declining overall health.

Parental bonding and the impact of PAE on child development

The bond between a parent and child plays a fundamental role in healthy development as love and affection is key to fostering optimal brain growth, self-confidence, and the capacity to establish and sustain meaningful relationships throughout life (Thompson, 2001). Children thrive in environments where they feel safe, valued, and nurtured, however, the ability to build a secure attachment can be more challenging for parents who may not have experienced a protective or validating upbringing themselves. Parental responsiveness - actively noticing and addressing a child's needs - promotes a sense of security and understanding. This feeling of safety enhances neuroplasticity - the brain's capacity to form and reorganise synaptic connections in response to learning, experiences, or injury. A nurturing home environment filled with love prepares children to navigate the complexities of the broader world. For children with FASD, securing emotional bonds with parents and caregivers are especially critical as these children face unique challenges related to brain development and emotional regulation. Consistent love, understanding, and responsiveness from caregivers can create a sense of safety, mitigating some of these difficulties. Such an environment supports their capacity to learn, adapt, and build self-confidence, laying a foundation for resilience that extends throughout life (Heindel et al., 2015).

These findings highlight the critical importance of abstaining from alcohol during pregnancy to safeguard fetal health and development. Comprehensive education and support initiatives targeting expectant mothers are vital for raising awareness about the risks of AOD use. Such interventions aim to reduce alcohol consumption during pregnancy and protect the well-being of future generations.

Challenges faced by parents

Parents of children with FASD encounter numerous challenges. Firstly, obtaining an accurate diagnosis is often difficult due to a lack of awareness from medical professionals and documentation of PAE (Benz et al., 2009). Additionally, parents face insufficient support from services due to professionals having inadequate training, not knowing the symptoms or process of FASD diagnosis. In some cases viewers believe

that behavioural problems in children are due to poor parenting, creating unnecessary stigma (Dempster et al., 2013). Additionally, FASD's neurodevelopmental nature may be overlooked, focusing solely on behaviour and neglecting cognitive needs. Peadon & Elliott (2010) suggests that individuals mistakenly believe individuals with FASD can 'grow out' of the condition, leading to insufficient long-term support. Misunderstanding FASD can lead to the neglect of co-occurring mental health issues, while the strengths of individuals with FASD are often underestimated or overlooked. For children with FASD, daily life can be especially challenging as they may require assistance with fine motor skills, sensory processing, and maintaining routines, all of which can create additional barriers to their development and independence.

A particularly critical issue is the services that cater to children with FASD stop once they approach the age of 18, many services they rely on for support during childhood, such as therapy or behavioural programs, are no longer available. This transition can be overwhelming and disruptive, as adult services are frequently limited or difficult to access (Flannigan et al., 2022). This can be seen as a critical issue because it often leads to gaps in support during a time when individuals with FASD face even more significant challenges, such as navigating employment, independent living, and maintaining mental health. Without the proper care and resources, individuals with FASD may experience increased vulnerability, social isolation, and worsening mental health or behavioural issues. Therefore, addressing the need for ongoing, accessible support throughout the lifespan is crucial to ensuring that individuals with FASD can lead fulfilling and independent lives.

Impact on family dynamics

Skorka et al. (2020), discusses the effects of FASD and the impact within family dynamics. They identify four key themes: self-care functioning, caregiver roles, caregiver physical and emotional health, and family dynamics. Caregivers often face significant challenges when managing the child's complex needs, which can lead to heightened stress and emotional strain when combined. This can hinder their ability to provide effective care and prioritise their own wellbeing. Additionally, sleep disturbances

in these children can disrupt caregivers' sleep patterns, further affecting their health. The difficulties faced by children with FASD can also put a strain on family relationships - constant supervision of the child impacting both immediate and extended family members, which may lead to social isolation and, in some cases, marital breakdowns. Furthermore, families may abstain from community activities due to their children's difficulties with social expectations and rule-following, leading to a loss of leisure opportunities.

Skorka et al. (2020) also emphasises the urgent need for better support systems. Some schools may offer Individual Learning Plans (ILPs), and some Non-Government Organisations (NGOs) provide diagnostic services, parent education, and workshops. However, access to these supports is inconsistent, particularly in rural and remote areas, where services and trained professionals are limited. Improving accessibility and expanding family counselling and peer support networks are vital steps toward creating a more equitable system of care. This includes increasing funding for diagnostic services, ensuring consistent access to ILPs across all schools, and training more professionals to work in underserved regions. Additionally, raising community awareness and fostering collaboration between government agencies, schools, and NGOs can help build a more comprehensive and reliable support network for families impacted by FASD.

Financial impacts on families

Families caring for children with disabilities, particularly those with severe disabilities, face substantial economic burdens, including non-reimbursed expenses for disability-related support, which can push them toward poverty. This financial strain is exacerbated by the impact on employment, as parents often need to take extended time off work, reduce their hours, or decline overtime to care for their child, leading to lower family incomes (Anderson et al., 2007). The National Disability Insurance Scheme (NDIS) is an option available that aims to alleviate some of these financial pressures by providing funding for various supports and services. However, navigating the NDIS can be complex and time-consuming, often requiring families to invest significant efforts to

understand their entitlements and access appropriate resources (Anderson et al., 2007). To qualify for support from the NDIS, individuals must have a ‘permanent and significant disability’ that requires ongoing assistance with everyday tasks. Children under the age of 7 with FASD are automatically eligible for NDIS funding. However, individuals over the age of 7 must provide evidence of severe functional impairment, which includes a formal FASD diagnosis and supporting reports from health professionals involved in their assessment and diagnosis (FASD Hub, n.d.).

The lack of standardised data on the costs incurred by families further also complicates matters, hindering the development of evidence-based policies. Policymakers frequently overlook the hidden costs these families endure, which can include not just direct expenses for services but also indirect costs such as lost income and emotional stress (Anderson et al., 2007). Without comprehensive data, it becomes challenging to advocate effectively for necessary changes and support systems that could alleviate the burdens on these families.

Challenges faced by young people in the juvenile justice system

Young people with FASD face complex challenges in the juvenile justice system, where cognitive impairments make it difficult for them to understand court orders, differentiate between right and wrong, and learn from their mistakes. These challenges are compounded by memory deficits, attention issues, and executive function (EF) impairments, which affect their ability to follow instructions, regulate impulses, and engage in effective planning (Fast & Conry, 2009). Language and communication difficulties exacerbate their struggles, often leading to misunderstandings of legal processes and misinterpretation of their behaviour as wilful noncompliance.

Emotional regulation impairments, including frequent mood swings and mental health issues such as anxiety and depression, significantly impact their ability to function socially and emotionally, while deficits in adaptive behaviour and social skills create barriers to independence and relationship-building. Systemic shortcomings, including misdiagnosis, a lack of awareness among professionals, and inadequate screening

practices, often result in insufficient support, inappropriate interventions, which in many cases - unnecessary detention. These interconnected challenges underscore the urgent need for early diagnosis, increased awareness, and the implementation of tailored interventions that address the specific needs of children with FASD, ultimately aiming to improve their outcomes within the justice system (Robards et al., 2024).

In Australia over the period of 2022-23, a total of $1.3 billion was allocated to detention-based supervision, community-based supervision and group conferencing (Productivity Commission, 2024). Of which, detention-based supervision accounted for the majority (64.7%, equate to $855.3 million) of the expenditure (Productivity Commision, 2024). In SA of the same period, an average of 255 young people aged 10 and over were under youth justice supervision daily (AIHW, 2024b). This data indicated a slight rise of 6% in youth under supervision, compared to 240 youths in detention in 2018-19 (AIHW, 2024b). Most of them (90%) were supervised in the community, while 11% of youths were in detention (AIHW, 2024b). A study conducted by Bower et al. (2018) in youth detention in WA revealed that 89% of youth sentenced to detention had at least one domain of severe neurodevelopmental impairment, with 36% diagnosed with FASD. This study highlighted the prevalence of FASD in the juvenile justice system. However, to the authors' knowledge, there is no current research in SA focusing on FASD screening and diagnosis for youths involved in the system. This calls for an urgent need for the SA state government to provide support and interventions for youths suspected of having FASD and their families in navigating the complexities of the justice system.

The role of social media in communicating FASD

The impacts and risks of alcohol consumption posted on social media is crucial to study. Firstly, social media can reflect and interact with the public’s understanding of a health issue, thereby setting public agendas and orienting public attitudes and behaviours (Bollen et al., 2011). Furthermore, there is concern that media reports may convey inaccurate or even harmful messages that can influence a large number of people (Doctors for Drug Policy Reform, 2013), leading to a misunderstanding of scientific

findings and creating unrealistic fears (Eguiagaray et al., 2016). Previous research highlighted the risks associated with industry-funded organisations discrediting, downplaying, and omitting information regarding the harmful effects of alcohol consumption (Petticrew et al., 2018; Pietracatella & Brady, 2020). Furthermore, emphasis has been placed on the use of terminologies or metaphors that may be interpreted as negative or stigmatising towards mothers, often failing to resonate with their actual situations (Holland et al., 2015). For example, industry-funded DrinkWise organisation in their DrinkWise awareness program states that FASD is 100% preventable (DrinkWise, n.d.). This assertion underpins the notion that it is individuals' responsibility for their health choices while ignoring the social determinants which influence drinking patterns (Vepsä, 2021). Regarding FASD knowledge, the study conducted by Schölin & Heenan (2022) found that most tweets - a short status update on the social networking site Twitter, officially known as X - provided generic information about FASD using vague language, with specific references to the impacts and manifestations of FASD being limited. This highlights the need for government-based and non-profit organisations to provide more frequent, concise, and clear messages on social media to reach broader audiences.

Strategic initiatives: Australian Government response to FASD

National strategies

In 2018, The Australian Government implemented the National FASD Strategic Action Plan 2018–2028, providing a comprehensive roadmap to enhance the prevention, diagnosis, support, and management of FASD nationwide. This plan reflects a collaborative effort involving governments, NGOs, family advocates, researchers, clinicians, and communities, all committed to raising awareness and improving outcomes for individuals impacted by FASD (Department of Health, 2018). Backed by dedicated funding, the action plan aims to reduce the prevalence of FASD, mitigate its impacts, improve the quality of life for affected individuals, and drive meaningful progress in addressing this significant public health issue.

The Action Plan is structured around four national priorities - supported by five enablers and seven guiding principles - to reduce FASD prevalence, lessen its impacts, and improve quality of life for Australians affected. The enablers include:

- **Recognising FASD as a disability**: Strengthen coordination across sectors (health, education, justice) and review policies to improve support.
- **Eliminating stigma**: Focus on stigma prevention in policies, compassionate public education, and responsible media portrayals.
- **Enhancing education and training**: Equip Australian professionals with skills to diagnose, manage, and support FASD.
- **Ensuring policy coordination**: Promote collaboration across governments and sectors to implement evidence-based strategies.
- **Promoting research and evaluation**: Advance data collection, national surveillance, and diagnostic and intervention practices.

Public health campaigns

In conjunction with national strategies, public health campaigns play a vital role in raising awareness and educating the community about FASD. These campaigns aim to promote responsible alcohol consumption, particularly during pregnancy, and combat stigma through non-judgmental messaging (see '*National public education campaigns*' for more information).

Local interventions

Local initiatives are crucial for translating national strategies into community-level impact. These interventions include providing training for frontline professionals in healthcare, education, and justice sectors to identify and support individuals with FASD effectively. Expanding FASD resources tailored to local contexts, integrating FASD-specific training into teacher and healthcare worker programs, and enhancing support services for families are key elements. These efforts should focus on building awareness, fostering collaboration between community organisations and government agencies, and creating culturally sensitive approaches to care. Additionally, ensuring consistent funding, monitoring program effectiveness, and engaging families and

individuals with lived experience in program development are essential steps for achieving sustainable and impactful results. By aligning national strategies, public health campaigns, and local interventions, the Australian government seeks to create a comprehensive, multi-tiered approach to preventing and managing FASD.

Pregnancy labels on alcoholic beverages

Pregnancy labels on alcoholic beverages aim to reduce alcohol consumption among pregnant women. Businesses must comply with the pregnancy warning labelling requirements for all alcoholic beverages by July 31st, 2023. Additionally, consumers had until February 1st, 2024 to implement these labelling standards (FSANZ, 2024). According to Thomas et al. (2012), these labels may raise awareness of the harmful effects of alcohol consumption during pregnancy, but they may not have a major impact on at-risk groups' behaviour. Although these labels have the power to initiate behavioural and cognitive awareness - including a rise in conversations about the dangers of drinking and plans to alter drinking behaviours - they have insignificant effect on changing behaviour. There is also little direct effect on lowering pregnant women's alcohol intake. Therefore, for effectiveness these labels must be more visible to be more effective.

Figure 5*:* Mandatory or Optional alternative pregnancy label types depending on beverage volume (FASD Hub, n.d.).

NOFASD Australia: advocating for FASD awareness and support

NOFASD Australia is a national non-profit organisation focused on supporting individuals and families affected by FASD while working to prevent the condition through advocacy and education. It provides essential resources such as a helpline for caregivers and families and develops training programs to help professionals, including educators and healthcare workers, better understand and support individuals living with FASD. The organisation was established in 1999 by Sue Miers AM, who founded it in response to her experiences raising a child with FASD and facing significant gaps in available support. Originally named the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), the name was updated to NOFASD Australia in 2013 to reflect evolving medical language (NOFASD, n.d.). Over time, the organisation has grown from a volunteer initiative into a well-established resource funded primarily by the Australian Government since 2012. Sue Miers has been widely recognised for her contributions to FASD advocacy, including receiving an Honorary Doctorate from the University of Western Australia in 2023 and being appointed a Member of the Order of Australia. NOFASD Australia's work continues to focus on reducing stigma, enhancing public understanding of alcohol-free pregnancies, and advocating for supportive policies that improve outcomes for those affected (NOFASD, n.d.).

Current strategies and support for individuals and parents affected by FASD

Whilst the goal of early intervention and prevention work is to eliminate FASD occurring, there are and may always be families affected by a child with FASD. Some resources and interventions are available to empower families with the tools they need to improve outcomes for their children while fostering family resilience. Additionally, public health campaigns targeting the general population or at-risk groups were implemented to improve awareness and provide reliable resources relating to FASD. These strategies aim to equip parents and caregivers, general population, educators and health professionals with the knowledge, skills, and resources necessary to effectively recognise and provide support for those affected by FASD.

NOFASD: an Australian toolkit for parents, caregivers and families.

'Fetal Alcohol Spectrum Disorder: an Australian toolkit for parents, caregivers and families' is a comprehensive resource developed by NOFASD Australia to support families dealing with FASD (NOFASD, 2020a). This toolkit is available on the NOFASD website (see https://www.nofasd.org.au/). The toolkit provides detailed information on understanding FASD, its diagnosis, and the effects of PAE. It includes practical strategies for managing daily life, addressing sensory processing issues, and supporting children across different developmental stages. The guide emphasises the importance of using respectful language, promoting dignity, and focusing on strengths rather than deficits. It also offers advice on navigating educational systems, accessing professional support, and advocating for children with FASD. Additionally, the toolkit addresses the unique challenges faced by adults with FASD and provides resources for caregivers to manage stress and seek support. The document underscores the significance of early diagnosis and intervention, and it aims to create a supportive environment for individuals with FASD to reach their full potential.

RFFADA in supporting FASD individuals

The Russell Family Fetal Alcohol Disorders Association (RFFADA) is a parent peer support network that equips families with practical tools and emotional resilience, and their training programs enhance the capacity of professionals—such as healthcare providers, educators, and social workers—to provide effective care (Healthdirect, 2023). The RFFADA is an Australian non-for-profit organisation based in Queensland (QLD). While it currently does not operate in SA, expanding its presence to this region is a recommendation worth considering. RFFADA raises awareness about the risks of alcohol consumption during pregnancy to prevent FASD while providing essential services like access to diagnostic support and tailored management plans.

A modified Alert Program

The Alert Program, developed by occupational therapists in 1990, is an intervention that specifically targets the improvement of children's EF and Self-Regulation (SR) abilities (Wagner et al., 2020). EF is vital for various aspects of daily life, encompassing higher-order cognitive processes essential for goal-directed behaviours, adaptive changes, social competence, and behavioural regulation (Anderson, 2008). SR refers to one's capacity to adjust or maintain emotions, thoughts, arousal states, or behaviours appropriately in different environments (Nigg, 2017). There exists a bidirectional relationship between EF and SR, where individuals utilise EF to regulate emotions, thoughts, and behaviours; and conversely, the body modulates arousal, thoughts, and emotions which influences EF (Nigg, 2017; Ursache et al., 2011). Previous research indicates that children with FASD often exhibit impaired EF, with common deficits including selective inhibition, arousal and attention, planning, working memory, and verbal and nonverbal fluency (Rasmussen & Bisanz, 2009). Schooling systems inherently expect students to utilise their EF and SR capabilities (McClelland & Cameron, 2012). This includes following instructions, classroom rules, solving problems, comprehending texts, socialising with peers and teachers, and applying transferable knowledge across various situations (Wagner et al., 2020). Consequently, students with FASD can have difficulties with basic school tasks due to their EF and SR impairments. This can lead to poor academic performance, conflicts with teachers, and disruptions in the learning environment for other students (Portilla et al., 2014).

The Alert Program has been adapted and trialled in schools and clinical settings, showing promising results in the FASD population (Nash et al., 2015; Wells et al., 2012). The first Australian Alert Program study was conducted in 2020, implementing an 8-week Alert Program in a remote primary school in an Aboriginal setting in WA (Wagner et al., 2020). While the research outcomes indicated insignificant improvements in children's EF and SR skills, those who participated in the program exhibited a reduced frequency of disruptive behaviours, as reported by teachers and parents (Wagner et al., 2020). The study outcomes were significantly influenced by student attendance, as only 50% of students in the study received more than half of the

Alert Program sessions (Wagner et al., 2020). On the other hand, this study (2020) also highlighted the positive changes when school staff are provided with support and training on FASD and strategies for managing difficult classroom behaviours. This leads to the implementation of strengths-based classroom strategies to better accommodate the needs of children with FASD (Wagner et al., 2020). These findings offer promising outcomes for the expansion of the program across Australia, including SA.

Getting on With It

Getting on With It (GOWI) is a course developed for parents and caregivers of children with FASD by Dr. Anita Gibbs - a qualified social worker - in New Zealand in 2017 (Gibbs, 2019). Following a successful initial pilot study of the GOWI course in Dunedin, New Zealand, Dr. Gibbs collaborated with NOFASD Australia to launch a digital online GOWI course in Australia in 2019 (Gibbs et al., 2020). This is considered the first course in Australia which was initiated specifically to provide parents and caregivers with FASD-specific online peer-to-peer mentoring, support and advocacy for the enduring impacts of FASD (Gibbs et al., 2020). The aim of the GOWI training is to assist parents and caregivers of children with FASD or suspected FASD in fostering greater resilience and strategies for a successful family life in a disabling society (Gibbs, 2019). The course contents for the Australian-operated GOWI have been adjusted to align with the Australian guidelines, the NDIS scheme, and available resources to support families (Gibbs et al., 2020). It is worth noticing that although participants were recruited from across Australia, many of them were from Perth, WA (Gibbs et al., 2020). This raises concern regarding FASD awareness in SA, given the lack of prevalence data and available local services.

The Australian GOWI course reflected the success of the original GOWI in New Zealand, with parents and caregivers overwhelmingly appreciating the support and knowledge gained throughout the training course (Gibbs et al., 2020). They also indicated that the course provided a safe environment for them to share difficult experiences with peers and experts (Gibbs, 2019). Overall, parents and caregivers

expressed satisfaction with the course, acknowledging that its non-judgmental environment facilitated learning and sharing, along with its flexible nature that accommodated their busy schedules and geographical locations (Gibbs et al., 2020). The positive outcomes observed in this initial training course shed light to potential expansion at both state and national levels. Following the successful of the pilot study, NOFASD was able to obtain fundings to run more online programs during the 2021-23 period, leading to the establishment of the Families Linking with Families (FLWF) program – an evolved version of GOWI with ongoing updated and adapted to the changes in social, political, economic, and geographical landscape in Australia (Gibbs et al., 2024). The SA state government could consider launching the first local GOWI course tailored to the specific context of SA, aiming to better support parents and caregivers of children with FASD in the region.

Strong Born campaign

The Strong Born campaign, launched in February 2023 by the National Aboriginal Community Controlled Health Organisation (NACCHO) in partnership with Aboriginal Community Controlled Health Organisations (ACCHOs), is Australia's first national health promotion initiative dedicated to preventing FASD within Aboriginal and Torres Strait Islander communities (Williams et al., 2024). Focusing particularly on rural and remote areas (NACCHO, n.d.), the campaign addresses a critical gap in health promotion and knowledge around FASD. Using a strengths-based and culturally informed approach, Strong Born developed culturally safe health promotion toolkits and provided FASD Communications and Engagement Grants to empower local communities. The campaign promotes alcohol-free pregnancies, aiming to ensure every baby is born healthy and strong, with the best possible start in life (Australian Government Department of Health and Aged Care, 2023). To date, 92 Strong Born community toolkits have been delivered by NACCHO across Australia, and 24 community grants have been allocated to ACCHOs (Williams et al., 2024). The campaign's great success within such a short time frame has led to additional fundings, allowing for an expansion into metropolitan areas of Adelaide. The fundings will also support the development of an animated version of the campaign on YouTube (Williams

et al., 2024). Overall, the campaign shows significant potential in strengthening the capacity of the ACCHO sector to provide better support for early diagnosis and intervention, ultimately improving the quality of life for children and adults with FASD in Australia (Williams et al., 2024).

National public education campaigns

National public education campaigns are aimed at preventing and raising awareness of the harmful impact of PAE, as outlined in the National FASD Strategic Action Plan 2018-2028. Notable campaigns include the Pregnancy and Alcohol poster, the DrinkWise FASD Awareness Program, Pregnancy and Alcohol: The Surprising Reality, Information You Might Not Know About Pregnancy and Alcohol brochure, FASD Awareness Day (e.g. Red Shoes Rock campaign), The Alcohol and Drug Foundation Fetal Alcohol Spectrum Disorder mini bulletin, Woman Want to Know, and Every Moment Matters. These campaigns consistently provide information recommending abstaining from alcohol during pregnancy and breastfeeding as the safest option (Curtis et al., 2022). However, not all campaigns offer evidence-based information or specific references for their materials (Curtis et al., 2022). For instance, the Pregnancy and Alcohol poster and Information You Might Not Know About Pregnancy and Alcohol brochure lack specific references. Additionally, the DrinkWise FASD Awareness Program, although references the NHMRC guidelines, does not provide further references (Curtis et al., 2022). Importantly, to the best of the authors' knowledge, there has been no evaluation of these campaigns, despite some of them being launched for nearly a decade. This highlights the need for further studies to assess the effectiveness and reach of these national campaigns in achieving the objectives of the National FASD Strategic Action Plan 2018-2028.

Future changes and actions

The Autism SA strategy in schools is primarily focused on supporting students with ASD. However, there are concerns about the exclusion of children with FASD, even though the challenges these children face - such as difficulties with social interaction, communication, and behavior - can overlap significantly with those of children with ASD (Department for Education, 2024). This overlap suggests that interventions designed for children with ASD may also be beneficial for children with FASD. However, the lack of inclusion of FASD in existing frameworks could potentially create gaps in the support these children receive. In many schools, dedicated staff members are responsible for providing support to children with disabilities. However, if these staff members are not trained to recognise and address the unique needs of children with FASD, the support may not be as effective as it could be (Autism Speaks, 2018).

To address this, further research should be conducted to explore the effectiveness of using ASD interventions for children with FASD. Incorporating this research into existing educational strategies like Autism SA could be a logical step toward ensuring that all children, regardless of their diagnosis, receive the tailored support they need to thrive academically and socially (Department for Education, 2024). This would require the engagement of services who work with the two conditions to develop collaborative strategies, subject to them agreeing that this is a functional way forward. Expanding educational frameworks to be more inclusive would help address these gaps, ensuring that all students are properly supported.

Conclusion

This report provides insight into the complexities of FASD, the prevalence, burden and occurring issues surrounding alcohol consumption in Australia. The report also focused on the experiences and various difficulties that parents and caregivers encounter, addressing the challenges, available resources, support networks, coping mechanisms and strengths utilised in parenting children with FASD. It is evident from looking at the physical, social, and emotional aspects of FASD that parents and caregivers need a lot of support juggling the responsibilities of raising children with FASD. This brings significant emotional, financial, and social challenges, as these struggles are intensified by the limited availability of specialised support services and resources. This is where social work professionals play a crucial role in supporting families, advocating for policy reforms, and ensuring the provision of specialised services. To empower families, encourage better results, and build community resilience, our research emphasises the necessity of increased access to resources and support systems.

Summarise key findings

The findings emphasise the urgent need to improve awareness, diagnosis, and support networks for individuals and families impacted by FASD in Australia. Despite the high prevalence of FASD, public information and resources are limited and outdated compared to countries like Canada, the United Kingdom (UK), and the United States of America (USA). This gap, combined with FASD is relatively new and under-recognised status, contributes to under-diagnosis and delayed intervention, leaving families without the tailored support they need. Children with FASD could benefit significantly from early interventions and specialised educational support. Healthcare providers play a crucial role in prevention yet discussion about alcohol during anti prenatal cares are limited. Regular conversations about alcohol consumption during pregnancy can help inform and educate expectant mothers, particularly those from vulnerable groups such as First Nations People, individuals in lower SES and those living in remote or rural areas. Youth in detention centres are disproportionately affected by FASD yet support for them and their families is minimal. This is particularly concerning in areas with high rates of incarceration, such as WA and the Northern Territory (NT), where more children with

FASD and related complexities are detained. Tailored interventions and programs are needed to assist families navigating these systems, as well as to provide better outcomes for the children involved. Diagnosis remains a major barrier, as there is no standardised screening process for FASD in Australia. Delayed or missed diagnoses exacerbate the challenges families face, leading to inappropriate and often costly interventions. Establishing standardised diagnostic criteria and expanding training for healthcare professionals to recognise signs of FASD are crucial steps. Finally, services such as diagnostic support, tailored management plans, parent peer networks, and professional training programs can strengthen local capacity, improve outcomes for individuals with FASD, and foster family resilience. Data collection on alcohol use during pregnancy and FASD prevalence is also necessary to develop effective, evidence-based interventions and policies. By addressing these interconnected challenges, we can improve understanding, prevention, and support for those affected by FASD, ultimately enhancing their quality of life and lived experiences of individuals and families affected by FASD.

Limitations of research

A primary limitation of research on FASD is the significant lack of comprehensive studies conducted in Australia, particularly in SA. This gap in research hinders our understanding of the prevalence, causes, and effects of FASD within the local context. Additionally, there is a troubling absence of recent data and statistics regarding maternal drinking patterns and their correlation with FASD diagnoses and support systems. Without up-to-date information, it is challenging to formulate effective intervention strategies or allocate resources appropriately. This lack of empirical evidence not only limits the ability of healthcare providers to support affected families but also impedes policymakers in developing informed, targeted programs that address the needs of at-risk groups, parents and caregivers, and individuals with FASD. Addressing these research gaps is crucial for improving awareness, prevention, and support for FASD in Australia not just within vulnerable communities, but also for the general Australian population.

Recommendations

To improve the quality of life and ensure better local support services for individuals and families affected by FASD, we recommend that the SA state government to implement the following strategies:

- Launching the first local GOWI course, RFFADA support network, and Alert Program tailored to the specific context of SA to better support parents and caregivers of children with FASD in the region. These initiatives could enhance local capacity to support individuals with FASD, foster family resilience, and equip professionals with the skills to deliver effective care, addressing a critical gap in the FASD support system in SA.
- To enhance educational outcomes for all students, it may be beneficial for the Autism SA strategy to expand its framework to include Fetal Alcohol Spectrum Disorder (FASD). This expansion could ensure that every child receives the tailored support they need to succeed in the classroom.
- Providing screening and diagnosis of FASD for youths involved in the juvenile justice system and improving support services for youths suspected of having FASD and their families to navigate complexities of the system.
- Adopting standardised diagnostic criteria for FASD to ensure early identification and intervention, enabling parents to access support at the earliest stage possible.

Given the roles and influences that health professionals have in preventing and providing early interventions for expectant mothers who happen to consume alcohol during their pregnancy, we recommend the following strategies:

- All doctors, nurses and midwives would benefit from training that empowers them to routinely ask mothers about alcohol consumption during pregnancy. It is crucial for healthcare professionals to ensure that expectant mothers are informed about the potential issues related to alcohol consumption while pregnant.

- Australian universities provide education in relevant occupations - including occupational therapy, speech and language therapy, education and teaching, medicine, midwifery, psychology and social work - to include AOD and FASD modules in their courses.

We recommend a nation-wide approach to the following strategies:

- Data for alcohol consumption during pregnancy across all social strata should be collected to accurately measure the prevalence and burden of FASD nationwide.
- Interventions and education programs should involve partners and immediate family, rather than focusing solely on the mother as primarily responsible for raising children with FASD.
- Providing support services for families to advocate for their children and navigate the complexities within the NDIS, education and justice systems.
- Expanding or providing ongoing and life-long support for individuals with FASD who are 18 years or over.
- Increasing funding for diagnostic services, ensuring consistent access to ILPs across all schools, and training more professionals to work in underserved regions.
- Government-based and non-profit organisations to be more active on social media platforms and provide concise and clear messages with non-stigmatising language to reach broader audiences.
- Families of higher education and SES levels would benefit from education about FASD and alcohol-related risks associated with fetal health, as this group would often be overlooked and excluded in campaigns aiming at early prevention and interventions of FASD.

Despite the high prevalence and the impacts of FASD on individuals, families and society, little research has been conducted in Australia. Therefore, we recommend:

- Future research to focus on examining changes in drinking patterns in Australia for more effective strategies aiming to promote healthier drinking choices and reduce risks associated with excessive drinking.
- Further research on the effectiveness of the national public education campaigns in aim of ensuring up-to-date and accurate information to be provided to the public.
- Conducting longitudinal studies to examine the outcomes of children with FASD, providing valuable insights into the effectiveness of early interventions and support strategies.

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Appendices

Appendix A - *Alcohol as teratogen and FASD pathophysiology*

Gestational alcohol consumption poses significant negative impacts on both the mother and fetus (Lee, 2020). The effects of alcohol during pregnancy are primarily dose-related, but other modifiable factors, such as demographic and individual differences, also play a crucial role (Lee, 2020). For instance, the effects on the mother, including maternal metabolism, diet, physical and psychological well-being, SES and interpersonal relationships, can indirectly influence fetal growth and development (Aiton, 2021). Additionally, maternal biological changes induced by alcohol consumption during pregnancy can affect pregnancy maintenance, hormonal environment associated with pregnancy, chorioamniotic and placental formation and functioning (Aiton, 2021). These factors are interconnected, either mitigating or exacerbating the severity of harm to the developing fetus (Aiton, 2021).

Alcohol rapidly transfers from the mother to the fetus (Burd et al., 2012). The chemical structure of alcohol enables it to easily diffuse across various membranes, including the placenta, causing the fetal Blood Alcohol Concentration (BAC) to approach the maternal BAC within 1 hour and reach equilibrium in 2 hours (see Figure 6; Burd et al., 2012). Following an increase in maternal BAC, fetal BAC can be detected within 1 minute (Waltman & Iniquez, 1972). Initially, the fetal BAC rises slower than the maternal BAC, but alcohol concentration quickly reaches equilibrium between the two and is primarily eliminated through maternal metabolism (Burd et al., 2012; Popova et al., 2023). This is because the placenta, despite its active metabolic functions, can only metabolise a minute amount of alcohol, thus unable to reduce the alcohol reaching the fetus (Burd et al., 2012). Furthermore, the fetus metabolises alcohol similarly to adults but with much lower enzyme levels and activity, thus dependent primarily on the mother for alcohol elimination (Gupta et al., 2016; Ehrhart et al., 2019).

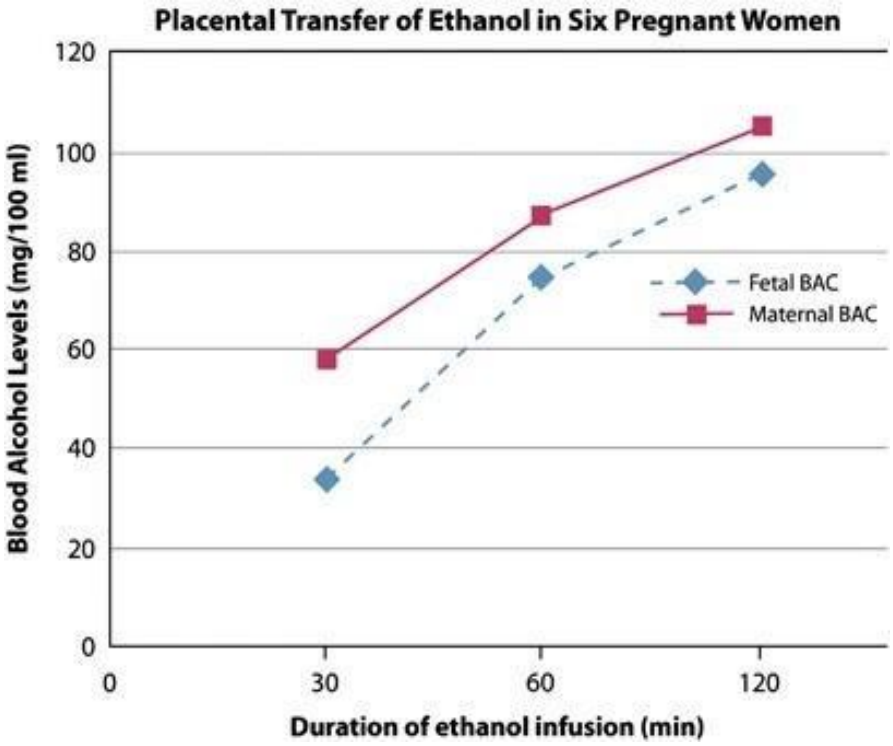

Figure 6: Blood Alcohol Concentrations (mg/100 ml) of the mother and fetus following alcohol infusion. The pink line represents maternal BAC, while the blue, dashed line represents fetal BAC. Despite the delay in the rise of fetal BAC, both lines come close or reach equilibrium as duration increases (Burd et al., 2012).

Placental formation is pivotal to healthy fetus development (Burton et al., 2010), serving as a nutrient sensor and nutritional transportation between the mother and fetus (Barker et al., 2010). Previous studies reported placental abnormalities following PAE, indicating approximately 68% of individuals with PAE or FASD have altered placental structure (Jarmasz et al., 2017; Steane et al., 2021). Evidence from animal models indicated early exposure to alcohol following conception can alter embryonic trophoblast cells, the precursors of placenta, leading to impaired placental formation, placental morphology, restricted blood flow, and subsequent Fetal Growth Restriction (FGR) (Kalisch-Smith et al., 2019; Kwan et al., 2020). Individuals born after experiencing FGR are more vulnerable to later health complications, including cardiovascular and renal diseases, as well as metabolic disorders such as type 2 diabetes mellitus, metabolic syndrome, or non-alcoholic fatty liver disease (Crispi et al., 2018; Heindel et al., 2015).

Alcohol disrupts fetal development in several ways, including molecular, cellular, physiological cascades, genetic and epigenetic across prenatal development stages (Wozniak et al., 2019). Previous research has identified several molecules and receptors critical for fetal development that are disrupted after one or two US standard drinks, equivalent to 1.5 or 3 Australian standard drinks (Dou et al., 2020; Lee et al., 2022). Therefore, repeated exposure to low or moderate levels of alcohol, or one episode of exposure during a critical period of fetal development, could significantly impact fetal health (Popova et al., 2023). While the understanding of the pathophysiological mechanisms of PAE on fetal development remains incomplete, the detrimental effects on various organ systems, particularly the Central Nervous System (CNS), are well-documented (Burd et al., 2012; Heller & Burd, 2014).

Consistent findings from previous studies have indicated brain abnormalities in individuals affected by PAE, such as total brain volume shrinkage and reduced sizes of specific brain regions like the cerebrum, cerebellum, and hippocampus (Muralidharan et al., 2013). Alcohol impacts all stages of brain development, leading to a range of brain abnormalities depending on the developmental stage at exposure (Muralidharan et al., 2013). This variation contributes to the continuous spectrum of symptom manifestations found in individuals with FASD (Higgins et al., 2024). Facial abnormalities induced by alcohol typically emerge early in pregnancy, around the third week (Ornoy, 2020). Prominent craniofacial dysmorphic features are associated with elevated levels of alcohol exposure, while minor facial abnormalities are often observed in low to moderate levels of alcohol intake (Ornoy, 2020). Oxidative stress resulting from alcohol metabolism can also induce facial dysmorphology, Deoxyribonucleic Acid (DNA) damage, and neurodegeneration, leading to the brain defects found in FASD population (Ehrhart et al., 2019; Wozniak et al., 2019).

Appendix B - ***Diagnosis of FASD***

FASD is the term given to a group of impairments linked to PAE that are now recognised. Terms like ARND and ARBD are used for clarity because FASD is a general term rather than a specific diagnosis (Jarmasz et al., 2017; Popova et al., 2023). The amount and pattern of alcohol consumption, the timing of exposure during pregnancy, as well as genetic and environmental factors, all have a significant impact on the severity of FASD. For example, compared to chronic low-level drinking, binge drinking frequently results in more severe effects. Different brain structures and functions can be affected differently by the timing of exposure; different developmental stages are affected by distinct crucial periods (Sulik, 2005; Livy et al., 2003). Furthermore, the results of FASD are influenced by environmental factors like diet and prenatal care, as well as genetic factors such as polymorphisms in genes related to alcohol metabolism (Warren & Foudin, 2001).

Appendix C - ***Drinking habits in Western culture***

In many western countries, health guidelines emphasise complete abstinence from alcohol during pregnancy. In contrast, in some cultures, alcohol consumption during pregnancy might be more socially accepted or less well-understood (Dejong et al., 2019). For example, in some European countries, there is a spectrum of attitudes towards alcohol consumption during pregnancy. Some countries recommend complete abstinence, while others may suggest moderation, although FASD awareness is growing. In Asia, attitudes towards alcohol consumption during pregnancy vary widely. In some countries, traditional beliefs and practices might influence alcohol consumption, and there may be less emphasis on the risks associated with FASD. And in some African communities, alcohol consumption during pregnancy might be less regulated which can contribute to a higher prevalence of FASD in certain areas.

Appendix D - ***applying social work practice***

The appropriate use of social work theories is crucial, as the misuse of these theories has often left many parents feeling isolated, guilty, and unfairly labelled as over-anxious or inadequate parents (Brown, 2015). Due to the under-diagnosis and lack of

recognition of FASD as a disability, inappropriate interventions and therapies can further compound the ongoing challenges faced by families of individuals with FASD. Additionally, social workers are often the frontline professionals in identifying characteristics that may suggest FASD (Boaden et al., 2023), thus, it is essential for social workers to acknowledge the complexity and enduring nature of FASD to provide proper long-term support to individuals with FASD and their caregivers (Brown, 2015).

Person in environment

This approach emphasises the interconnectedness between individuals and their environments, illustrating how they navigate and function under diverse interpersonal and social-political systems (Hare, 2004). By mapping these systems and exploring how individuals interact with each one, social workers can better understand the supports and risks individuals might encounter (Bardy & Choate, 2000). Furthermore, this approach also enables social workers to assess service users' perceptions, and the risks perceived by them according to their circumstances.

Strengths-based approach

This approach highlights strengths and resilience, shifting away from the traditional focus on deficits in professional practices (Van Breda, 2018). Instead of ignoring weaknesses, the approach utilises strengths to counterbalance them (Bardy & Choate, 2015). It has been suggested that this approach is effective in different disability communities (Hammel et al., 2008), suggesting its potential applicability to populations impacted by FASD.

Systems theory

This approach further enhances the person-in-environment and strengths-based approaches by examining how systems impact individuals' daily lives, assisting social workers in identifying systemic issues and gaps for policy advocacy (Bardy & Choate, 2015). By considering the interconnectedness and intersectionality of systems, social workers can assess how changes in one system can affect another and how these changes influence the service user's life. It is especially crucial, particularly in First

Nations communities, given their history of state-imposed traumas and ongoing oppressions across generations (Bardy & Choate, 2015). Therefore, communal trauma histories need to be understood when working with clients.

Reducing stigma

Current public health messages indicate that FASD is ‘totally' preventable. For example the DrinkWise awareness program states that FASD is 100% preventable (DrinkWise, n.d.). This assertion underpins the notion that it is individuals' responsibility for their health choices while ignoring the social determinants which influence drinking habits (Vepsä, 2020). The stigma around FASD is the intertwine of blame and shame - labelling women who consume alcohol as responsible and intentionally causing their child's disability, while maintaining that FASD is entirely preventable (Evans, 2024). The social worker can challenge FASD-related stigma by acknowledging the social context and lived experience of individuals and families living with FASD (McCormack et al., 2022). By addressing misconceptions and misinformation around FASD, social workers can assist individuals and families experiencing FASD in receiving effective and informed support from health professionals (McCormack et al., 2022).

Glossary

Term	Definition or meaning
ACCHO	Aboriginal Community Controlled Health Organisations
AD	Alcohol Dependence
ADHD	Attention-Deficit/Hyperactivity Disorder
AIHW	Australian Institute of Health and Welfare
AOD	Alcohol and Other Drugs
ARBD	Alcohol-Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorder
ASD	Autism Spectrum Disorder
Binge drinking	Binge drinking, or heavy episodic drinking, is drinking alcoholic beverages with an intention of becoming intoxicated by heavy consumption of alcohol over a brief period of time, but definitions vary considerably.
BAC	Blood Alcohol Concentration
CD	Conduct Disorder
COC	Community Outreach Centre
CNS	Central Nervous System
DNA	Deoxyribonucleic acid
EF	Executive Functioning
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FGR	Fetal Growth Restriction
FLWF	Families Linking with Families
FSANZ	Food Standards Australia - New Zealand

GP	General Practitioner
GOWI	Get on With it
ILPs	Individual Learning Plans
IQ	Intelligence Quotient
NACCHO	National Aboriginal Community Controlled Health Organisation
NDIS	National Disability Insurance Scheme
Neuroplasticity	The brain's capacity to form and reorganise synaptic connections in response to learning, experiences, or injury (Weyandt et al., 2020).
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
NOFASARD	National Organisation for Fetal Alcohol Syndrome and Related Disorders
NOFASD	National Organisation for Fetal Alcohol Spectrum Disorder
NT	Northern Territory
ODD	Oppositional Defiant Disorder
PAE	Prenatal Alcohol Exposure
Parental responsiveness	Family interactions in which parents are aware of their children's emotional and physical needs and respond appropriately and consistently (National Physicians Centre, n.d.).
pFAS	Partial Fetal Alcohol Syndrome
QLD	Queensland
RAD	Reactive Attachment Disorder
RFFADA	Russell Family Fetal Alcohol Disorders Association
SA	South Australia

SANDAS	South Australian Network of Drug & Alcohol services
SES	Socioeconomic Status
SIDS	Sudden Infant Death Syndrome
SR	Self-regulation
Teratogen	An environmental factor that permanently disrupts the structure and function of the embryo or fetus (Chudley, 2010).
UniSA	University of South Australia
UK	United Kingdom
USA	United States of America
WA	Western Australia

Disclaimer

The authors as current social work students recognise that some language used in previous studies is stigmatising, stereotyping, and perpetuating the oppression of vulnerable groups mentioned throughout the report. Therefore, we have employed social work languages for the following terms:

Problematic Language	Appropriate Language
Alcoholic/addicted mother	Mother who is alcohol dependent
Addiction	Substance dependence
Substance/AOD abuse	Problematic substance/AOD use
Drinking habits	Drinking patterns

This report has been prepared with a commitment to using person-centred, non-stigmatising language in line with best practices highlighted by Network of Alcohol and Other Drugs Agencies (n.d.).

The words we choose hold significant influence, particularly when addressing topics related to alcohol, drugs, and those impacted by them. Language that perpetuates stigma can reinforce harmful stereotypes and unintentionally foster discrimination. Adopting person-first language prioritises the individual, emphasising their autonomy, dignity, and inherent value.

While every effort was made to use inclusive and considerate terminology, we acknowledge that language evolves and individual preferences may vary.