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Exploring Fetal Alcohol Spectrum Disorder (FASD) From an Aboriginal Lens in Western Australia: Survey Results to Inform Cultural Security, Policy, and Service Delivery

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ABSTRACT

Issue Addressed: The exploration of awareness and knowledge on FASD amongst the Noongar people in the Southwest region of Western Australia (WA) was the focus of this research. FASD is a neurodevelopmental disability caused by prenatal alcohol exposure resulting in lifelong disabilities impacting children, families, kinship caregivers, foster carers, and communities.

Methods: This Aboriginal led research was underpinned by Indigenous methodology utilising a developed culturally appropriate survey tool completed by 180 Aboriginal people in WA. Questions included the history of colonisation in Australia. Quantitative analysis of the survey results was undertaken.

Results: It was identified by 92% of respondents that they felt it was important to know about FASD and low awareness of FASD exists, and only 20% had received information on FASD. Participants wanted to receive more information on FASD and culturally preferred approaches to training included small groups, community forums, or one to one learning. The majority of participants identified that they had experienced the removal of an immediate member of their family or themselves, or were a member of the Stolen Generations.

Conclusions: The results highlight that awareness, knowledge, and education can contribute to the prevention of FASD and support effective interventions on country and in the community.

So What? The impact of FASD, a neurodevelopmental disability, has largely gone unrecognised, prompting an urgent need to support children, families and communities in Australia.

1 | Introduction

FASD remains significantly under-resourced in Australia, and national prevalence studies on FASD do not exist [1, 2]. For individuals with FASD, affected areas include learning, cognition, and socialisation, all of which may contribute to a predictable adverse trajectory that includes involvement with child welfare and justice [3, 4]. Alcohol use is recognised as a significant public health issue in Australia and has been linked to child contact with the justice system in Western Australia [4–6]. To date,

health promotion and educational opportunities on FASD have been ad hoc within Australia [7]. Evidence recently provided continues to identify poor sector awareness on FASD amongst health professionals in Australia [1, 8], indicating that only 16% of Australian health professionals were confident in identifying the essential features of FASD [1].

FASD remains a global mainstream health concern and a concern for any community where prenatal alcohol exposure occurs during pregnancy. One of the barriers in the prevention of FASD has been stigma and the lack of consistent robust health promotions on FASD, and appropriate services [9, 10]. Another compounding factor is that FASD has been excluded from mainstream disability policies and supports globally and is often associated with stigma [4, 11]. In Australia, the Aboriginal and Torres Strait Islander community (hereafter Aboriginal) has a history of leadership in addressing FASD, particularly due to the intersection of poor engagement of mainstream disability services and systematic racism [4, 10, 12]. The terms Aboriginal and Indigenous will be used interchangeably in this article. The term Aboriginal as identified in this paper reflects the local context in WA while the term refers to communities beyond the Australian context.

This study was Aboriginal led and responded to the requests from the local Aboriginal community to address concerns of undiagnosed FASD amongst Aboriginal children, particularly those in the kinship care system [13, 14]. This project took place in Perth and the southwest region of WA, that is home to the Noongar people in Western Australia [13]. The study engaged with 180 Aboriginal participants and the results included identifying culturally secure approaches to FASD in the Aboriginal community. Leading authors Williams, Farmer and Kelly are Noongar people with direct kinship ancestry to Noongar people and country. To the knowledge of the authors, this study is the largest consultation on FASD with Aboriginal people in Australia. The survey results reported herein were part of a broader study on FASD completed with the Aboriginal community in Western Australia.

2 | Identifying FASD in the Australian Context

It is well established that prevalence rates of FASD in Australia remain unknown [1, 2]. FASD is not an Aboriginal problem or located in a single geographical area and remains a concern in any community where there is limited awareness of the impact of alcohol use during pregnancy [5, 15]. Notably for Aboriginal people in Australia, FASD exists against the backdrop of Colonisation, Stolen Generations, inter-generational trauma and systemic racism [15–17]. Colonisation has contributed to the disproportionate burden of harm and trauma for Indigenous communities in the world, including the removal of children, displacement from traditional lands and institutionalised racism [15–18]. The Stolen Generations refers to the lengthy period of Australian colonisation, where Aboriginal children were forcibly removed from their families from the late 1880s to the mid 1970s [19]. A history of inter-generational trauma has been identified as a common cause for individuals to self-medicate with alcohol and other drugs to cope with their experiences [20].

The parallels of colonisation and child removal are not unique to Australia and are similar to the experiences of First Nations people in Canada and the US. With the same history of removal of children over many decades, it is recognised that there are devastating outcomes and legacies associated with colonisation and intergenerational trauma [4, 16, 21]. The resulting inherited disparities are now reflected in the poor social determinants of health and the overrepresentation of First Nations children in child protection, incarceration and with potentially higher prevalence rates of FASD [4, 22]. Against this legacy of colonisation and the intersection of systemic racism, it is essential to decolonise FASD to promote the development of culturally secure approaches to interventions for Aboriginal people within Australia [4, 12–13].

Historically, Aboriginal people in Western Australia (WA) were prohibited from purchasing alcohol for many decades until the 1960s [13, 23]. Most Aboriginal people in Australia do not consume alcohol [24]. However, those that do often do so at risky levels [15]. For Indigenous people, especially women who have experienced adverse childhood experiences (ACES) and who live with historical trauma, they are more likely to consume alcohol during pregnancy due to a history of anxiety and depression [22, 25–26]. It is reported that Aboriginal Australians have 2.7 times higher rates of disability than non-Indigenous people and experience increased rates of family caregiving due to cultural and family obligations [27].

Importantly, the Aboriginal response and voice on FASD is emerging and offering critical perspectives that dissent from mainstream approaches to FASD and call for a 'strengths-based and culturally responsive FASD knowledge, assessment, diagnosis and support services among Aboriginal people' [12], p. 2. It is well established that mainstream health programs and interventions on FASD targeted at First Nations communities generally experience low engagement [4, 21]. Further, research has identified that interventions on FASD must be decolonised in a manner that acknowledges the historical landscape and social context of First Nations people [4, 28–30].

3 | Methods

This research study applied a mixed method approach including qualitative and quantitative methods. The qualitative research involved interviews with six caregivers of Aboriginal children with FASD highlighting carer experiences which has been reported in a previous publication [14]. This article reports on the quantitative research undertaken through the development of an original survey called, 'Our Gurlonngas, Our Futures'. The term *Gurlonngas* is the Noongar word for babies and children [13]. The lead researcher is an Aboriginal woman with ancestral links to the Southwest of WA. A Critical Reference Group (CRG) was established and included both Aboriginal and non-Aboriginal people with clinical expertise in Aboriginal health, psychology, community development and policy as well as parents who care for children with FASD. The CRG had a critical role in the establishment of culturally sound protocols and in

the development of the quantitative survey tool reported on in this paper.

3.1 | Our Gurlonngas, Our Future (Artwork Depicting the Birthing Tree by Noongar Artist Peter Farmer Snr)

The artwork design in Figure 1 was chosen by CRG Aboriginal members and symbolises the birthing tree. In traditional times, the birthing tree was the place where childbirth occurred under the protection and supervision of Aboriginal women who were well experienced in the traditional ways of childbirth [13].

3.2 | Content of the Survey

The survey included five sections and an overall total of 50 questions. The titles of each section included: Section 1: Demographics; Section 2: Understanding FASD; Section 3: Alcohol; Section 4: History and family; Section 5: Information required on FASD.

The results from the quantitative survey are presented in this paper.

3.3 | Piloting the Surveys

Before finalising the survey instrument a pilot was undertaken to identify any potential challenges with the tool. The survey tool was piloted amongst 10 Aboriginal participants, including males and females ranging from 18 to 70 years of age in Perth, WA. The feedback from the participants provided information supporting that the language applied in the survey was easy to understand, and no questions were reported to be invasive or offensive. Participants were receptive to the design of the survey and were comfortable in completing the survey form [13].

FIGURE 1 | Our Gurlonngas, our future.

3.4 | Duty of Care and Engagement of Participants for Survey

The lead researcher practised duty of care in approaching the sensitive topic of FASD within the Aboriginal community, including engaging and working at a pace that responded to the social and emotional needs of the Aboriginal community. The lead researcher was flexible when engaging with the community in both rural towns and the metropolitan area. This included ensuring the involvement of Elders in each town and engagement with local community members, which served to guide the researcher in seeking participants, while minimising the risk of triggering potential trauma for participants. The criteria for participation in the survey were Aboriginal people aged 16 years and older, including both males and females living in

TABLE 1 | Marital and child status ($n = 180$).

Characteristics	Frequency	Percentage
Status		
Single	73	40.6
Married	47	26.1
Defacto—not legally married	53	29.4
Divorced/widowed	7	3.9
Do you have any children		
Yes	143	78.9
No	37	20
Age of respondents at first childbirth		
15–19	60	33.3
20–24	83	46.1
No child	37	20.6
How many children do you have?		
1 child	25	13.9
2 children	22	12.2
3 children	24	13.3
4 children	31	17.2
5 children or more	23	12.8
Not sure	20	11.1
Not applicable	35	19.4

Note: The majority of participants, 78.9%, had children and 30% had either 4 or 5 children. In response to the age participants were when they had their first child, the majority of participants (79.4%) were aged 15–24 years. At least 60 participants (33.3%) had their first child between 15 and 19 years of age. The marital and child status survey questions were utilised as a means to ascertain and build a profile of family configurations amongst participants in WA and provide valuable information about family structure. Of particular importance was the information on the age of respondents when they had their first child, supporting recognition that many participants became parents at a young age. This is important as it coincides with mid to late adolescence where experimentation with alcohol is not uncommon.

TABLE 2 | Information on alcohol ($n = 180$).

Item description	Frequency	Percentage
Growing up did you see any drinking of alcohol		
A lot	106	58.9
Sometimes	52	28.9
A little	19	10.6
No	3	1.7
Do you drink alcohol		
Yes	85	47.2
No	56	31.1
Never drank	7	3.9
Not any more	32	17.8
Family members and consumption of alcohol		
Mum	71	39.4
Dad	104	57.8
Nan	34	18.9
Pop	47	26.1
Aunty	113	62.8
Uncle	124	68.8
Brother	63	35.9
Sister	58	32.2
Cousin	85	47.5
Standard daily drinks		
1–2	23	12.8
3–4	17	9.4
5–6	21	11.7
7–9	7	3.9
10 or more	17	9.4
Not applicable	95	52.8
Six or more standard drinks on occasion		
Never	98	54.4
Less than monthly	27	15.0
Monthly	23	12.8
Weekly	21	11.7
Daily or almost daily	5	2.8
Not applicable	6	3.3
If you have a partner how often do you both have a drink together		
Single (not applicable)	46	25.6
Never	85	47.2
Less than monthly	27	15.0
Monthly	11	6.1
Weekly	9	5.0
Daily or almost daily	2	1.1

Note: In responding to questions on alcohol, 58.9% reported they had seen a lot of alcohol consumption growing up, 28.9% reported sometimes, and 10.6% reported they had not seen any drinking of alcohol. In relation to themselves, 47.2% reported they drink alcohol, and 3.11% reported that they do not drink, and 17% reported they no longer drink alcohol. Only 3.9% of participants indicated they 'never drank'. In response to how many standard drinks, 12.8% reported drinking 1–2 drinks; 9.4% reported 3–4 drinks; and 11.7% reported 5–6 drinks. In response to the question, how often do you have six or more standard drinks, the majority of participants, 54.4% reported never; 15.0% reported less than monthly; 12.8% reported monthly, and 11.7% reported weekly. In response to the question, how often do you drink with a partner, the majority, 47.2% reported never, and 15.0% reported less than monthly.

the Southwest region of Western Australia. In this context, local people informed on important issues such as 'sorry business' where a family member may have recently experienced a loss or funeral in their family [31].

3.5 | Data Collection Procedure

All surveys were administered by the lead researcher and first author at each site due to the sensitive nature of FASD, and the need to support cultural security and safety in engaging with the Aboriginal community. The paper-based survey was filled out by each participant and a total of 180 surveys were completed. An online survey tool would not have provided the opportunity for yarning about FASD while in the community. Yarning was identified by as a legitimate research method, and a culturally secure approach for working within the Aboriginal community [32]. Wilson [33, 34], identified that a critical aspect of Indigenous methodology is about 'relational accountability' (p. 177), and that gathering knowledge is a relational experience. In keeping with this approach, the lead researcher who is Noongar was immersed at each stage of the research, from the design of the survey tool, data collection, data entry, and data analysis in the Statistical Package for Social Science (SPSS). It is important that the instrument is administered, and data is collected in a standardised manner [35].

3.6 | Data Analysis

Participants characteristics and other key independent variables were presented as frequency and their percent. The prevalence of participants knowledge and awareness of FASD was also presented as frequency distribution. The quantitative data was entered and analysed using SPSS (version 20).

4 | Results

This research took place in WA and surveys were completed in six sites (one urban and five regional) including Northam

TABLE 3 | Awareness of fetal alcohol spectrum disorder (FASD) ($n = 180$).

Awareness of FASD	Frequency	Percentage
Yes	110	61.1
No	70	38.9
Length aware of FASD		
Recently within the last 12 months	26	14.4
Between 1 and 2 years ago	18	10.0
Longer than 2 years ago	136	75.6
Source of information		
Family member	38	21.1
Health professional (Nurse, GP, Health worker)	40	22.2
Health promotion	26	14.4
School teacher	3	1.7
Social worker	5	2.8
Police	3	1.7
Media	10	5.6
Aboriginal organisation	22	12.2
Other	10	5.6
Level of FASD awareness		
A lot	18	10.0
A little	100	55.6
None	62	34.4
Important to know about FASD		
Yes	165	91.7
No	7	3.9
Unsure	8	4.4
Family received information on FASD		
Yes	36	20.0
No	76	42.2
Unsure	68	37.8
Anyone in your family possibly have FASD		
Yes	68	37.8
No	26	14.4
Unsure	86	47.8

Note: The majority of participants, 61.1% reported awareness of the term FASD, and 38.9% reported no awareness. The majority, 75.6% had been aware of FASD for longer than 2 years and 24% had only been familiar with the term in the past 12 months to 2 years. However, only 10% felt they had a strong awareness of FASD, and the majority, 55.6% felt they only had limited awareness of FASD, and 34.4% stated they had no awareness of FASD. As noted above, 38.9% reported no awareness of FASD generally, and when asked about their level of awareness, 34.4% reported they had none, reflecting a slight discrepancy in reporting. In response to where they obtained their knowledge on FASD—Source of Information, 22.2% identified health professionals, 21.1% identified their family; 14.4% stated health promotion, and 12.2% identified Aboriginal organisations. An overwhelming 91.7% felt that it was important to know about FASD. In terms of whether participants family had received any information on FASD, 42.2% stated no, 37.8% were unsure, and 20.0% identified yes. In response to the question, do you think anyone in your family, extended or immediate, may have FASD; the majority, 47.8% were unsure; 37.8% identified yes, and 14.4% believed they did not have a family member living with FASD.

TABLE 4 | Has received information on FASD ($n = 180$).

	Frequency	Percentage
Has received information on FASD ($n = 180$)		
Yes	121	67.2
No	46	25.6
Unsure	13	7.2
Preferred types of health promotion ($n = 121$)		
Basic information	113	93.4
Referral for diagnosis	54	44.6
Referral for help with other services	55	45.5
Supporting a family member with FASD	57	47.1
Prevention	58	47.9
All of the above	51	42.1
Other	26	21.6
Preferred ways to receive FASD health promotion ($n = 121$)		
Small groups	55	45.5
One on one	22	18.2
Community forums	67	55.4
Online	18	14.9
Not sure	17	14.0

Note: In response to the question: Have you ever received any information on FASD, 67.2% reported 'yes'; and 25.6% reported 'no' and 7.2% reported to be unsure. The information community participants identified they would like to receive on FASD included the following: 93.4% indicated basic information, 44.6% reported referral for diagnosis, 45.5% reported referral for help with other services, 47.1% reported supporting a family member with FASD, 47.9% reported prevention and 4.12% reported all of the above. In response to how would you like information on FASD delivered, the majority 45.5% reported small groups, 55.4% reported community forums and 18.2% reported one on one training or learning.

(11 participants), Albany (17 participants), Katanning (30 participants), Tambellup (34 participants), Bunbury (21 participants) and Perth (67 participants). Participants were invited to complete a survey that gathered information about their age, gender, Aboriginal identity—described as Noongar, Wongi, Yamatji, and Noongar/Yamatiji; Noongar/Wongi and included three Aboriginal Australian language groups—Wongi, Yamatji, and Noongar. Participants were asked survey questions regarding their employment, parenting, level of education attained, experiences of trauma, and if they had a family connection to the Stolen Generations. The survey results include Marital and Child Status; Alcohol Consumption; Awareness of Fetal Alcohol Spectrum Disorder (FASD); Willingness to Receive Information on FASD; Consumption of Alcohol During Pregnancy—specifically, awareness of effects of alcohol on pregnancy and lactation; and History of Family—specifically Stolen Generations and Trauma and Support.

A total of 180 Aboriginal people participated in the survey, including 109 females (60%) and 71 males (40%). The age range of participants was 16–67 years of age, the median age was 44 and

TABLE 5 | Awareness on effects of alcohol on pregnancy and lactation ($N = 180$).

Awareness on effects of alcohol on pregnancy and lactation	Frequency	Percentage
Perceived adverse effects of drinking alcohol during pregnancy		
Yes	146	81.1
No	15	8.3
Unsure	19	10.6
Perceived adverse effects of drinking alcohol whilst breastfeeding a baby?		
Yes	154	85.6
No	11	6.1
Unsure	15	8.3
Do you know anyone (female) that drinks alcohol during pregnancy?		
Yes	122	67.8
No	58	32.2
Do you think it is common to drink alcohol during pregnancy		
Yes	58	32.2
No	91	50.6
Unsure	31	17.2
Was the woman who drank whilst pregnant?[a]		
Family member	109	60.6
Friend	70	38.9
Other	58	32.2

Note: The majority of participants, 81.1%, were aware of adverse effects of consuming alcohol during pregnancy and while breastfeeding. Most participants, 67.8%, indicated that they knew a female who had consumed alcohol during pregnancy. Thirty-two percent indicated it was common to consume alcohol during pregnancy and 60.6% identified that the female was a family member.
[a]Multiple responses and participants were able to tick more than one response for the above question as applicable.

TABLE 6 | History of family: Stolen Generations ($n = 180$).

	Frequency	Percentage
Were you or anyone else in your family part of the Stolen Generations?		
Yes	101	56.1
No	68	37.8
Unsure	11	6.1
If yes, was it?		
Me	24	13.3
Brother	20	11.1
Sister	21	11.7
Nan	43	23.9
Pop	30	16.7
Mum	34	18.9
Dad	35	19.4
Aunty/s	44	24.4
Uncle	36	20.0
Cousin	31	17.2
Great grandparents	22	12.2

Note: In response to the question was anyone in your family part of the Stolen Generations, the majority, 56.1% reported yes, and 37.8% reported no. For other family members, participants reported that 23.9% had a grandmother (Nan) removed under policies, 18.9% reported Mum, 19.4% Dad, 24.4% Aunty, 12.2% great grandparents, and 12.2% reported themselves removed under the policy of the Stolen Generations.

the standard deviation was 14 years. The majority of participants identified as being Noongar, 79%, 12% as Yamatji from the Gascoyne area and 7% as Wongi from the Goldfields region. Growing up, the majority of participants, 84%, were cared for and raised by their mother and 46% by their father, 17% by a grandmother and 12% by a grandfather. For the majority of participants, there was no change of the primary caregiver during their childhood, and only 17.8% experienced a change of primary caregiver. While the majority of participants were raised by their mother, other family carers included Dad, Sister, Brother, Nan, Pop, Aunty, Uncle, Cousin and 3.9% of participants were raised by foster carers.

4.1 | Personal Characteristics of Participants

The majority of participants (79.4%) had children, and their first child was born between the ages of 15 and 24 years, and 30% of participants had either 4 or 5 children. In relationship status, 40% of participants reported single status, 26% were married, and 29% were in a relationship but not legally married. The survey also collected data on employment status, housing, accommodation, and attained level of education. While the majority of participants had stable housing, sources of income varied, and 63% of participants reported receiving some form of Centrelink support [36]. Centrelink provides social security payments to Australians in need, and given the high number of participants receiving low income, poverty is a concern for many individuals.

In relation to education status, the majority of participants, 30% had completed year 10, 14% reported completing year 11, and 12% year 12 of high school. Seventeen percent had completed a degree or diploma. Five percent were currently attending high school, 5% were attending TAFE College, and 3% were attending university. The majority of participants at the time of this survey were not currently studying.

Participants were asked to share information about their marital and child status as described in Table 1.

5 | Discussion

This research explored the knowledge and understanding of FASD from a Noongar perspective in Western Australia and offers insights into topics such as experiences connected to alcohol

awareness around pregnancy and awareness of FASD. This research was contextually grounded in its recognition that many participants had a family history and connection to the Stolen Generations and the impact of this experience. It is recognised that alcohol use during pregnancy is a sensitive topic and that individuals living with FASD face many challenges over their lifespan. As such, this research offered insight into the experiences of Aboriginal people in Western Australia around FASD and it is recognised that the need exists to develop policy and best practice in this area. Further, broader policy development on FASD prevention and support across the lifespan is an important aspect in the development of evidence informed approaches and interventions [4, 6]

The results of this study support a sense of urgency to develop strong policy frameworks across relevant jurisdictions in WA including child protection, health, education, and justice settings where FASD often intersects [4, 37–38]. To underscore this point, the results of the Banksia Hill study identified the highest prevalence rate of FASD globally amongst incarcerated youth in WA [38]. Policy needs to address screening, access to diagnosis, and to support evidence-based interventions to support children, youth, and adults living with FASD, particularly adolescents involved in the justice system, as well as child and maternal health programs [4].

Community participants informed that 58.9% had witnessed alcohol consumption growing up, and while 61% of participants reported awareness of FASD, only a minority, 10%, rated their knowledge as strong (Table 2). Participants reported that approximately 33.3% had their first child between 15 and 19 years of age and 46.1% had children by age 24 years, reflective of a young parent demographic. Further, participants had on average 4–5 children and 78.9% of participants were parents (Table 1). A key finding was 32.2% of participants found it was common to consume alcohol during pregnancy (Table 3), and this closely aligns with research where a rate of alcohol consumption of 34% was identified for Aboriginal women during pregnancy [39]. This statistic alone suggests the time to provide education, training, health promotion and culturally secure intervention in response to FASD is now.

The survey results affirm that the family is at the centre of the Aboriginal community, with 21% of participants identifying the family as their key source of informing them on FASD (Table 4). Importantly, the need exists for local education and training opportunities on FASD that are culturally secure and grounded in community [15]. These findings support that the Aboriginal community in WA is seeking information on all aspects of FASD, including information relating to accessing diagnosis and supporting a family member with FASD (Table 4).

The majority of participants reported that either themselves (56.1%) or a family member was part of the Stolen Generation, which supports recognition of the impacts of colonisation on Aboriginal families (Table 5). Consequently, leadership and input from the Aboriginal community are essential in continuing to inform culturally secure service delivery approaches on FASD. Notably, a key finding was that 37% of participants indicated they had a family member with FASD (Table 6).

Cultural safety frameworks play a key role in informing communities about public health issues such as FASD [10]. Conducting this research led to opportunities to provide ongoing workforce training on FASD for key Aboriginal and non-Aboriginal agencies in Perth and the Southwest region of WA. Further, the Aboriginal community from each site requested training workshops on FASD, resulting in the lead researcher adapting FASD training by integrating a cultural lens, subsequently providing training on FASD to each site involved in the original study [13].

Culturally secure approaches recognise the need for training on FASD to be delivered on country in local communities by experienced and trained Aboriginal people that contextualise the historical and contemporary context of colonisation and FASD [4, 13]. Approaching FASD from a culturally secure position such as the Strong Born FASD campaign has done under the auspices of the National Aboriginal Community Controlled Health Organisation (NACCHO) will assist in alleviating stigma associated with FASD and will inform health promotion and service delivery [10]. Further, approaching FASD from a culturally secure position is key to alleviating stigma associated with FASD and enhancing access to diagnosis and early intervention [4, 12, 21]. In terms of cultural security in this study, participants identified their preferred approaches on FASD as in community forums, small groups, and one-on-one, allowing for the opportunity to yarn, debrief, and share information on the sensitive topic of FASD (Table 4). Culturally secure training on FASD for the Aboriginal community is recommended for building community capacity, particularly as the family was identified as a key source of informing on FASD [13].

6 | Conclusion

The results of this study offer insight into the experiences of 180 Aboriginal participants in Western Australia in relation to FASD. Given the intersection of colonisation, and particularly, the removal of Aboriginal children over many decades in WA, it is recognised that the impact of these experiences is deep and lasting. Awareness exists on the impact of alcohol use and pregnancy, yet poor awareness generally exists overall on FASD, which reflects a gap. In order to address this gap, it is important to offer training on FASD on country wherever possible and to continue to promote knowledge, develop policy, and best practice in this area. The engagement of 180 Aboriginal participants reflects both the deep concern and interest in FASD in the Aboriginal community.

Further, it is important to develop services and improve advocacy for children and adults living with FASD through supporting assessment, prevention, and interventions across the lifespan. It became evident through conducting this study that a genuine need exists for resourcing Aboriginal organisations to be effectively supported to engage in all levels of responding to FASD. This requires the development of infrastructure through the provision of adequate and sustainable funding in the interest of health promotion that includes the support of critical activities related to screening, assessment, diagnosis, disability awareness, planning, and the opportunity for people living with FASD to receive disability supports across their lifespan. Decolonising FASD in Australia means the provision of culturally safe and secure approaches and

resources to this lifelong disability. Responding to FASD requires a whole-of-community response, and prevention of FASD requires grassroots community involvement.

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Ethics Statement

Ethical approval was received from the Western Australian Aboriginal Health Ethics Committee (WAAHEC, Reference number 484) and Curtin University (HR 175).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data reported in this research can be located in the original dissertation by RW. Available online: https://espace.curtin.edu.au/handle/20.500.11937/70736.

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