

Making FASD History in the Pilbara

Consultation Report: Community and Stakeholder Consultations 2015



in partnership
with the Hedland
FASD Network





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Table 1: Acronyms and Abbreviations used in this Report.

Acronym/Abbreviation	Definition
FASD	Fetal Alcohol Spectrum Disorders
WACHS	Western Australian Country Health Service
Hedland	Encompassing Port and South Hedland, Yandeyarra and Warralong
CPAR	Community Participatory Action Research
HYSAG	Hedland Youth Services Action Group
PIWAC	Pilbara Indigenous Women’s Aboriginal Corporation



1 Introduction

Initiated in 2015, the Hedland Fetal Alcohol Spectrum Disorder Project (the Hedland FASD Project) was developed to address both a growing community concern (see Section 2.1) and evidence from other Northern Western Australian communities (see Section 2.2) that drinking in pregnancy and FASD are an issue of increasing concern in the Hedland and surrounding communities.

Working with existing Hedland services, networks and communities, the project aims to build an evidence base of what works in preventing FASD and assists in supporting children and families affected by FASD, in a locally contextualised manner. To this end, the study specifically aims to:

1. Identify rates of alcohol use in pregnancy using AUDIT-C data routinely collected by midwives during antenatal care;
2. Reduce the rates of alcohol use in pregnancy among local Aboriginal women; and
3. Increase the capacity of the local community and services to care for and support individuals and families affected by FASD.

Funded by BHP Billiton, the Hedland FASD Project is utilising a Community Participatory Action Research (CPAR) and a mixed methodological approach to develop and trial programs, strategies and activities aimed at preventing FASD, and increase support available to children and families dealing with FASD. This approach involves a number of steps, including:

1. Establishing a governance structure that will facilitate comprehensive and meaningful engagement of partners, stakeholders and communities;
2. Employing a community-based participatory research methodology that empowers community partners, community leaders and community members in designing, implementing and evaluating the Hedland FASD Project;
3. Establishing baseline data collection processes using the AUDIT-C questionnaire, medical records and Knowledge, Attitudes and Practices surveys;
4. Conducting formative research and community scoping to confirm the specific features and implementation processes of the Hedland FASD Project;
5. With partners, stakeholders and community groups, designing, piloting, and evaluating FASD prevention and support strategies;
6. Evaluating the impact of the overall project on rates of pregnant women abstaining from alcohol or significantly reducing alcohol consumption during pregnancy and changes in effectiveness of support for children with FASD, as well as secondary outcomes; and
7. Facilitating training of health practitioners and midwives to conduct AUDIT-C, and brief interventions and educators to diagnose and manage children more effectively.

This report outlines the process and results of initial consultations undertaken with stakeholders, community members and project partners in order to address steps 2 and 4 above.

2 Background

2.1 Past Consultation and Research

Prior to the commencement of the Hedland FASD project, a number of community consultations were undertaken by other service providers and organisations which have been made available publicly or to members of the project team, including:

- ▶ Pilbara Indigenous Women's Gathering (PIWAC, 2010);
- ▶ Maternal and Child Health Program consultations (Telethon Kids Institute; 2014);
- ▶ Staying on Track and Starting on Track project consultations (Telethon Kids Institute, 2008); and,
- ▶ Pilbara Aboriginal Health Planning Forum.

In addition, a number of NGO and governmental reports have been released in the last decade relating to alcohol use and social issues in the Pilbara, such as:

- ▶ The Forrest Review: Creating Parity (Commonwealth of Australia, 2014);
- ▶ West Pilbara: Report on Alcohol-related Harm, Ill-health and Disorder (West Pilbara Alcohol Management Group, 2011); and
- ▶ Parliamentary Submissions 2011

The FASD Model of Care produced in 2010 by the Department of Health WA is informed by experiences and responds to findings from key experts and practitioners in the Pilbara and the Kimberley.

These consultations and reports highlight the level of local community concern about the health and social impacts of alcohol in Hedland, the Pilbara, and Aboriginal communities more broadly. Furthermore, outcomes and recommendations from these reports and projects support the findings of the current consultation activities, specifically that:

- ▶ Alcohol consumption in the north-west of WA, and among remote Aboriginal communities, is of major concern;
- ▶ Aboriginal women in remote Australia are at an increased risk of bearing a child with FASD;
- ▶ Many young Aboriginal women and men who are parents may have FASD;
- ▶ Coordinated prevention strategies are required to address the harmful impacts of alcohol misuse, including FASD; and
- ▶ Complimentary legislative responses to alcohol use can improve the efficacy of prevention interventions.

The following summaries provide a brief overview of these results.

2.1.1 Pilbara Indigenous Women's Gathering

Held over two days in 2010, the Pilbara Indigenous Women's Gathering hosted a series of workshops, presentations and activities for Indigenous women in the East Pilbara lands of the Baniyma People.

“Sadly the story for many Aboriginal kids is a steady and slow descent into drugs, alcohol, solvent sniffing, crime and repeated prison terms.”

While not focused explicitly on issues around alcohol use and abuse, the Gathering raised issues often implicitly related to alcohol and other drug issues such as:

- Violence and domestic violence;
- Sexual abuse, trauma and healing;
- Crime;
- Housing; and
- Education.

The Gathering report, in part, highlighted the ongoing issues of drug and alcohol abuse in young people, the relationship of such abuse to crime and incarceration, and the lack of resources dedicated to preventative practices.

“...the Royalties for Regions scheme has paid over four million dollars to the Department of Corrective Services to deal with Aboriginal children and crime ... , little has been channelled towards preventative practices on how to keep kids alcohol and substance-free.”

2.1.2 The Forrest Review: Creating Parity

Released in 2014, the Forrest Review aimed to identify the causes of disparity between educational and employment/economic outcomes between Aboriginal and non-Aboriginal Australians. Importantly, in the context of the impact of Alcohol on Aboriginal communities, the report identified that one measure of success in creating parity would be that: **“Foetal alcohol spectrum disorder is a historical regret and is no longer apparent in the nation's births.”** (Commonwealth of Australia, 2014, page 63).

The report continually references the impact of alcohol and in particular FASD on remote Aboriginal communities, highlighting the significance of FASD and the strong need for effective prevention programs.

“A healthy pregnancy is crucial to the early stages of a child's life. Tragically, alcohol and drug consumption during pregnancy does occur — quite often out of ignorance. Foetal alcohol spectrum disorder is a significant issue and we should be on the constant lookout to prevent it.”

The Forrest Report also pointed out that, for an Aboriginal woman in remote Australia, the likelihood of bearing a child with FASD is much increased.

2.1.3 West Pilbara: Report on Alcohol-related Harm, Ill-health and Disorder

The West Pilbara Report was released in 2011 as a component of the West Pilbara Alcohol Management Strategy. The report and associated consultation and research were undertaken by the West Pilbara Alcohol Management Group, a multi-stakeholder group responsible for a range of alcohol management initiatives.

As with the Forrest Report, and the results of the Pilbara Indigenous Women's Gathering, the West Pilbara Report highlights the impact of alcohol on Aboriginal communities in the Pilbara, and identifies the need for locally specific prevention activities and programs.

The report acknowledges the high level of alcohol consumption in the West Pilbara being higher than the WA state average. Recommendations in the report include complimentary alcohol restrictions to fit within a broader context of education, treatment and support.

“...liquor restrictions have the greatest chance of success if implemented alongside other initiatives. In regions where levels of consumption and related harm are concerning, liquor restrictions can provide and environment that supports change to occur and the opportunity for other programs and strategies to be more effective.”

2.1.4 Telethon Kids Institute: Starting on Track – Staying on Track 2007-2009

Concerns around alcohol and pregnancy in the Pilbara were first raised with the Telethon Kids Institute between 2007 and 2009 during the implementation of two projects: *Starting on Track: implementation of the Australian Early Development Index (AEDI)* and *Staying on Track: substance misuse reduction among young people*. Both projects were primarily funded by BHP Billiton, although considerable additional funds were leveraged to undertake a range of locally driven interventions.

With respect to the *Starting on Track* project, the results of the AEDI for 844 children in the Pilbara region, for example, highlighted high levels of vulnerability among children aged 4 to 5 years across five developmental domains – physical, cognitive, social, communication and emotional – far higher than levels reported for the national population rates. Consultations with teachers and key stakeholders in all towns and including South Hedland and Port Hedland at the time attributed some of the physical and cognitive issues being identified in schools as FASD. Concerns associated with infectious and chronic diseases (ears, respiratory, gastroenteritis and skin) were also reported.

		Social competence					Language/cognitive		Number of domains:	
		Physical	↓ Emotional	↓ Communication	↓ Cognitive	↓ Language	↓ Cognitive	↓ Language	1+	2+
EXMOUTH	22	31.8	40.9	10.0	50.0	27.3			54.5	40.9
KARRATHA/DAMPIER	247	3.5	1.8	4.1	10.6	3.5			15.9	5.3
MARBLE BAR & SURROUNDS	26	12.5	34.8	33.3	52.2	39.1			62.5	45.8
NEWMAN	90	16.1	7.0	4.8	15.1	11.5			26.4	14.9
ONSLOW/PANNAWONICA	26	19.2	19.2	7.7	26.9	19.2			34.6	26.9
PARABURDOO	40	0.0	0.0	5.4	10.8	0.0			13.5	2.7
PORT HEDLAND	49	8.7	13.0	8.7	21.7	15.2			26.1	17.4
PUNMUI/PARINGURR/JIGALONG	41	45.2	45.2	21.4	74.2	67.7			80.6	71.0
ROEBOURNE	26	12.0	28.0	8.0	44.0	32.0			52.0	28.0
SOUTH HEDLAND	151	17.4	13.0	11.7	24.2	6.8			34.8	18.2
TOM PRICE	76	5.9	14.7	13.2	8.8	5.9			23.5	13.2
WICKHAM	50	6.4	6.4	2.1	12.8	12.8			23.4	10.6

= 33 children

Similar issues were raised during the implementation of the *Staying on Track* project. Extensive consultations with a range of agencies and members of the Hedland Youth Stakeholder Action Group (including Bloodwood Tree, the Youth Involvement Council and the Pilbara Alcohol and Drug Program) also expressed concerns about high levels of drinking among young people and high rates of antisocial behaviour around Hedland: disengagement from school, involvement with juvenile justice issues and low levels of employment and participation in training options. The majority of key stakeholders reported these issues at the time as being attributable to many of these young people being 'victims of FASD'. One stakeholder observed:

‘...women have their children very young – I believe we are beginning to see the impacts of alcohol on a third generation of kids.’

A community survey conducted in the Town of Port Hedland in 2009 to update its community safety and crime prevention plan noted high levels of drinking among young people as a

serious issue. In turn, a 'Shout Out' workshop with young people in Hedland highlighted issues of boredom, family violence, community safety, alcohol and drugs, and lack of employment or futures, as key issues impacting on their health and wellbeing. Young people estimated that between 35 and 50 per cent of young people under 18 years (and as young as 12 years) were regularly drinking alcohol or using drugs at risky levels. The proportion of the population in the Pilbara region aged 14 years and over who reported drinking alcohol at risky or high risk levels of harm in the short term was 41.3%, similar to the WA average of 39.1%. However, drinking at levels of high-risk for long term harm was almost double, with 22.1% in the Pilbara region compared to 11.4% for WA. In 2006, residents in the Pilbara health region were hospitalised a total of 393 times for alcohol-related conditions.

Other concerning statistics identified at the time included that the majority (63 per cent) of Hedland Disability Services Commission clients are aged 25 years and under, and the majority of those are young Aboriginal people. Young adults 16-24 years (the majority of whom are Aboriginal) residing in Hedland, when compared to the whole WA population, have at least double the proportion of young adults at risk of both short- and long-term harm due to drinking alcohol, and this rate was slightly higher than in the Pilbara generally.

“People are turning a blind eye, or burying their heads in the sand – however you want to say it, but a report by Taylor and Scrambary identified an estimated population increase of 50% among 5 and 19 year olds in the next decade and unless the levels of alcohol and substance use which are rife in the communities and around town are dramatically reduced, we are in for a tsunami of serious issues among our young people which will be devastating.” (Government Stakeholder 2008)

The report by Taylor and Scrambary (2005) suggested that the projected Indigenous population for the Pilbara region is anticipated to reach 8,515 by 2016, with a majority being school age and below, and the largest proportion of this population living in the town of Port Hedland and South Hedland.

2.1.5 Telethon Kids Institute: Maternal and Child Health Program

The *Maternal and Child Health* program commenced in Newman and the Western Desert in 2010, in part in response to high levels of vulnerability reported in the East Pilbara AEDI results for 2007, 2008 and 2009. Initial consultations with community elders, young mothers, health practitioners, teachers and early years' stakeholders and non-government agencies (World Vision Australia and YMCA) also highlighted concerns about women drinking alcohol in pregnancy. These concerns were recorded in the half-yearly reports to BHP Billiton and conference and workshop presentations. In consultations with the communities, Martu elders expressed real concerns about young women drinking during pregnancy and the need for young mothers to learn 'the strong way from her granny and mothers'. One elder stated:

“The strength of our culture will make the young ones strong; they need to learn the Law, learn our traditions; learn from the land and the old ones' wisdom. We can show the young people how the old ones lived, how our mob is a family.” (Martu Elder)

A key challenge and opportunity for the team was to determine how we could work together in ways that are empowering and that support cultural continuity and connection, and strengthen the capacity and capability of individuals and communities, in order to improve maternal and child outcomes (Walker, Scrine & Murray 2011).

Extensive consultations with relevant stakeholders highlighted the significance and impact of FASD for these communities in the East Pilbara, as well as the issues impacting children in schools and the education system, given the lack of early diagnosis of FASD or other global developmental delay issues including speech, social and emotional issues.

A report by Walker, Scrine and Langridge (2013), *Factors Influencing Maternal and Early Child Development for Martu Communities in the East Pilbara*, noted:

'...repeated concerns expressed by community health nurses regarding the young women drinking alcohol and smoking while breastfeeding and the urgent need to address these issues through health promotion and education.'

The report also highlighted the critical need to develop health promotion and health prevention and early intervention initiatives, such as involving Aboriginal community care workers and health workers to help strengthen women and enhance their understanding and behaviours around maternal health to encourage them to access antenatal services.

2.2 The Marulu FASD Strategy: Fitzroy Valley

The Marulu FASD Strategy began in 2007, initiated by a group of Fitzroy Valley Aboriginal women, responding to community concerns related to suicide, death, health and education, and links to alcohol abuse.

The Marulu FASD Strategy indicated that in communities with high levels of drinking, FASD was likely to be highly prevalent, with up to 1 in 5 children suffering from the disorder in the Valley. Throughout the project, an evidence base has been developed highlighting the importance of:

- Broad awareness raising;
- Targeted education and information;
- Antenatal care and support; and
- Postnatal support programs.

3 Methodology

The overall project design of the Hedland FASD project is based on a model of Community Participatory Action Research (CPAR). CPAR is a cyclical research framework that is iterative and reflective, and allows for the results of each phase of research to be incorporated into subsequent research design and methodology (see Figure 1). At a general level, the process identifies four key processes: *observe*, *reflect*, *plan* and *act*. A unique feature of CPAR is the participation of those affected by the issue of interest in the process, both in designing and responding to the research questions (Crane and O'Regan, 2010). Importantly, CPAR aligns with the NHMRC *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*.

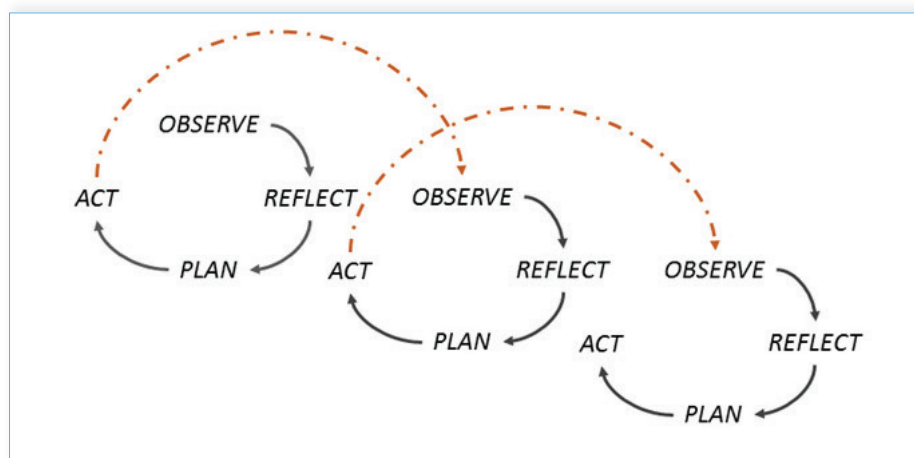


Figure 1. The iterative process of CPAR.

3.1 Consultation Methods

Under the framework of CPAR, the purpose of the interviews was not only to identify major themes and issues for the purpose of confirming the design of future elements of the study, but additionally to:

- Introduce the project and members of the project team to community and service provider stakeholders;
- Develop relationships in order to foster an environment of collaboration throughout the life of the project, and sustained into perpetuity; and
- Enable a sense of local ownership over the direction, process and outcomes of the research.

Consultations were undertaken by members of the project team including A/Professor Roz Walker (CI; Principal Research Fellow), Kristen White (Program Manager Aboriginal Health Kimberley and Pilbara) and David Tucker (Coordinator Prevention Research Hedland FASD Project).

These consultations were undertaken by contacting key stakeholders to discuss the project and then using a snowballing technique to make further contact with additional key stakeholders and relevant community people in Hedland. The main purpose of the consultations was to:

- Talk with groups about the Hedland FASD project;
- Ascertain their perspectives regarding FASD in Hedland and gauge their support for the project;
- Assess the extent of currently available resources being used or that people were aware of;
- Identify what parents and carers of children with FASD (or developmental issues) see as the key issues (i.e. resources and support services); and
- Ascertain what service organisations see as the key issues.



Consultation included unstructured one-on-one interviews addressing the aims listed above, and group discussions using a yarning methodology (Bessarab 2009) to capture the key issues of concern to people related to drinking in Hedland and communities. The research team also conducted minute taking at local community and service provider groups, including the Hedland Youth Services Action Group (HYSAG), Early Years Working Group, the Hedland Aboriginal Consultation Forum and the Hedland FASD Network among others (see Section 5 for more detail).

3.2 Participants

Forty-four stakeholders and community members were consulted in 2015. Of these consultations, 75 per cent of participants were female, and more than a quarter were Aboriginal (27 per cent; Figure 2).

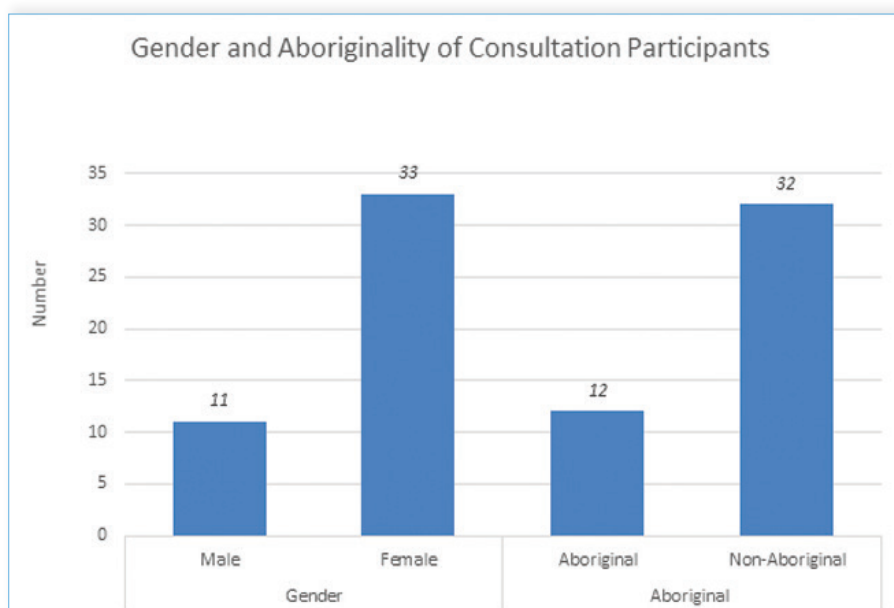


Figure 2. Gender and Aboriginality of Participants

Consultations included interviews with workers from local government (15%), Aboriginal organisations (13 per cent), state government departments (11 per cent) and WACHS (10 per cent), as illustrated in Figure 2.



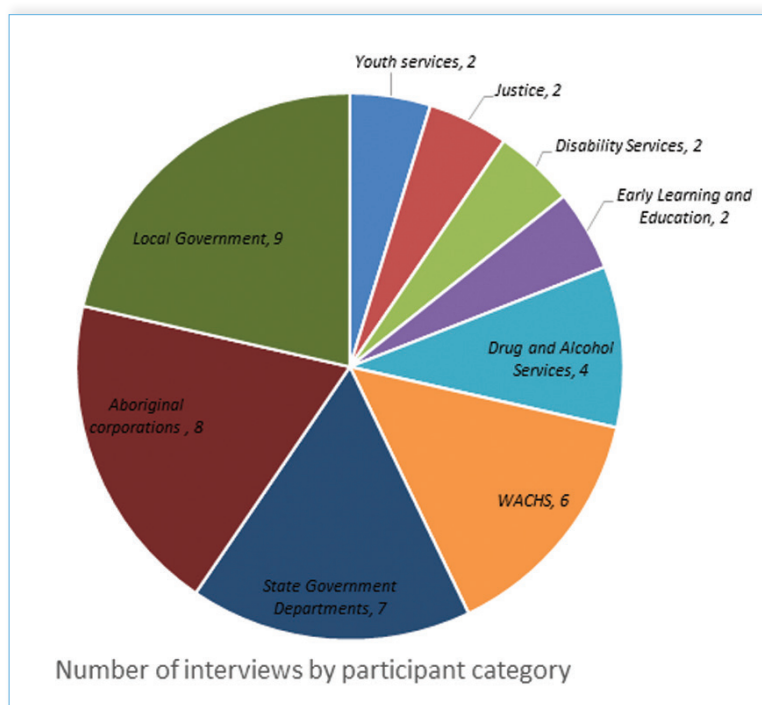


Figure 3. Stakeholder Consultation Categories.

3.3 Analysis

Qualitative data analysis (thematic analysis) was undertaken using QSR International's NVivo 11 software. Thematic analysis is a process by which transcripts or recordings of interviews and consultations are examined to identify recurrent and/or important themes. For example, where every consultative interview refers to the prevalence of alcohol consumption in Hedland, this would be considered a major theme in the results below.

4 Results

4.1 Overview

As detailed below, a number of themes, or issues, were identified through the consultative process. In order to better understand the relative importance, or relative risk, of these themes they have been categorised according to the immediacy of required response, and who is likely responsible for making such a response. The importance of themes was assigned based on participants' perceptions of relative importance, as well as interviewers' interpretation. Inter-rater reliability was calculated for the three interviewers' interpretation of relative importance of categories, and yielded a result of one (the highest possible).

Key themes were further categorised according to the perceived response priority as identified by both participants and researchers. Table 2 highlights each of the key themes, along with the suggested response priority alongside existing strengths, potential responses and who might be best situated to respond to the identified needs.

Table 2. Key Themes, Response Priority and Suggested Responses.

Key themes	Response priority	Existing strengths	Potential responses	Responsibility for response
High rates of alcohol and other drug use in Hedland	Critical Priority / Immediate	Current alcohol restrictions have been effective in reducing rates of consumption and alcohol related incidents	Tightening in alcohol restrictions Increased access to drug and alcohol services	Department of Racing, Gaming and Liquor Community organisations and members to advocate for increased restrictions
Inadequate knowledge of referral pathways		A capacity and willingness from the Pilbara Aboriginal Drug and Alcohol Programs to act as a central point of referral	Facilitate a workshop with all drug and alcohol service providers to map out all programs and activities. Develop a drug and alcohol specific Port Hedland information pamphlet to distribute among service providers and community members	Telethon Kids Institute – Facilitation PADAP Bloodwood Tree Association Yaandina Family Services Mission Australia
Staff continuity – Burnout and turnover		While turnover is high, there are a number of clinicians and service providers who have been in the town for many years	Capacity building – increasing the skills and employment opportunity for local people to reduce staff turnover Increased funding for additional positions where programs are under-resourced	Telethon Kids Institute and Wirraka Maya – Capacity building for local Aboriginal people through the FASD Prevention Strategy Telethon Kids Institute – Possible advocacy role in program funding
Knowledge and Awareness		Awareness of FASD and alcohol related harm are high in Hedland, however knowledge of the specific issues and causes needs to be improved	Targeted and culturally appropriate local awareness raising campaigns Continuation of broad awareness campaigns such as the Mary G ads and utilising the Pilbara and Kimberley Women's alcohol project developed in 2010 Strong Spirit Strong Culture training	Telethon Kids Institute and Wirraka Maya – The FASD prevention project will work with local communities to identify appropriate messages and delivery methods for knowledge and awareness campaigns DAO – DAO have committed to continuing the Mary G ads in selected timeframes through 2016
Lack of accessible and appropriate drug and alcohol rehabilitation services	High Priority / Short term (within 6)	Rehabilitation services and facilities exist and are becoming better utilised, however access to detoxification services is missing.	Better awareness of currently available services Provision of detoxification services	Telethon Kids Institute – facilitation All local drug and alcohol service providers
Increased training and education	High Priority / Intermediate (within 12 months)	Non-local services such as DAO and NoFASD offer online training modules	Increased training resources for carers and parents Increased training opportunities for service providers and clinicians	Telethon Kids Institute and Wirraka Maya – Facilitate Pilbara training by Canadian Expert Caroline Hartness in 2016 Telethon Kids Institute – Implementation of the Alert program in local schools including teacher and parent training/education Patches Paediatrics – Deliver clinical diagnostic training and education sessions through Hedland, Roebourne and Newman. Telethon Kids to offer Audit C training
Normative pressures and precursors to alcohol use	High Priority / ongoing	Alcohol is a community identified issue in Hedland, indicating that injunctive social norms around alcohol consumption are changing	Community owned processes and campaigns to influence societal and cultural norms. Community and cultural champions to advocate for changes in drinking norms	Telethon Kids Institute – current research using a Community Participatory Action Research framework Wirraka Maya & Telethon Kids Institute – To help develop and support existing local champions
Community ownership		Alcohol and FASD are community identified issues and the local community are seeking a central role in the process	Responses to FASD to be community driven, locally specific and culturally relevant	Telethon Kids Institute and Wirraka Maya – the current FASD project CPAR framework facilitates the community ownership process
Increased focus on early intervention	Moderate Priority / Intermediate	Multiple working groups and services are currently focusing on youth and young people for e.g. the Hedland Youth Services Action Group Schools are well engaged and prepared to be involved	FASD education to be built into existing programs such as Health and Sexual Education Core of Life	

			Formal network of providers to design and implement an up to date referral resource	
The need for culturally safe services (including accommodation)		Local Aboriginal employment and representation exists within both NGO's and Government Departments	<p>Increasing cultural awareness training</p> <p>Consultation with Aboriginal people regarding what makes a space or service culturally safe</p> <p>Negotiate and Facilitate processes to conduct cultural competence audit with Hedland Campus</p> <p>Encourage through WNH and Reference Group</p> <p>Increasing access to short term accommodation for community members accessing Hedland medical facilities</p>	<p>Wangka Maya Language Centre – Facilitation of cultural awareness training</p> <p>Town of Port Hedland – utilising the quarterly Aboriginal Consultation Forums as a means of cultural safety consultation</p> <p>Consult with local reference group and adapt if necessary organisational and professional Cultural competence audit</p> <p>Telethon Kids to advocate for making Aboriginal culture visible in the physical environment of hospital to bring Aboriginal peoples and health care providers together on the journey of reconciliation and connection.</p> <p>Telethon Kids Institute – Potential to provide advocacy for services</p>
The need for a separate women's hostel for women attending Hedland for birthing or extended antenatal visits			Increasing access to short term accommodation for women and their families members accessing Hedland medical facilities	Advocacy regarding rehabilitation and reinstating Naburu Rose

4.2 Critical Priorities

The following themes were identified by all or most consultation participants, and were considered to be issues that were of a critical nature and requiring an immediate response. Strategies for addressing these priorities, including the contribution of the current Hedland FASD Project to addressing the issues, can be seen in Table 2 and in Section 6 below.

4.2.1 Alcohol and Other Drugs in Hedland

All consultation participants agreed that alcohol use in Hedland had created significant negative social impacts, and in particular was associated with:

- Accidents and accidental death;
- High levels of hospitalisation;
- Long-term health impacts;
- Drink driving;
- Crime;
- Violence and domestic violence;
- Child neglect;
- Children being placed in care;
- Mental health issues;
- Intergenerational trauma; and
- Increased suicide and suicide attempts

From a policing perspective, alcohol was identified as the biggest issue being dealt with on a day-to-day basis, and was seen as responsible for the issues identified above. While many participants spoke of the impact of alcohol on Aboriginal communities in particular, it was also acknowledged that Port Hedland had a culture of drinking that was community wide, irrespective of cultural background.

“Of substantial concern was the impact of alcohol use on the sustainability of Aboriginal culture and language. If anything for us as a people smoking and alcohol is going to destroy our intellectual knowledge and culture.”

In addition to concerns relating to alcohol abuse, consultations indicated that other drugs including crystal methamphetamine (ice) and marijuana (gunja) which were seen as an increasing issue, and once again were seen as impacting on child neglect and suicide and depression.

“Kids with parents who use drugs become isolated and prone to suicide even if they don’t use drugs themselves.”

A review of Section 64 alcohol restrictions that were trialled in Port Hedland between 2004 and 2005 indicated that many issues associated with alcohol use such as accidents, trauma and violence reduced with the implementation of trading and volume restrictions. Evaluated by the NDRI, these restrictions were widely supported by service providers and community members, and remain in place some 11 years on. This result is indicative of the contribution of alcohol consumption to social issues such as domestic violence and violence, trauma and crime in the Port Hedland area.

“Serial measures of consumption and harm indicated that the restrictions have objectively made a difference, although not necessarily at the time of mandated implementation”

4.2.2 Referral Pathways

Referral pathways for people experiencing issues with alcohol and other drugs exist in Hedland and include utilising specialised services such as the Pilbara Aboriginal Drug and Alcohol Program (PADAP), Bloodwood Tree Association, Mission Australia and the Turner River Facility. However, a number of service providers stated that they would not know where to send clients if they were asked for help to cut down or abstain from drinking.

This finding led to a conversation with members of the PADAP team and an agreement that the TKI would facilitate workshops with PADAP and interested stakeholders to clarify and develop appropriate referral pathways.

The Port Hedland area is generally well serviced with regard to primary and secondary health, perinatal support, and drug and alcohol services through a range of government and non-government organisations. Through the consultation process it was apparent that while many of these groups communicated regularly and effectively, many groups providing similar or complimentary services were not well informed as to other groups' programs or activities. This suggests that, at least in part, the lack of knowledge of referral pathways may be the product of low levels of inter-organisational communication.

4.2.3 Staff Continuity

Staff continuity was raised as an issue throughout the consultation, and was evident through the process of undertaking consultation over a number of months. Over the short period of consultation, the number of participants who vacated their position – on more than one occasion for another position in Port Hedland, though more often than not taking a position outside the town – appeared to be inordinately high.

While much of the staff turnover could be explained by non-local workers returning home or a partner seeking new employment, it was suggested by some participants that staff burnout may also be a contributing issue. As an example, it was pointed out by a consultation participant that a local non-government organisation had over 300 clients listed on the books for services being managed by only two staff members.

This was seen as an issue leading not only to a lack of staffing continuity, but also contributing to disconnect between services and the community, as the services struggled to keep up with demand.

“The problem with service providers is that they get bogged down with the running of the organisation and lose touch with the community.”

In addition to staff retention, attraction of qualified staff was also seen as an issue, and a number of key positions were identified as vacant for this reason.

“We don’t have an Aboriginal Health Worker for maternity and paediatric services – it’s a position that’s been vacant for 7 years, the whole time I’ve been here.”

4.2.4 Knowledge and Awareness

The importance of knowledge and awareness of the impacts of alcohol during pregnancy were seen as key to changing behaviours and social norms. While it was agreed that many, if not most, people were aware that drinking during pregnancy was potentially harmful to the baby, the mechanisms of that harm and the outcomes on the babies’ health were much less known. It was suggested that a lack of education about basic maternal biology could be contributing to a perception that the baby is safe within the amniotic sac, without an understanding the teratogenic nature of alcohol.

4.3 Themes of High Priority

The following themes were indicated as being of high priority by consultation participants, while not critical in their required response priority. Strategies for addressing these priorities, including the contribution of the current Hedland FASD Project to addressing the issues, can be seen in Table 2 and in Section 6 below.

4.3.1 Appropriate and Accessible Drug And Alcohol Rehabilitation

Consultation indicated a wide-ranging perception of a lack of services relating to alcohol detoxification, rehabilitation and reintegration into the community. In particular, while many participants acknowledged the work of the Turner River Rehabilitation Facility (operated by the Yaandina Family Centre), concerns were raised as to what support was offered to clients upon leaving the facility.

“[Turner River is] not addressing issues of people leaving and going back to same community and situation. There was supposed to be a halfway house for people coming out.”

Additional concerns were raised about the lack of detoxification services. The Turner River Facility requires clients to be drug and alcohol free on arrival, and participants pointed out that there were currently inadequate facilities for people to get help and support to detox prior to entry, which meant that many people did not seek support from the facility. A number of participants also expressed concern that there were no facilities dedicated to youth drug and alcohol rehabilitation.

Not having access to detoxification and rehabilitation facilities in town was seen by some as an issue, with those seeking services needing to leave town. However, this was also seen as a

positive by others, being seen as an opportunity to disengage with family or social networks that might be encouraging or supporting negative behaviours.

Whole of family treatment was raised as important, and while it was stated that the Turner River Facility had at one point allowed women to undergo treatment with their children staying with them at the facility, this was seen by some as an environment that might not be safe or appropriate for children.

4.3.2 Cultural Security and Safety

A number of participants spoke about the importance of cultural security and safety, particularly in response to the concept of safe places. The Hedland Health Campus was mentioned as an example of a place where Aboriginal women do not feel culturally safe, for a variety of reasons.

“Not having a safe place to stay if coming in from out of town to give birth – men and women having shared space at hostels is not appropriate.”

The lack of women-focused hostel facilities for women to access when coming into town from outlying communities was also frequently raised, and this was seen as leading to greater difficulties in supporting and tracking women, and making sure that appropriate prenatal and postnatal care was being offered.

“Now young women from the community go straight through the hospital and we have no idea what the numbers are or if people are receiving pre and postnatal care.”

4.3.3 Training and Education

The need for additional training and education for staff working with people with alcohol issues and FASD was a recurrent theme throughout the consultation. There was a perception that although there were a number of counsellors and counselling services available, some of those may not have adequate training or experience.

“[There are] lots of nice people in counselling but [I’m] not sure how particularly well trained they are.”

A large number of consultation participants raised previous training opportunities, with a strong desire for the opportunities to be offered again to staff and residents in Hedland. Among these, the two most commonly raised were the Strong Spirits Strong Futures training, and workshops undertaken by Carolyn Hartness.

Train the Trainer-based courses were also suggested, and June Councillor (CEO Wirraka Maya Health Services) suggested that Wirraka Maya should organise a trainer to train Hedland service providers on a regular basis to maintain the number of trained individuals on FASD to overcome volunteer turnover.

Concerns about school-based education particularly within remote communities, which was seen as deteriorating over time, were raised by participants.

“Strelley School has lost one classroom each year for the last five years”

Resourcing for schools was seen as a critical issue in order to appropriately manage and benefit children with FASD. In being able to better provide for children with FASD, the evident perception was that all children would benefit.

“Principals raised that if they were given resources to deal with kids with FASD then it would benefit the whole classroom”

The education system was seen as needing to adapt to better cater for the needs of Aboriginal children, and in particular having the assistance to deal with children needing higher care, in order to also provide the best benefit for more mainstream students.

“The education system needs to be able to cater to that mob, whether they have their own programs or not – the teachers need to be able to focus on the bigger group to get most through and they find themselves times strapped to work with the others.”

4.3.4 Social Norms and Alcohol Use

Consultation participants highlighted a number of factors leading to excessive alcohol consumption in Hedland, including:

- Stress;
- Domestic violence;
- Environmental influences (e.g. housing);
- Social norms and pressures;
- FASD; and
- Inadequate social and family support.

Many of the issues identified were seen as cyclical, contributing both to alcohol consumption and being exacerbated, or in some cases even caused, by alcohol abuse. While it was reiterated throughout the consultation process that alcohol issues were not to be seen as an Aboriginal issue only in Hedland, peer pressures and social norms were seen as particularly problematic within Aboriginal communities.

“Peer pressure and trying to fit socially, if her man is drinking she’ll want to have a drink too. Keeping up with the mob. That’s what some of my clients say, it’s really hard to give up if everyone else is drinking. Then if you go away from them there is a disconnect, and people say oh you think you’re better than us, you think you’re someone.”

The above quote highlights the complexities of the social pressures operating. It is indicative not only of a descriptive social normative pressure, but also a fear of ostracism and rejection.

This social pressure was also evident in suggestions given for the focus of prevention activities, with many people indicating a strong need for partner involvement in helping women to not drink during pregnancy. This was seen as being exacerbated by a perceived lack of programs or services tailored specifically for men.

“[There are] no programs for men. No health care, no primary health care and no perpetrator counselling or intervention.”

4.3.5 Community Ownership

The following themes were indicated to be of moderate priority through the consultation process. While still considered important, these issues were seen as less critical than those outlined in sections 4.2 and 4.3. Strategies for addressing these priorities can be seen in Table 2 and section 6 below.

4.4 Themes of Moderate Priority

4.4.1 Early Intervention and Education

A recurrent theme throughout the consultation was the need for early education and awareness for young men and women. School-based programs for educating children and young adults about the consequences of drinking during pregnancy were seen as ideal, as were educational elements to existing youth diversion programs.

Many of the service providers who were consulted – and a number who were not – were in fact already undertaking programs with young people with components of early intervention. Some

of these programs are outlined in more detail in the Institute's Environmental Scan Report (Telethon Kids Institute; 2016).

The importance of early intervention was somewhat moderated by the need to engage with youth in a meaningful and appropriate way. As one participant pointed out *“kids aren’t going to sit down and listen to a big lecture – hence the importance of activities like the SLAM”* (referring to the fortnightly basketball-based diversion program at the JD Hardie Youth Zone).

While still advocating an early intervention approach, an additional recurring theme was that youth programs and early years’ interventions need to engage with the whole family. A key criticism of existing programs was that they failed to undertake this holistic approach, and that many *“...programs are looking at the kids in isolation”*.

The concept that beginning a conversation about reducing or ceasing alcohol consumption at the point at which a woman is pregnant is too late was also recurring. Taking this concept further, it was additionally suggested that it would be easier to encourage young people to avoid initiating a drinking habit than to help them stop once started.

“By the time we see them here the horse has usually bolted.”

Activities for 8-12 year olds and in particular self-esteem building activities in upper primary school-aged girls, are keys to preventing early drinking and under-age pregnancy in later years but they are a particularly difficult group to engage – not so interested in sport, and feeling a lot of shame about participating in group activities.

5 Participation and Collaboration

Throughout the course of the Hedland FASD Project a large proportion of the local services and stakeholders have been consulted or have met Telethon Kids Institute project staff at local events and action group meetings. Figure 4 below indicates the services and groups that have been introduced to the project and the team, and highlights the depth and breadth of local engagement. The trust, openness and engagement of participating communities and individuals is as important as the scientific rigour of the investigation (NHMRC 2003). Respectful engagement is fundamental to sustainable research relationship and requires ongoing consideration to cumulative decisions of participating communities and to the engagement of individuals.

All community members and service providers met with have indicated an interest and commitment to reducing the rate of FASD in Port Hedland, and a strong desire to work collaboratively with Telethon Kids and Wirraka Maya to help achieve this goal. Engagement is ongoing, and regular attendance by multiple varied agencies at the Telethon Kids/Wirraka Maya monthly FASD network meetings highlights this important element of the FASD Project.



Figure 4. Services and Groups Engaged with the Hedland FASD Project.

6 Addressing Key Issues

A number of potential responses to address the key issues identified in this report have been summarised in Table 2. Many of the suggested responses are activities and processes already built into the Telethon Kids Institute's Hedland FASD Project, and working alongside community and local providers it is anticipated that these steps will be undertaken over the coming years, if not already underway. A summary of the key areas that will be addressed by the project, and the specific elements of the project that aim to address them, are detailed in Table 3 below.

Key Issue	Hedland FASD Project activities/processes to address identified issues
Inadequate knowledge of referral pathways	Through the Hedland FASD Network, the project is linking health, allied health, Department of Community Protection, Early Childhood Services and other relevant service providers and will provide a structured process for identifying referral pathways. Once identified, this information will be provided to all service providers, in addition to being made available to community members through consultation and the KAP survey implementation.
Staff continuity – Burnout and turnover	A key aim of the Hedland FASD Project is to increase the capacity of local Aboriginal people to gain employment in research, health and related industries. Increasing local capacity and employment is likely to lead to increases in staff retention.
Knowledge and Awareness	Increasing knowledge and awareness of alcohol and pregnancy and FASD within the community is central to the aims of the FASD Prevention Strategy. This will be achieved through a variety of activities, including broad awareness-raising campaigns, and targeted communication with women of childbearing age.
Increased training and education	Training and education will be provided in part through the FASD Project's implementation of the Alert Program in local schools, in addition to quarterly information and diagnostic training to be provided by PATCHES Paediatrics. Engagement with Early Years Networks Additionally, Wirraka Maya and Telethon Kids have secured funding through Healthways for a visiting expert from Canada to provide training and information sessions for maternal and child health and relevant agencies for a period of 7 weeks in 2016. Training and information resources will be developed to ensure ongoing sustainability.
Community ownership	The Hedland FASD Project is committed to utilising a Community Participatory Action Research Methodology to ensure local ownership of the project and its outcomes and increase the sustainability of such outcomes moving forward.

Table 3. Key Issues and the Hedland FASD Project.

Those areas of impact that are not currently being addressed through the current Hedland FASD Project may require additional consultation and advocacy from the Institute to identify and support possible organisations and groups to address them. Importantly, this includes:

- Shifting social norms;
- The need for culturally safe services (including accommodation);
- Focus on early intervention; and
- High rates of alcohol and other drug use.

While not explicitly targeted within the Hedland FASD Project, it should be noted that the Telethon Kids Institute is committed to working with local communities and service providers to address these issues and to providing support and advocacy where appropriate.

It is recommended that the results of this report be disseminated among identified collaborators to initiate discussions around possible actions and responses to the identified issues.

References

Bessarab, D., & Ng'andu, B. (2010). *Yarning about yarning as a legitimate method in Indigenous Research*. *International Journal of Critical Indigenous Studies*, 3(1), 37-50.

Commonwealth of Australia (2014). *The Forrest Review: Creating Parity*. Available online at <https://indigenousjobsandtrainingreview.dpmc.gov.au/sites/default/files/files/3838%20Forrest%20Review%20Update%20-%20Full%20Report%20-%20Complete%20PDF%20PRO1.pdf>.

Crane, P., & O'Regan, M. (2010). *On PAR : Using Participatory Action Research to Improve Early Intervention*. Department of Families, Housing, Community Services and Indigenous Affairs, Australian Government, Canberra. Available online at https://www.dss.gov.au/sites/default/files/documents/05_2012/reconnect_0.pdf

Taylor, J., & Scrambary, B. (2005). *Indigenous people and the Pilbara mining boom: A baseline for regional participation*. Centre for Aboriginal Economic Policy Research, Australian National University Canberra. Research Monograph No. 25.

Walker, R., Scrine, C & Murray, R. (2011). *Report on Aboriginal women's uptake of the Antenatal and Child Health Service at Newman, with particular reference to Martu women: Interim Findings 2011 Final Report*. Telethon Kids Institute, The University of Western Australia.

Walker, R., Scrine, C & Langridge, A. (2013). *Factors Influencing Maternal and Early Child Development for Martu Communities in the East Pilbara*. Centre for Research Excellence In Aboriginal Health and Wellbeing, Centre for Child Health Research, University of Western Australia, Telethon Institute for Child Health Research.

West Pilbara Alcohol Management Group (2011). *West Pilbara: Report on Alcohol-related Harm, Ill-health and Disorder*. Available online at http://www.rgl.wa.gov.au/docs/default-source/rgl/report_director_liquor_licensing_on_alcohol_related_harm_in_pilbara.pdf?sfvrsn=0.





100 Roberts Road, Subiaco Western Australia 6008
PO Box 855, West Perth Western Australia 6872

T | 08 9489 7777
E | contact@telethonkids.org.au
W | telethonkids.org.au



in partnership
with the Hedland
FASD Network

