

## It takes a village: Influencing policy and practice to prevent alcohol use in pregnancy and promote better outcomes for individuals living with Fetal Alcohol Spectrum Disorder

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### Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder caused by exposure to alcohol in utero. It has pervasive, lifelong impacts and is recognised as a major public health concern in many countries where alcohol is used. The FASD Research Australia Centre of Research Excellence (CRE) was funded by the National Health and Medical Research Council to generate and translate evidence to address prevention, diagnosis, and management of FASD in Australia. The current paper describes the approach to policy and practice impact taken by our CRE, including our stakeholder engagement processes and the key principles that underlie our approach. We provide examples of policy and practice influence in FASD prevention, diagnosis and management that have been achieved over the past five years and discuss challenges that are routinely faced in the translation of our work.

### Keywords

fetal alcohol spectrum disorder; policy; research translation; consumer involvement; alcohol

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## Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong neurodevelopmental condition characterized by severe impairments across several domains of functioning. It is caused by prenatal exposure to alcohol and is associated with pervasive health and psychosocial impacts across the life course. With a global prevalence of 0.77% [1] and significantly higher prevalence in special subpopulations such as children in out-of-home care, special education, and justice settings [2], FASD is considered to be the most prevalent “largely preventable” disability [1]. In Australia, as in many countries around the world, a high prevalence of alcohol use in pregnancy coupled with the pervasive impacts of FASD have underscored the need for a comprehensive multi-sector response to prevention, diagnosis, and management. FASD Research Australia, a Centre of Research Excellence (CRE), was established in 2016 with funding from Australia’s National Health and Medical Research Council (NHMRC) [3]. The CRE takes a national approach to research and translation, with three aims: (1) preventing alcohol use in pregnancy and its effects on child health; (2) decreasing the incidence of FASD; and (3) improving national FASD diagnostic capacity and management through effective interventions. Our network includes sixteen senior investigators and thirteen staff and post-graduate students working across clinical and research fields including public health, epidemiology, paediatrics, neuropsychology, speech-language pathology, molecular biology, health systems research, and economics; a consumer reference group of sixteen, including Aboriginal and Torres Strait members; and a national network of affiliates in health, justice, education, and disability sectors.

A key outcome measure of the CRE is the effective transfer of research outcomes into policy and practice. Our approach (illustrated in Figure 1) is based on the established Promoting Action on Research Implementation in Health Services (PARIHS) framework [4] in which successful implementation is considered to be a function of the nature and type of evidence (e.g., research, clinical experience, consumer experience, local information), the context (e.g., culture, leadership, evaluation), and facilitation of the implementation process (e.g., internal and external persons as facilitators). Thus, central to our approach, in addition to the collection and generation of evidence to fill knowledge gaps, is the importance of understanding the contexts in which evidence is to be translated, as well as the role of communication, facilitation, and advocacy for effective translation. Given the prevailing view that consumers, researchers, practitioners, and policymakers comprise fundamentally different communities, we recognise the need for multiple, targeted mechanisms to improve crosstalk between communities and increase the efficiency of the research-to-impact cycle. This includes comprehensive and ongoing stakeholder engagement, structures to enhance communication and knowledge exchange, and engagement with individuals in research, practice and policy settings who are trained to form bridges between different settings and stakeholders. In the current paper, we outline our approach to influencing policy and practice and provide examples of policy and practice impacts achieved over the past five years.

## Our approach

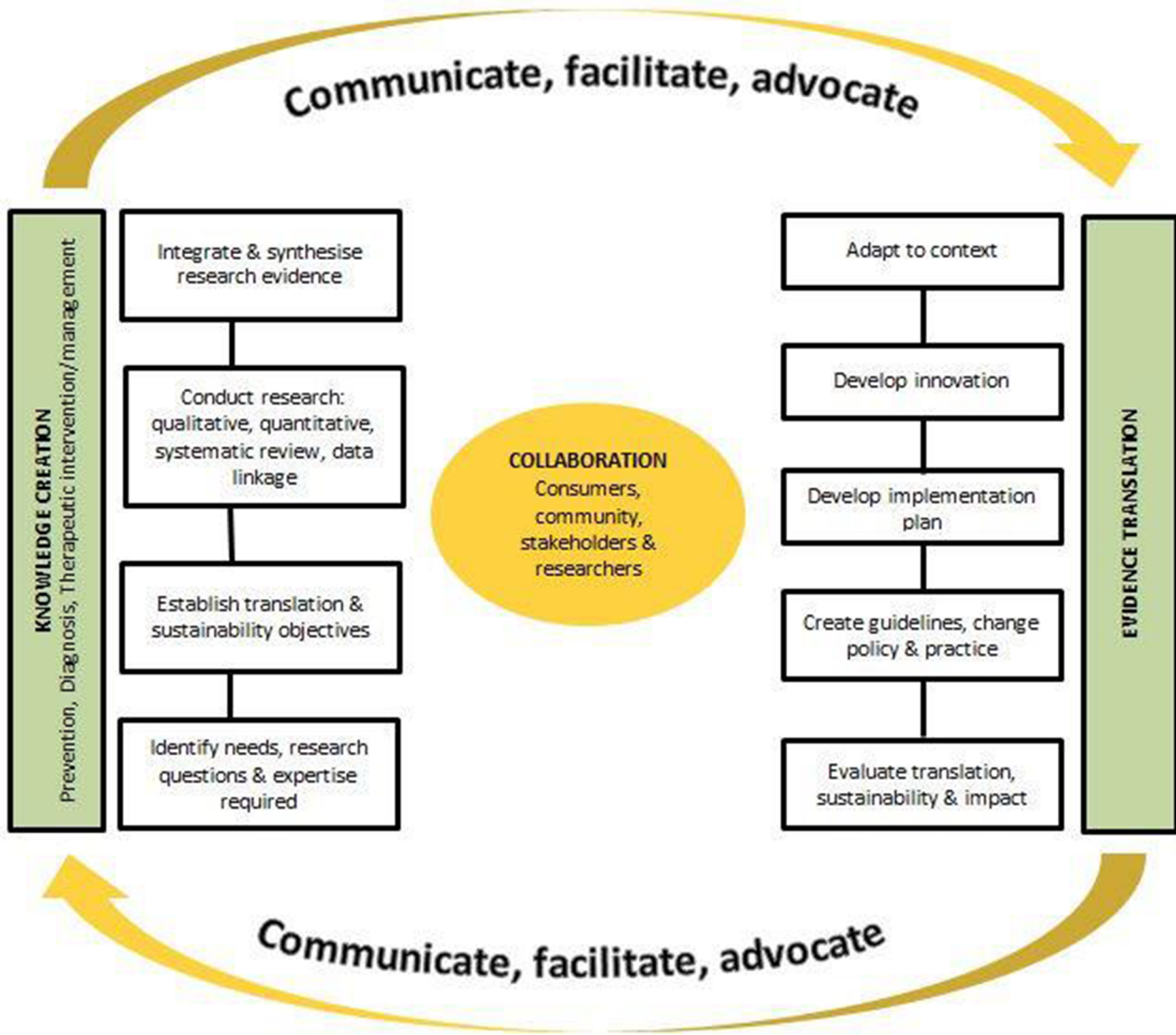
As demonstrated in Figure 1, partnerships between consumers, community members, stakeholders, and researchers are at the core of our approach to influencing policy and practice. Accordingly, the first step is to identify relevant stakeholders in the fields of prevention, diagnosis, and management of FASD. This includes decision-makers and service-providers across an array of sectors and fields, including public health, antenatal care, substance dependence, pediatrics, allied health, child protection, disability, education, justice, and community-based agencies that support families. Consumers and community members – including members of the public and those with lived experience of FASD – are key stakeholders in our work. We developed a consumer and community engagement plan to ensure that these groups can engage in our work in a way that is safe, respectful, and empowering.

Consumer and community involvement is integrated into all types of research conducted within the CRE, as outlined in Figure 2. Individual projects have specific consumer groups, and we established an overall CRE Consumer Reference Group, co-chaired by two consumer members. The Consumer Reference Group members live in six different States/Territories, and four members are from non-metropolitan locations. These stakeholders are routinely involved in guiding and advising on CRE research priorities and methods and engaging in translation and dissemination activities. For example, in 2018 we established a priority-setting partnership to facilitate community involvement in identifying the Top 10 priorities for FASD research in Australia and setting our research direction [5]. This process was designed to ensure that research undertaken by our CRE is relevant and meaningful. The need to change societal views and beliefs about alcohol use during pregnancy through a national public health campaign was identified as the most urgent priority. Information about the priorities for research was included in lobbying and advocacy to government, which with strong lobbying from our colleagues at the Foundation for Alcohol Research and Education (FARE) and NOFASD Australia (the national peak organisation representing the interests of individuals and families who are living with FASD), resulted in funding in 2020 for a national awareness campaign [6].

## Communication

Communicating our research process and outcomes to multiple stakeholder groups requires curiosity about the meaning of different types of evidence for different audiences, and how that meaning can be conveyed in an accessible and engaging manner. Examples of diverse research and translational outputs for different stakeholder groups include a policy brief on reducing harms related to alcohol use in pregnancy [7], the Australian Guide to the Diagnosis of FASD (and associated e-learning modules) [8], an e-learning module for health professionals, video and online resources for General Practitioners [9] and a report documenting recommendations regarding screening for FASD [10] (see Table 1). Research data generated by the CRE were presented to a Senate Inquiry into FASD [11–13], and influenced government policy through inclusion in the National Action Plan for FASD (2018–28) [14].

Figure 1: FASD Research Australia, NHMRC Centre of Research Excellence: approach to policy and practice influence



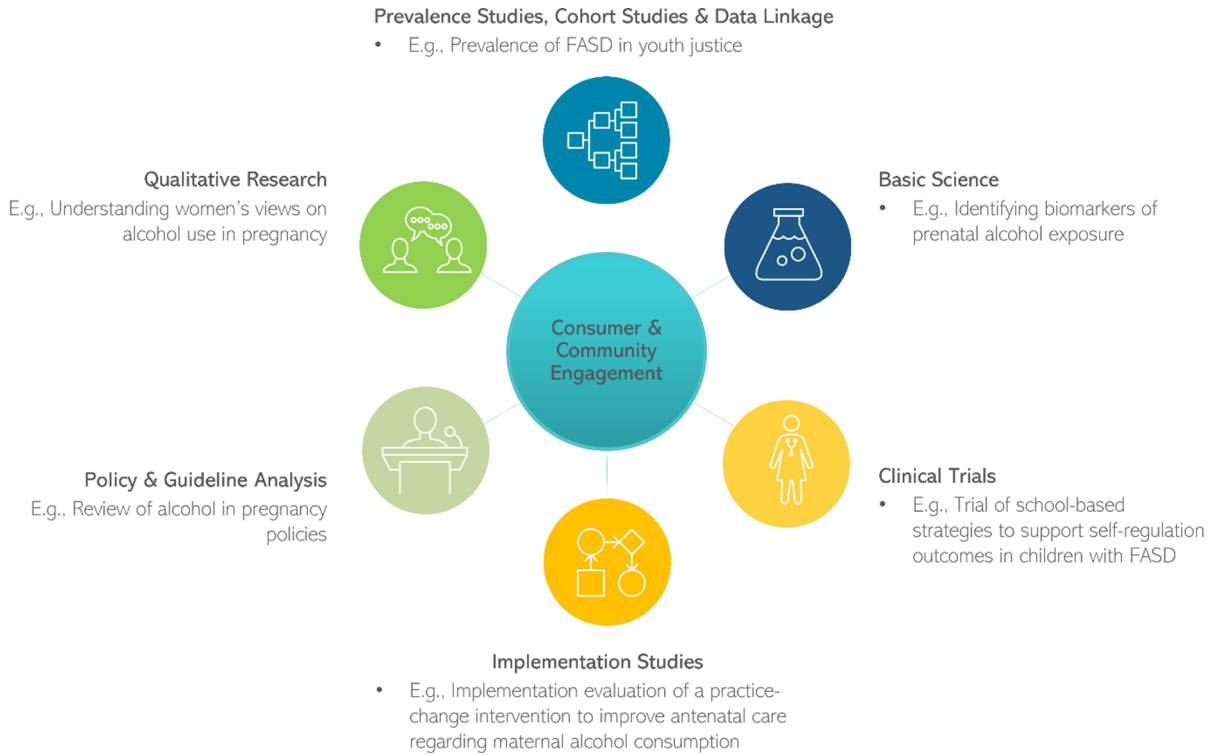
Fundamental to our approach is the view that communication is not a unidirectional *push* of evidence into policy and practice, but rather an ongoing dialogue between researchers and consumers, clinicians, and/or policy makers to understand the demands and constraints of policy and practice settings, gain insight into the needs of different stakeholders, and determine the value proposition of research translation outputs. Mechanisms for multi-way communication with consumers include community consultation, an overarching consumer reference group for the CRE (in addition to project-specific groups), and community forums. Other mechanisms include conferences, such as the Australasian FASD Conference [15] convened by FASD Research Australia, in which consumers were invited to co-chair sessions, present their lived experience, and network with researchers and other stakeholders. A major initiative has been the development, maintenance and expansion of resources for stakeholders including via the government-funded FASD Hub Australia, a website ([www.fasdhub.org.au](http://www.fasdhub.org.au)) led and run by CRE investigators and partners. This Hub provides current, high-quality, evidence-based information about alcohol use,

pregnancy and FASD, including resources on prevention, diagnosis, and treatment in Australia, for health and other professionals, researchers, policy makers, parents and carers and the public.

### Facilitation

Facilitating the translation of evidence into practice has required us to understand the barriers to translation e.g., [16] and have an ongoing commitment to next steps for pursuing translation, dissemination and implementation of research outputs long after the research cycle has ended. For example, having established through community focus groups that women expect health professionals to provide consistent advice about alcohol use in pregnancy, and recognizing the need to build workforce capacity in this area, we worked with a range of stakeholders to develop a brief learning guide for health professionals [17]. The guide set out the why, how, and when of screening women for alcohol use during pregnancy, highlighting the importance of asking women about their alcohol use when pregnant, and providing guidance for

Figure 2: Overview of different types of research conducted within the CRE



midwives on using the Alcohol Use Disorders Identification Test (AUDIT-C), an evidence-based alcohol screening tool, for this purpose. By embedding research into our dissemination and implementation strategies, we can gauge whether we have impacted practice as intended. For example, in a health service test of the learning guide, we saw a 200-fold increase in alcohol screening scores being accurately recorded at least once in women's medical records following introduction of the guide. Once the learning guide for asking about alcohol use in pregnancy was developed, we worked with decision-makers at the state health system level to have the learning guide added to the Western Australia (WA) Health education portal. Similarly, in response to our work on interventions for managing alcohol use in pregnancy [18], the New South Wales government agreed to incorporate the AUDIT-C into electronic maternity records state-wide to enable clinicians to ask and advise about alcohol use in pregnancy and refer women for support.

## Advocacy

Across our research and translation activities, we also aim to understand and be informed by the broader policy context of the practice changes for which we advocate. This helps us to be responsive to systemic barriers and facilitators to practice change, which is crucial given that promoting clinical practice changes is challenging in a health environment where everyone is asked to do more with less. For example, to complement practice changes driven by the introduction of our learning guide, we advocated at a systems level for a policy change; the inclusion of alcohol screening scores in the WA Midwives Notification Form (MNF). The MNF is a mandatory administrative data collection form that is routinely completed by midwives for each birth of a fetus or infant born more than

20 weeks gestation or 500grams in weight. MNF data are incorporated into a comprehensive perinatal data collection, maintained by the state Health Department. Achieving the inclusion of alcohol screening scores in the MNF acts as a consistent prompt to midwives that alcohol screening outcomes is a routine reporting requirement. Furthermore, it provides data to measure the sustainability of practice changes, as well as providing an indicator of the impact of initiatives designed to prevent alcohol use in pregnancy. We also advocate through media engagement. Further examples of how communication, facilitation and advocacy have been embedded in our research to support policy and practice impact are described below.

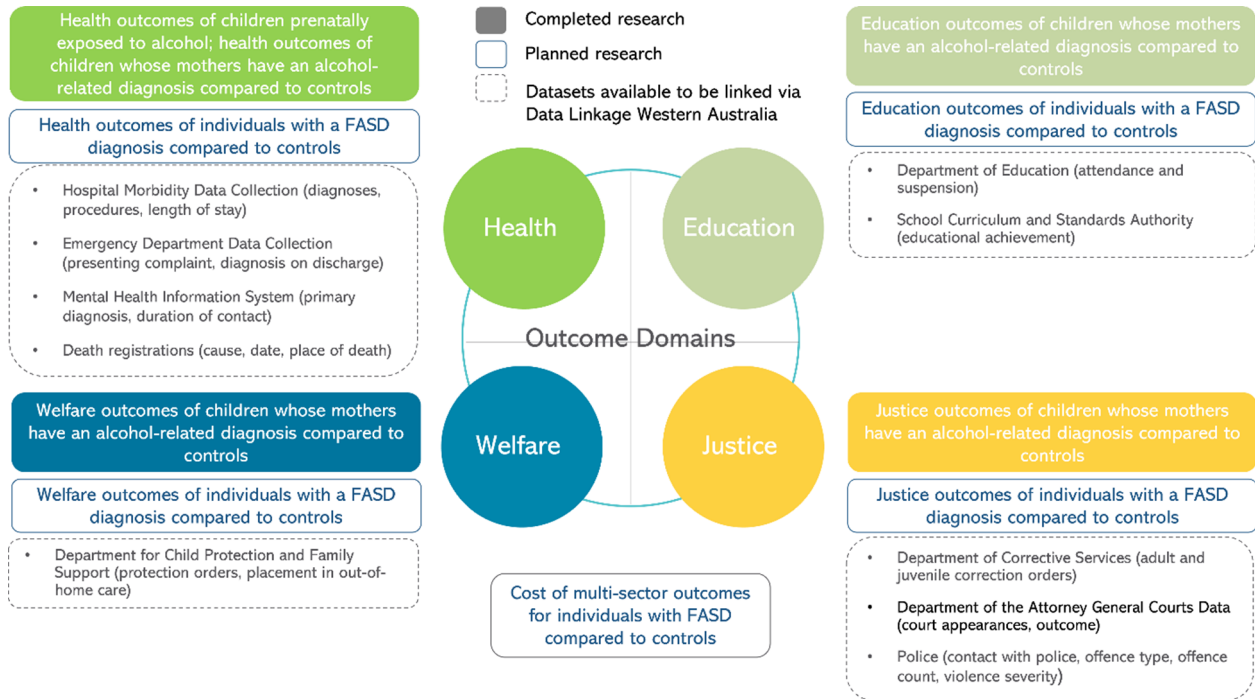
## Discussion

Data generated by the CRE have identified and filled knowledge gaps and informed clinical practice and policy in the prevention, diagnosis and management of FASD (Table 1). We contributed invited Evidence-Practice/Policy Gap (EPPG) synopses for the NHMRC's 2020 EPPG (Indigenous Health) report [19, 20] and informed the National Action Plan for FASD [14] and the Senate Inquiry into Effective Approaches to Prevention, Diagnosis and Support for Fetal Alcohol Spectrum Disorder [13]. Several of our studies (both completed and planned) rely on the use of existing data infrastructure, such as administrative data that can be linked to maternal alcohol use disorders [21], prenatal alcohol exposure [22] or cases of FASD (see Figure 3). It is also important to acknowledge the diversity of perspectives, research focus areas, and outputs that have influenced policy and practice change; collectively the importance of our ongoing work to public health was highlighted in a case study by the NHMRC [23]. Below, we

Table 1: Examples of policy and practice influences from our CRE research

Type of influence and associated CRE research	Examples of policy and practice influence
<b>Prevention</b>	Contributions and submissions to the following: Australian Government FASD Roundtable 2016; National FASD Strategy 2017; NHMRC review of Alcohol Guidelines 2017–2020, Global Alcohol Strategy 2017; National Breastfeeding Strategy 2017 and Beyond; National Alcohol and Drug Strategy 2018, Treatments for Drug and Alcohol Disorder, Mandatory Labelling of Alcohol, 2018; National Clinical Practice Guidelines – Pregnancy Care 2018; Mandatory Recording of prenatal alcohol exposure, 2018; WA Chief Health Officer’s Submission to the licensing authority in respect to the extent of alcohol related harm being experienced in Hedland and surrounds; The Senate Community Affairs References Committee for Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder.
Submissions and contributions to policy development, government Inquiries, and advisory committees regarding the prevention of alcohol use in pregnancy [7, 26, 27, 61, 62]	FASD Hub Australia; Development of WA health professionals’ learning guide; Integration of AUDIT-C, advice and referral, into NSW e-maternity records; Development of GP education modules, available Australia-wide
Building workforce capacity to prevent FASD by asking about, and advising on, alcohol use in pregnancy [18, 19, 26–29]	Pilot study of Parent Child Assistant Program in WA, in partnership with Women’s Health and Family Services built capacity of our service partner while generating crucial data for the feasibility of the program in WA
Partnering with service providers to implement and evaluate tertiary alcohol harm reduction programs	Invited report: Screening for fetal alcohol spectrum disorder (FASD) in Western Australia: Policy and Practice recommendations (WA Health) [10] National FASD surveillance: Australian Paediatric Surveillance Unit and FASD Registry.
<b>FASD Screening, Diagnosis, and Surveillance</b>	Development of the Australian Guide to the Diagnosis of FASD (the Guide) and associated e-learning modules; training health professionals in use of the Guide; involvement in several working groups for the revision to the Guide. Service Guide and information on diagnosis provided on FASD Hub Australia
Submissions and contributions to policy development, government Inquiries, and advisory committees regarding screening for FASD [63, 64]	Response to the Coroner’s report on the Kimberley Youth Suicides (Coroner’s Court of Western Australia); The Royal Commission into Institutional Responses to Child Sexual Abuse, Australian Government; Australian Government response, Senate Community Affairs References Committee Inquiry report: Accessibility and quality of mental health services in rural and remote Australia.
Building workforce capacity to diagnose FASD [8]	Feedback on FASD in schools online learning modules (Department of Education, Western Australia); Alert program in the Fitzroy Valley WA; Positive parenting training to education, health and other professionals, Fitzroy Valley, WA.
<b>FASD Management</b>	Development of Reframe training; Involvement in the development of Australia’s first Clinical Guideline for Speech Pathology in Justice (Speech Pathology Australia); Contributed to development and implementation of the speech pathology program in youth justice in Queensland (Department of Justice and Attorney-General, Queensland); Provision of requested proposal to train intermediaries (communication assistants) for court contexts (Department of Justice, WA).
Submissions and contributions to policy development, government Inquiries, and advisory committees regarding assessment and support of individuals with FASD in the health system	Revision of the Western Australian Supreme Court Equal Justice Bench Book (Department of Justice, Western Australia); Council of Attorneys-General Age of Criminal Responsibility Working Group Review (Australian Government); A Therapeutic Approach (Pilot Court) for Protection and Care in the Children’s Court of WA, Discussion paper (Department of Justice, Western Australia); Review of the Young Offenders Act 1994 (Department of Justice, Western Australia); The Royal Commission into the Protection and Detention of Children in the Northern Territory (Australian Government); Terms of Reference for Incarceration Rates of Aboriginal and Torres Strait Islander Peoples (Australian Government); Commonwealth Senate Community Affairs Reference Committee on Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia (Australian Government).
Building education workforce capacity to support students with FASD [51, 53]	
Building justice workforce capacity to support justice-involved youth with FASD and other neurodevelopmental disorders [65–69]	
Submissions and contributions to policy development, government Inquiries, and advisory committees regarding assessment and support of individuals with FASD in the justice system [67–69]	

Figure 3: Overview of completed and planned work conducted using linked administrative data



document examples of policy and practice influence across our three key focus areas, and discuss the strengths and limitations of our approach, as well as future challenges for the field.

## Prevention of FASD

Our research documented ongoing high rates of alcohol use ( $\geq 50\%$ ) in pregnancy cohorts in several Australian regions [24–28]. Some of this consumption is in unplanned pregnancies, often with binge drinking in the very early stages, indicating that although many women will stop drinking once aware of their pregnancy, others continue, unaware or disbelieving of potential harms to the unborn baby. Our research also indicates that women want to receive information from health professionals [29]; together, these findings informed strategies to prevent alcohol use in pregnancy. For example, CRE investigators helped develop and advocate for mandatory, evidence-based pregnancy warning labels on alcohol harms [30]. Strong relationships with NOFASD Australia and FARE ensured scientific evidence and stories from families with lived experience were presented to the Australian and New Zealand Ministerial Forum on Food Regulation and formed the basis of a national campaign. When the ministers met in July 2020 to vote, they listened to the community and placed the health and safety of families first by voting to have mandatory, visible and effective health warning on alcohol products legislated from 2023 [31]. Our work also supported the updated NHMRC guidelines to prevent harm from alcohol use in pregnancy [32] and the Australian government’s commitment to the National FASD Program (<https://fare.org.au/fasd-program/>) to prevent harms from alcohol use in pregnancy, for which CRE members contribute to the national Steering Committee.

Prevention of alcohol use in pregnancy also involves specialised, long-term support for women with complex

alcohol use behaviours. The Parent-Child Assistance Program (PCAP), designed to address this need, was developed in the United States [33] to assist pregnant women at high risk of prenatal alcohol exposure. PCAP is effective in helping clients access treatment, reduce alcohol and drug use, maintain child custody, and preventing future births of AOD exposed infants [34–36]. Our CRE investigators conducted the first PCAP pilot trial in Australia, in partnership with a local service provider. The pilot highlighted the need for better capturing positive outcomes associated with the program that are not assessed by the standard questionnaires. Therefore, a process has begun to co-design new evaluation tools with inclusion of clients, case-managers, and government representatives. Inclusion of government policymakers in this process will improve the relevance of outcome measures collected and their capacity to influence decision-making for future funding of evidence-based prevention program.

## Screening, diagnosis and surveillance

Earlier research by CRE members [37] indicated that Australian clinicians were unskilled or unwilling to make a FASD diagnosis and did not know where to refer for assessment or FASD management, leading government to fund diagnostic guidelines. The CRE Directors successfully tendered to develop the Australian Guide to the Diagnosis of FASD [8] and accompanying e-modules for health professional training [38]. Funding was also provided for national prospective surveillance of FASD through the Australian Paediatric Surveillance Unit [39] and development of the FASD Australian Registry [40]. Since publication of the Guide in 2016, CRE members have trained health professionals nationally in its use and over 600 incident cases of FASD, diagnosed using criteria in the Guide, have been documented, providing current data to inform future education and prevention policy and health service

planning. This research identified the need for more diagnostic services and influenced the provision of government funding for expansion of diagnostic services [41]. CRE members are also exploring potential new methods to confirm FASD diagnoses, which will ultimately inform clinical guidelines. For example, through the Lililwan Project, we identified the appropriate normative charts for use in assessing the sentinel facial features of FASD in Australian Aboriginal children [42]. In partnership with external collaborators, CRE investigators are exploring new methods for FASD assessment, including using 3D facial imaging (39, 61), identifying novel facial features [43], and conducting epigenetic studies [44]. The Guide is now undergoing review, with CRE members serving on review panels and steering groups.

Another key success of the CRE and its influence on policy was our study of FASD prevalence in youth detention (45). This study was the first to explore the prevalence of FASD among young people involved with the Australian youth justice system, following international data indicating that youth with FASD were 19 times more likely to be incarcerated when compared to their peers without FASD [45]. The research was guided by a consumer reference group, a steering group (representatives from detention centre, Aboriginal legal services, a national disability network and NOFASD), and a reference group from the state government Departments of Justice and Child Protection and Family Services. Our study identified the highest known prevalence of FASD in a corrective setting worldwide (36%) and provides evidence of an extraordinary level of neurodevelopmental impairment amongst sentenced youth in WA [46].

Since the completion of the prevalence study, multi-disciplinary neurodevelopmental assessments are now frequently being requested during Children's Court proceedings nationally, and our research team has been consulted to explore how neurodevelopmental assessment could become routine for youth in detention in several states and territories. Within WA, the team has been invited to contribute to internal business proposals for the Department of Justice and advise on appropriate assessment tools and operational plans. New information sharing methods have been implemented across the WA youth justice system because of our study, with implementation of a new electronic notification system to inform staff of a young person's neurodevelopmental needs and diagnosis. Communication with other youth justice agencies in Australia has indicated that several jurisdictions plan to implement recommendations from our study, with the New South Wales, South Australia and Queensland youth justice agencies employing allied health professionals for the purpose of carrying out more comprehensive assessment and intervention approaches.

## Management of FASD

CRE research has also influenced management of FASD. For example, the Lililwan Project [47] identified rates of alcohol use in pregnancy (55%) [48] and FASD (19%) [49, 50] in remote Aboriginal communities that are amongst the highest in the world and identified almost universal early life trauma, learning, developmental and behavioural problems. In response, a randomised-controlled trial of a

culturally appropriate modification of the Alert program was trialled in primary schools to address impulse control and executive functioning [51]. Additionally, a community-modified, Indigenous Triple-P (positive parenting program) called Jandu Yani U [52] was introduced and shown to increase parents' skills and confidence, decrease challenging behaviours and decrease parental anxiety [53]. This in turn provided data for advocacy and resulted in funding for continuation of the program. At the Aboriginal community's request, we are currently undertaking a 10-year follow-up study on the Lililwan cohort (the Bigiswun Kid Project) to understand and advocate for the needs of adolescents with FASD [54].

Similarly, our study of FASD prevalence in youth detention has had significant implications for the justice system at all stages, and for other sectors who engage with vulnerable populations of children and young people. In particular, the findings drew attention to the immediate need to efficiently identify individuals with FASD and other neurodevelopmental impairments who are involved with the justice system, and to provide appropriate rehabilitation and therapeutic interventions and management during their involvement with the system. Immediate translational outcomes of our study included: tailored reports of each young person's strengths and difficulties provided to parents and carers, guiding service provision within and after detention; individual reports developed from assessments and used in court to mitigate sentencing and set legal precedents for how FASD is considered in court proceedings; engagement of interpreters in the forensic context for young people whose first language is not Standard Australian English; widespread FASD awareness raising through consumer and community engagement and media coverage. Also as part of the study, we worked closely with the WA youth justice workforce to develop Reframe Training, an evidence-based training intervention for management and support strategies most appropriate for youth in the justice system who may have FASD or other neurodevelopmental impairments [55]. After developing, implementing and evaluating Reframe Training with over 100 staff at WA's Banksia Hill Detention Centre, the program has since been delivered to over 400 justice and community services professionals across WA and the Northern Territory. To date, all other youth justice agencies across Australia have expressed interest in accessing Reframe Training, and multiple other sectors nationally and internationally have requested access to the training, including the police, child protection, education and health sectors. This research demonstrates a clinically and empirically-grounded approach to achieving sustainable improvements in knowledge and practices to ensure better care for young people with FASD, and has potential to create pivotal policy and practice change across Australia regarding the daily management and support of young people with FASD and neurodevelopmental impairment.

## Strengths and limitations of our approach

The breadth and scope of our multidisciplinary network and partnerships with stakeholders across sectors, including government, are a notable strength of our CRE and our translation framework. Coordinated stakeholder engagement

at multiple levels supports the capacity of government and non-government organisations to contribute to FASD prevention, diagnosis, and management, and ensures that knowledge translation outcomes, program structure and strategic directions of our CRE respond to stakeholder-identified priorities. This is spearheaded by strong leadership from our CRE Directors, who support integration of research and translation outputs across all themes of our CRE and ensure consistent advocacy for evidence-based policy and planning. Both CRE Directors are recognised nationally and internationally as leaders in FASD research and translation and were invited members of the Australian Health Department's national Advisory Group on FASD strategy. In turn, the success of the CRE has been enhanced through the national focus on FASD and funding from the Commonwealth government. Having a coordinated and diverse network of researchers, practitioners, consumers, and advocates working under the guidance of our Directors supports impact across multiple, interactive policy and practice contexts that is difficult to achieve with smaller or less coordinated efforts. Importantly, involvement in this network allows our early- and mid-career researchers to conceptualise the policy and practice implications of their work from the outset, and the opportunities afforded through the CRE have supported them to develop skills necessary to achieve and articulate research impact.

Nevertheless, there are several limitations of our approach that we continuously strive to address. For example, in determining translation objectives for our research, we aim to balance perspectives of consumers and community members with those of service-providers, policymakers, and decision-makers. However, priorities are not always aligned and ensuring equal representation of voices – particularly from marginalised groups – is not always possible. Promoting the engagement of representatives from marginalised groups in our research is an ongoing priority for our CRE. Furthermore, while there are specific “levers” that are highly influential for policy and practice change, our access to these levers is usually contingent on obtaining funding to do the necessary research. For example, economic evidence on the costs of FASD in Australia is critical for informing resource-allocation decisions, however we have been unable to secure funding to undertake this research, despite having access to extensive, record-linked datasets to enable such analyses.

## Challenges and future directions

Reducing harms associated with alcohol use in pregnancy and increasing Australian capacity for FASD diagnosis and management remain a challenge. Alcohol policy in general is a complex issue with strong socioeconomic implications such that people who experience greater socioeconomic disadvantage are more likely to experience complex harms related to alcohol use and less likely to benefit from universal prevention efforts. Accordingly, policy and practice efforts to reduce harms associated with alcohol use must not inadvertently widen health disparities after implementation [7]. Furthermore, the complexity of alcohol policy is heightened with regard to alcohol use during pregnancy, where the imperative to reduce harm to the unborn child intersects with the need to

protect women's autonomy [56]. These competing concerns are centred in public dialogue regarding alcohol use and impact on the degree to which changes to alcohol policy and practice feasibly influence alcohol use behaviours.

Another major challenge to reducing harms associated with alcohol use in pregnancy is the influence of the alcohol industry in policy arenas [57, 58]. The alcohol industry can impact policy in several ways: (1) by influencing the framing of policy debates so that issues that conflict with commercial interests are excluded from the agenda [59]; (2) by building relationships with key actors in policy arenas to reduce threats to commercial interests [59]; (3) through misuse of evidence [57]; and (4) by rejecting the effectiveness of evidence-based policies [57]. Such activities undermine the progression of evidence-based alcohol policy; for example, delaying the implementation of mandatory alcohol health warning labels in Australia [60]. Future advocacy in this area should focus on demanding that governments exclude the alcohol industry from consultation on strategies designed to regulate alcohol products [30].

Equitable access to FASD diagnostic and support services remains a major policy challenge nationally. Individuals with FASD experience complex social, health, and educational difficulties throughout the lifespan. Accordingly, lifelong supports and services are required to help manage these difficulties and promote improved health and wellbeing. Our FASD prevalence study in youth detention highlighted that access to diagnostic services for justice-involved youth and other vulnerable populations is imperative to ensure equality before the law for those with FASD. Despite this high level of need, there are few examples of diagnostic services accessible to individuals with unidentified neurocognitive impairment who are involved in the justice system. Similarly, in Indigenous, education and disability sectors where funding for accommodations and support is contingent on diagnosis, inequitable access to diagnostic services can compound the challenges faced by individuals with FASD over the long term. Stigma surrounding FASD is also a key challenge to be addressed if efforts to improve diagnostic and management capacity in Australia are to achieve equitable impacts.

As in almost every area of research, the efficiency with which research is translated into policy and practice is a major challenge. We aim to increase efficiency through maintaining long-term stakeholder partnerships and advocating for targeted research funding to address recognised policy and practice gaps. Nevertheless, we cannot always get the traction we want with policymakers, nor are we always able to produce evidence that policymakers require when they need it. Although the five-year funding afforded through a CRE supports capacity for comprehensive and targeted research and translation, more integration of researchers and stakeholders is required to establish and maintain momentum for translation. Moreover, it is important to note that funding support of this duration is increasingly the exception rather than the rule in health research. Universally, ongoing funding security is necessary if researchers are to be more agile and responsive in the face of shifting policy and practice priorities. Another challenge to the efficiency of research translation is the question *what is the threshold at which there is enough evidence to act?* For decades, debate about the impact of small to moderate levels of alcohol use in pregnancy has



raised questions about acceptable levels of risk and concerns about “moral panic” in FASD prevention. Yet the question of evidentiary thresholds is not one that applies only to prevention, but also to our efforts to improve diagnostic precision and effective management for those living with FASD. The evolving nature of evidence means that research and translation should be an iterative, ongoing process. This requires funding stability, employment security for research personnel, engagement with stakeholders and consumers over the long term, and time to evaluate the effectiveness of prevention, diagnosis and management strategies.

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## Ethics and consent

This paper reports no original data and is therefore exempt from ethical review.

## Conflicts of interest

None declared.

## References

1. Lange S, Probst C, Gmel G, Rehm J, Burd L, Popova S. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis. *JAMA Pediatr.* 2017;171(10):948–56. <https://doi.org/10.1001/jamapediatrics.2017.1919>
2. Popova S, Lange S, Shield K, Burd L, Rehm J. Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction (Abingdon, England).* 2019;114(7):1150–72. <https://doi.org/10.1111/add.14598>
3. FASD Research Australia. FASD Research Australia Centre of Research Excellence Australia: FASD Hub Australia; 2021. Available from: <https://www.fasdhub.org.au/research-and-publications/fasd-research-australia/>
4. Kitson A, Harvey G, McCormack B. Enabling the implementation of evidence based practice: a conceptual framework. *Quality in Health Care.* 1998;7(3):149–58. <https://doi.org/10.1136/qshc.7.3.149>
5. Finlay-Jones A, Symons M, Tsang TW, Mullan N, Jones H, McKenzie A, et al. Community priority setting for fetal alcohol spectrum disorder research in Australia. *International Journal of Population Data Science.* 2020;5(3). <https://doi.org/10.23889/ijpds.v5i3.1359>
6. Foundation for Alcohol Research & Education. FARE welcomes federal government commitment to fetal alcohol spectrum disorder Canberra, ACT: Foundation for Alcohol Research & Education; 2020. Available from: <https://fare.org.au/fare-welcomes-federal-government-commitment-to-fetal-alcohol-spectrum-disorder/>
7. Finlay-Jones A. Reducing harms related to alcohol use in pregnancy: policy and practice recommendations. Canberra, ACT: Deeble Institute for Health Policy Research; 2018. Available from: [https://ahha.asn.au/system/files/docs/publications/deeble\\_issues\\_brief\\_no.\\_28\\_reducing\\_alcohol\\_use\\_in\\_pregnancy.pdf](https://ahha.asn.au/system/files/docs/publications/deeble_issues_brief_no._28_reducing_alcohol_use_in_pregnancy.pdf)
8. Bower C, Elliott AJ, Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)". Australia; 2020. Available from: [https://www.fasdhub.org.au/contentassets/32961d4a5cf94de48ebcf985c34d5456/australian-guide-to-the-diagnosis-of-fasd\\_all-appendices\\_feb2020.docx.pdf](https://www.fasdhub.org.au/contentassets/32961d4a5cf94de48ebcf985c34d5456/australian-guide-to-the-diagnosis-of-fasd_all-appendices_feb2020.docx.pdf)
9. FASD Research Australia. GPaskthequestion Australia: FASD Hub Australia; 2021. Available from: <https://www.fasdhub.org.au/fasd-information/understanding-fasd/alcohol-use-in-pregnancy/gpaskthequestion/>
10. Lim YH, Watkins R, Jones H, Finlay-Jones A. Report on screening for fetal alcohol spectrum disorder (FASD) in Western Australia: Policy and Practice recommendations. Perth, Western Australia: Report prepared for the Western Australian Department of Health; 2021. Available from: <https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/Child-and-Health-Youth-Network/Screening-for-FASD-in-Western-Australia-Policy-Report.PDF>
11. Elliott E, Bower C, on behalf of the chief investigators and supporting partners of FASD Research Australia, an NHMRC Centre of Research Excellence. Submission to the Australian Parliament Senate Inquiry into effective approaches to prevention, diagnosis and support for fetal alcohol spectrum disorder: Submission 42. Australia; 2019. Available from: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/FetalAlcoholSpectrumDi/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/FetalAlcoholSpectrumDi/Submissions)
12. Jandu Yani U Project team. Submission to the Senate Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder: Submission 49. Australia; 2019. Available from: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/FetalAlcoholSpectrumDi/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/FetalAlcoholSpectrumDi/Submissions)

13. Senate Standing Committees on Community Affairs. Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. Canberra, ACT: Commonwealth of Australia; 2021. Available from: [https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc\\_pdf/Effectiveapproachesto prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder.pdf](https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachesto prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder.pdf)
14. Australian Government Department of Health. National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-2028. Canberra ACT: Australian Government Department of Health; 2018. Available from: <https://www.health.gov.au/resources/publications/national-fetal-alcohol-spectrum-disorder-fasd-strategic-action-plan-2018-2028>
15. FASD Research Australia. FASD Research Australia Conference and Events Australia: FASD Hub Australia; 2021 Available from: <https://www.fasdhub.org.au/research-and-publications/fasd-research-australia/cre-conference-and-events/>
16. Doherty E, Kingsland M, Wiggers J, Anderson AE, Elliott EJ, Symonds I, et al. Barriers to the implementation of clinical guidelines for maternal alcohol consumption in antenatal services: A survey using the theoretical domains framework. Health Promotion Journal of Australia. 2020;31(1):133–9. <https://doi.org/10.1002/hpja.258>
17. Reibel T, Giglia R. WA Health Audit-C learning guide. Perth, WA: Telethon Kids Institute; 2016. Available from: <https://www.fasdhub.org.au/siteassets/pdfs/wa-health-audit-c-learning-guide-2016-web-version.pdf>
18. Kingsland M, Doherty E, Anderson AE, Crooks K, Tully B, Tremain D, et al. A practice change intervention to improve antenatal care addressing alcohol consumption by women during pregnancy: research protocol for a randomised stepped-wedge cluster trial. Implementation Science. 2018;13(1):112. <https://doi.org/10.1186/s13012-018-0806-x>
19. Tsang TW, Bower C, Elliott EJ. Culturally safe advice on alcohol cessation in pregnancy 2020. Available from: <https://www.nhmrc.gov.au/about-us/resources/culturally-safe-advice-alcohol-cessation-pregnancy>.
20. Tsang TW, Bower C, Elliott EJ. Early diagnosis of Fetal Alcohol Spectrum Disorder in Indigenous children 2020. Available from: <https://www.nhmrc.gov.au/about-us/resources/impact-case-studies/early-diagnosis-fetal-alcohol-spectrum-disorder-indigenous-children>.
21. O’Leary C, Lawrence D, Hafekost K, Zubrick SR, Bower C. Maternal Alcohol-Use Disorder and Child Outcomes. Pediatrics. 2020;145(3). <https://doi.org/10.1542/peds.2019-1574>
22. Dossetor PJ, Fitzpatrick EFM, Glass K, Douglas K, Watkins R, Oscar J, et al. Emergency Department Presentations by Children in Remote Australia: A Population-based Study. Global Pediatric Health. 2021;8. <https://doi.org/10.1177/2333794X21991006>
23. National Health and Medical Research Council. Fetal alcohol spectrum disorder: Public health case study 2021. Available from: [www.nhmrc.gov.au/about-us/resources/impact-case-studies/fetal-alcohol-spectrum-disorder-public-health-case-study](http://www.nhmrc.gov.au/about-us/resources/impact-case-studies/fetal-alcohol-spectrum-disorder-public-health-case-study).
24. Tsang TW, Kingsland M, Doherty E, Anderson AE, Tully B, Crooks K, et al. Predictors of alcohol use during pregnancy in Australian women. Drug and Alcohol Review. 2021. <https://doi.org/10.1111/dar.13330>
25. Hutchinson D, Wilson J, Allsop S, Elliott E, Najman J, Burns L, et al. Cohort Profile: The Triple B Pregnancy Cohort Study: A longitudinal study of the relationship between alcohol, tobacco and other substance use during pregnancy and the health and well-being of Australian children and families. International Journal of Epidemiology. 2018;47(1):26–7. <https://doi.org/10.1093/ije/dyx126>
26. Muggli E, O’Leary C, Donath S, Orsini F, Forster D, Anderson PJ, et al. “Did you ever drink more?” A detailed description of pregnant women’s drinking patterns. BMC Public Health. 2016;16(1):683. <https://doi.org/10.1186/s12889-016-3354-9>
27. Muggli E, O’Leary C, Forster D, Anderson P, Lewis S, Nagle C, et al. Study protocol: Asking QUESTions about Alcohol in pregnancy (AQUA): a longitudinal cohort study of fetal effects of low to moderate alcohol exposure. BMC Pregnancy Childbirth. 2014;14:302. <https://doi.org/10.1186/1471-2393-14-302>
28. McCormack C, Hutchinson D, Burns L, Wilson J, Elliott E, Allsop S, et al. Prenatal Alcohol Consumption Between Conception and Recognition of Pregnancy. Alcoholism, clinical and experimental research. 2017;41(2):369–78. <https://doi.org/10.1111/acer.13305>
29. Tsang TW, Peadon E, Bower C, D’Antoine H, Payne J, Elliott E. Health professionals are the preferred source of information on alcohol use in pregnancy for Australian women: A national survey. Journal of Fetal Alcohol Spectrum Disorder. 2020;3(1):e1–e11. <https://doi.org/10.22374/jfasrp.v3i1.8>
30. Smith JA, Reid N, Hewlett N, D’Antoine H, Gray L, Elliott E. Mandatory pregnancy health warning labels on alcohol: Listen to the experts not the industry. Health Promotion Journal of Australia. 2020;31(3):327–9. <https://doi.org/10.1002/hpja.385>
31. Food Standards Australia New Zealand. Pregnancy warning labels on alcoholic beverages 2020. Available from: [www.foodstandards.gov.au/industry/labelling/Pages/pregnancy-warning-labels.aspx](http://www.foodstandards.gov.au/industry/labelling/Pages/pregnancy-warning-labels.aspx).
32. National Health and Medical Research Council, Australian Research Council, Universities Australia. Australian guidelines to reduce health risks from drinking alcohol Canberra, ACT: National Health and Medical Research Council; 2020. Available from: <https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-reduce-health-risks-drinking-alcohol>.

33. Grant TM, Ernst CC, Streissguth AP. Intervention with high-risk alcohol and drug-abusing mothers: I. Administrative strategies of the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*. 1999;27:1–18. [https://doi.org/10.1002/\(SICI\)1520-6629\(199901\)27:1<1::AID-JCOP1>3.0.CO;2-3](https://doi.org/10.1002/(SICI)1520-6629(199901)27:1<1::AID-JCOP1>3.0.CO;2-3)
34. Ernst CC, Grant TM, Streissguth AP, Sampson PD. Intervention with high-risk alcohol and drug-abusing mothers: II. Three-year findings from the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*. 1999;27(1):19–38. [https://doi.org/10.1002/\(SICI\)1520-6629\(199901\)27:1<19::AID-JCOP2>3.0.CO;2-K](https://doi.org/10.1002/(SICI)1520-6629(199901)27:1<19::AID-JCOP2>3.0.CO;2-K)
35. Grant T, Ernst CC, Pagalilauan G, Streissguth A. Postprogram follow-up effects of paraprofessional intervention with high-risk women who abused alcohol and drugs during pregnancy. *Journal of Community Psychology*. 2003;31(3):211–22. <https://doi.org/10.1002/jcop.10048>
36. Grant TM, Ernst CC, Streissguth A, Stark K. Preventing Alcohol and Drug Exposed Births in Washington State: Intervention Findings From Three Parent-Child Assistance Program Sites. *The American Journal of Drug and Alcohol Abuse*. 2005;31(3):471–90. <https://doi.org/10.1081/ADA-200056813>
37. Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E, et al. Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy. *Australian and New Zealand journal of public health*. 2005;29(6):558–64. <https://doi.org/10.1111/j.1467-842X.2005.tb00251.x>
38. FASD Research Australia. FASD eLearning modules Australia: FASD Hub Australia; 2021. Available from: <https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/eLearning-modules>
39. Australian Paediatric Surveillance Unit. Current studies: Fetal alcohol spectrum disorder NSW, Australia: The Australian Paediatric Surveillance Unit; 2021. Available from: <https://www.apsu.org.au/studies/current>
40. Australian Paediatric Surveillance Unit. Fetal Alcohol Spectrum Disorder Australian Registry (FASDAR) NSW, Australia: The Australian Paediatric Surveillance Unit; 2021. Available from: <https://www.apsu.org.au/home/fetal-alcohol-spectrum-disorder-australian-registry/>
41. Australian Government Department of Health. Australia leading the fight against FASD ACT, Australia: Australian Government Department of Health; 2021. Available from: <https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/australia-leading-the-fight-against-fasd>
42. Tsang TW, Laing-Aiken Z, Latimer J, Fitzpatrick J, Oscar J, Carter M, et al. Digital assessment of the fetal alcohol syndrome facial phenotype: reliability and agreement study. *BMJ Paediatrics open*. 2017;1(1):e000137-e. <https://doi.org/10.1136/bmjpo-2017-000137>
43. Palmer RL, Helmholtz P, Baynam G. Cliniface: Phenotypic visualisation and analysis using non-rigid registration of 3D facial images. *International archives of the photogrammetry, remote sensing and spatial information sciences*. 2020;XLIII-B2-2020:301–8. <https://doi.org/10.5194/isprs-archives-XLIII-B2-2020-301-2020>
44. Loke YJ, Muggli E, Nguyen L, Ryan J, Saffery R, Elliott E, et al. Time- and sex-dependent associations between prenatal alcohol exposure and placental global DNA methylation. *Epigenomics*. 2018;10(7). <https://doi.org/10.2217/epi-2017-0147>
45. Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J. Fetal Alcohol Spectrum Disorder Prevalence Estimates in Correctional Systems: A Systematic Literature Review. *Canadian Journal of Public Health*. 2011;102(5):336–40. <https://doi.org/10.1007/BF03404172>
46. Bower C, Watkins RE, Mutch RC, Marriott R, Freeman J, Kippin NR, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*. 2018;8(2):e019605. <https://doi.org/10.1136/bmjopen-2017-019605>
47. Fitzpatrick JP, Elliott EJ, Latimer J, Carter M, Oscar J, Ferreira M, et al. The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities. *BMJ Open*. 2012;2(3):e000968. <https://doi.org/10.1136/bmjopen-2012-000968>
48. Fitzpatrick JP, Latimer J, Ferreira ML, Carter M, Oscar J, Martiniuk ALC, et al. Prevalence and patterns of alcohol use in pregnancy in remote Western Australian communities: The Lililwan Project. *Drug and Alcohol Review*. 2015;34(3):329–39. <https://doi.org/10.1111/dar.12232>
49. Fitzpatrick JP, Latimer J, Olson HC, Carter M, Oscar J, Lucas BR, et al. Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Research in Developmental Disabilities*. 2017;65:114–26. <https://doi.org/10.1016/j.ridd.2017.04.001>
50. Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project. *Journal of paediatrics and child health*. 2015;51(4):450–7. <https://doi.org/10.1111/jpc.12814>
51. Wagner B, Latimer J, Adams E, Carmichael Olson H, Symons M, Mazzucchelli TG, et al. School-based intervention to address self-regulation and executive functioning in children attending primary schools

- in remote Australian Aboriginal communities. *PLoS One*. 2020;15(6):e0234895-e. <https://doi.org/10.1371/journal.pone.0234895>
52. Andersson E, McIllduff C, Turner K, Thomas S, Davies J, Elliott EJ, et al. Jandu Yani U 'For All Families' Triple P—positive parenting program in remote Australian Aboriginal communities: a study protocol for a community intervention trial. *BMJ Open*. 2019;9(10):e032559. <https://doi.org/10.1136/bmjopen-2019-032559>
  53. Andersson E, McIllduff C, Davies J, Cox E, Thomas S, Hand M, et al. Jandu Yani U ("for all families") project report. Sydney, Australia: The University of Sydney; 2020. Available from: [https://cdn.shopify.com/s/files/1/1502/9380/files/Jandu\\_Yani\\_U\\_-\\_Final\\_Report\\_2019.pdf?v=1612768144](https://cdn.shopify.com/s/files/1/1502/9380/files/Jandu_Yani_U_-_Final_Report_2019.pdf?v=1612768144)
  54. Thomas S. Bigiswun kid project gains funding boost: Marninwarntikura Women's Resource Centre; 2020. Available from: [http://www.mwrc.com.au/blogs/news/bigiswun-kid-project-gains-funding-boost?\\_pos=1&\\_sid=ad769920a&\\_ss=r](http://www.mwrc.com.au/blogs/news/bigiswun-kid-project-gains-funding-boost?_pos=1&_sid=ad769920a&_ss=r)
  55. Passmore HM, Mutch RC, Watkins R, Burns S, Hall G, Urquhart J, et al. Reframe the Behaviour: Evaluation of a training intervention to increase capacity in managing detained youth with fetal alcohol spectrum disorder and neurodevelopmental impairments. *Psychiatry, Psychology, and Law*. 2020;1–26. <https://doi.org/10.1080/13218719.2020.1780643>
  56. Bell K, McNaughton D, Salmon A. Medicine, morality and mothering: public health discourses on foetal alcohol exposure, smoking around children and childhood overnutrition. *Critical Public Health*. 2009;19(2):155–70. <https://doi.org/10.1080/09581590802385664>
  57. Stafford J, Kypri K, Pettigrew S. Industry Actor Use of Research Evidence: Critical Analysis of Australian Alcohol Policy Submissions. *Journal of Studies on Alcohol and Drugs*. 2020;81(6):710–8. <https://doi.org/10.15288/jsad.2020.81.710>
  58. Avery MR, Droste N, Giorgi C, Ferguson A, Martino F, Coomber K, et al. Mechanisms of influence: Alcohol industry submissions to the inquiry into fetal alcohol spectrum disorders. *Drug and Alcohol Review*. 2016;35(6):665–72. <https://doi.org/10.1111/dar.12399>
  59. McCambridge J, Mialon M, Hawkins B. Alcohol industry involvement in policymaking: a systematic review. *Addiction*. 2018;113(9):1571–84. <https://doi.org/10.1111/add.14216>
  60. Mathews R, Thorn M, Giorgi C. Vested interests in addiction research and policy. Is the alcohol industry delaying government action on alcohol health warning labels in Australia? *Addiction*. 2013;108(11):1889–96. <https://doi.org/10.1111/add.12338>
  61. Reid N, Gamble J, Creedy DK, Finlay-Jones A. Benefits of caseload midwifery to prevent fetal alcohol spectrum disorder: A discussion paper. *Women and Birth*. 2018. <https://doi.org/10.1016/j.wombi.2018.03.002>
  62. Muggli E, Matthews H, Penington A, Claes P, O'Leary C, Forster D, et al. Association Between Prenatal Alcohol Exposure and Craniofacial Shape of Children at 12 Months of Age. *JAMA Pediatrics*. 2017;171(8):771–80. <https://doi.org/10.1001/jamapediatrics.2017.0778>
  63. Watkins RE, Elliott EJ, Halliday J, O'Leary CM, D'Antoine H, Russell E, et al. A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Pediatrics*. 2013;13:13. <https://doi.org/10.1186/1471-2431-13-13>
  64. Finlay-Jones A, Varcin KJ, Leonard H, Bosco A, Alvares G, Downs J. Very early identification and intervention for infants at risk of neurodevelopmental disorders: A transdiagnostic approach. *Child Development Perspectives*. 2019;13(2):97–103. <https://doi.org/10.1111/cdep.12319>
  65. Kippin N, Leitao S, Watkins R, Finlay-Jones A, Condon C, Marriott R, et al. Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry*. 2018;61:40–9. <https://doi.org/10.1016/j.ijlp.2018.09.004>
  66. Reid N, Kippin N, Passmore H, Finlay-Jones A. Fetal alcohol spectrum disorder: the importance of assessment, diagnosis and support in the Australian justice context. *Psychiatry, psychology, and law*. 2020;27(2):265–74. <https://doi.org/10.1080/13218719.2020.1719375>
  67. Hamilton S, Reibel T, Maslen S, Watkins R, Freeman J, Passmore H, et al. Disability "In-Justice": The Benefits and Challenges of "Yarning" With Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center. *Qualitative Health Research*. 2020;30(2):314–27. <https://doi.org/10.1177/1049732319882910>
  68. Hamilton SL, Reibel T, Watkins R, Mutch RC, Kippin NR, Freeman J, et al. 'He Has Problems; He Is Not the Problem . . .' A Qualitative Study of Non-Custodial Staff Providing Services for Young Offenders Assessed for Foetal Alcohol Spectrum Disorder in an Australian Youth Detention Centre. *Youth justice*. 2019;19(2):137–57. <https://doi.org/10.1177/1473225419869839>
  69. Passmore HM, Giglia R, Watkins RE, Mutch RC, Marriott R, Pestell C, et al. Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ open*. 2016;6(6):e012184-e. <https://doi.org/10.1136/bmjopen-2016-012184>