National Indigenous Corporation
for Fetal Alcohol Syndrome
Education Network (NICFASEN)
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Senate Select Committee on Regional and Remote Indigenous Communities
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Submission to: Senate Select Committee on Regional and Remote Indigenous Communities

Submission from: The National Indigenous Corporation for Fetal Alcohol Syndrome Education Network (NICFASEN) (prepared by Lorian Hayes on behalf of NICFASEN)

Re: Terms of Reference
This submission will address the impact of Fetal Alcohol Spectrum Disorder (FASD) in relation to the following Senate Inquiry Terms of Reference

The health, welfare, education and security of children in regional and remote Indigenous communities.

The founding director of NICFASEN, Lorian Hayes makes this submission based on research, evidence, and my personal experiences as a researcher and Fetal Alcohol Spectrum Disorder (FASD) Educator, who has provided education of the dangers of maternal alcohol consumption during pregnancy and raising the awareness of Fetal Alcohol Spectrum Disorder (FASD) to Aboriginal and Torres Strait Islander community members in forty one communities across Australia. During the past twenty years this training has been provided to all members of the community as well as to educators, police, judiciary, medical professionals and allied health workers who provide services that ultimately impact on children who have Fetal Alcohol Spectrum Disorder (FASD), their families and communities.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term describing the range of effects that can occur in an individual as a result of the mother drinking alcohol during pregnancy. The consequences of alcohol exposure are physical, mental, behavioral, and learning disabilities with possible lifelong implications. The term Fetal Alcohol Spectrum Disorder (FASD) is not intended for use as a clinical diagnosis; it refers to conditions such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Prenatal alcohol exposure is also the leading and most easily preventable cause of mental retardation in the western world.

It is estimated that as a result of research undertaken by Hayes[1] 2000, in remote and rural Aboriginal communities, it has been shown that in one community alone, where data were collected about the drinking history of the women who attended the antenatal clinic during a 12 month period 92% of the women drank alcohol at harmful and hazardous levels, 100% of the women used marijuana with 17% using other substances. In this same community during 2001, a chart audit was undertaken;

there were 640 children aged between birth to 12 years of age, the data has shown that 540 of these children were born to mothers who drank alcohol during their pregnancies, this means 84% of this total population of children have been during this period have been exposed to alcohol inutero. Binge drinking women continue to drink alcohol throughout their pregnancies

The behavioral and cognitive effects of prenatal exposure to alcohol have devastating consequences for the foetus. Evidence pointing to high rates of alcohol use by women in the both the Indigenous and non-indigenous community suggests it is likely that many children as a consequence have developmental problems and learning disabilities. Unpublished research on Fetal Alcohol Spectrum Disorder (FASD) undertaken by Hayes 2001, showed a need for systematic quantitative data on prenatal use of alcohol in the Aboriginal and Torres Strait Islander Indigenous communities in Australia.

It is obvious that the duration of one's pregnancy is a very important stage for the development of both the mother and infant. From the view-point of health, there is a significant risk attached to the relationship between alcohol and pregnancy. For many Aboriginal and Torres Strait Islander women alcohol is a normative part of their social and cultural environment and lifecycle as is pregnancy. Where there is clear evidence of family breakdown, abuse and isolation, fear, loss of respect, violence and grief, alcohol and alcoholism is a major contributing factor in the distribution of un-wellness of the individual as well as the communities. Fetal Alcohol Syndrome has been identified at the community level as a priority health issue for both Aboriginal and Torres Strait Islander people as well as non-indigenous people throughout Australia. The Fetal Alcohol Spectrum Disorder (FASD) workshops are a community based initiative. Throughout the past and present management issues are of concern especially when ensuring access and equity to appropriate community care and support services across education, health, community services, and employment along with criminal justice sectors for the communities, families and individuals impacted with Fetal Alcohol Spectrum Disorder (FASD).

As a result there is evidence that little attention has been given to the prevention of secondary disabilities for affected children and youth within the health and education sectors. Community health workers, nurses and other allied health professionals express concern and frustration about responding to the birth defects that they are observing as serious health problem that has continued to be ignored in Aboriginal and Torres Strait Islander communities and the broader communities within Australia. NICFASEN will continue raising the awareness of the prevalence and impact of Fetal Alcohol Syndrome (FAS) and the health consequences of maternal alcohol use in Australia

Until 1996, efforts to identify children with FAS and prevent its associated secondary disabilities through early diagnosis and interventions were constrained by the lack of efficient and effective surveillance and screening tools. In 1996 the Institute of Medicine released detailed diagnostic criteria for partial FAS/FAE which identifies a complex pattern of behavioral and or cognitive dysfunction that is unrelated to developmental maturity or to family or home environment, and includes:

- Difficulty in learning
- Poor school performance
- Poor impulse control
- Problems in relating to others

- Deficits in language and poor ability for abstract thinking
- Poor arithmetic skills
- Problems in memory, and attention or judgment (O'Leary, 2004)

The teratogenic effects of prenatal exposure to alcohol can have devastating outcomes on the developing embryo and foetus in many different ways causing a whole spectrum of disorders**.** More recently Astley and Clarren (1996) have developed a 4 Digit Diagnostic Code to demonstrate how the two measures of FAS Facial Phenotype correlate with brain function and structure. The surveillance and screening program devised as part of NICFASEN's proposed research project will be based on the proposal of diagnostic techniques which recommends the 4 Digit Diagnostic Code.

When diagnosing children who have been exposed to alcohol whilst in utero, the following criteria should be adhered to:

FAS/FAE *with confirmed history of alcohol exposure;* these patients meet the full diagnostic criteria of:

1. Growth deficiency, prenatally or postnatally, for height, weight, head circumference
2. A specific pattern of minor facial anomalies that includes short palpebral fissures, a complex lower facial malformation that is typified by epicanthal folds, a flat midface, short upturned nose, a smooth or a long philthrum and a thin upper lip.
3. Some CNS damage, including microcephaly, tremors, hyperactivity, fine gross motor problems, attentional deficits, learning disabilities, intellectual or cognitive impairments and or seizures.
4. Alcohol related birth defects to denote the presence of congenital anomalies known to be associated with a history of prenatal alcohol exposure.
5. Alcohol related neuro-development disorder requiring a confirmed history of parental alcohol exposure and evidence of CNS abnormalities.

When diagnosing Foetal Alcohol Syndrome (FAS) it is important to explore the history of significant prenatal alcohol exposure. As suggested by Stressguth, (1997), and the Institute of Medicine (1996) that two classifications of FAS are evident: one with and one without confirmed maternal alcohol consumption.

FAS/FAE *without a confirmed history of alcohol exposure;* these patients have the same phenotype findings as above, but no history of alcohol can be confirmed due to the availability of the family or origin.

Atypical FAS/FAE is when individuals have a phenotype that very nearly is complete for FAS and has a confirmed history of alcohol exposure, but lack growth deficiencies.

Through the varying techniques used in qualitative and quantitative research, research that NICFASEN proposes to undertake will raise the awareness of the prevalence and impact of Foetal Alcohol Syndrome and the health consequences of other commonly used substances. NICFASEN will continue to engage communities in communication and participation and to educate all community members to gain an in-depth understanding of Fetal Alcohol Spectrum Disorder (FASD).

Research proposed by NICFASEN will significantly contribute to the knowledge of Fetal Alcohol syndrome (FAS) in Australia. It will also add to the baseline data in this country for Aboriginal and Torres Strait Islanders who have been prenatally exposed to alcohol by carefully screening the Indigenous populations. It also will raise the awareness of the prevalence and impact of Fetal Alcohol Syndrome (FAS) and the health consequences of maternal alcohol use in Australia

Through the varying techniques used in qualitative and quantitative research, the research project proposed by NICFASEN will raise the awareness of the prevalence and impact of Fetal Alcohol Syndrome (FAS) and the health consequences of other commonly used substances. The proposed project will:

1. Determine the prevalence of fetal alcohol syndrome and related syndromes in selected Aboriginal communities.
2. Assess the effects of alcohol use on foetal and child health considering tobacco and cannabis as confounders.
3. Validate an existing FAS screening tool to assess children 7-8 years who were exposed prenatally to alcohol, tobacco and other drugs.
4. Prevent FAS births through increasing awareness of the impact of FAS/FAE and to inform the community members of the dangers of maternal alcohol, consumption during pregnancy as an important health issue.

By raising the awareness of Fetal Alcohol Syndrome amongst community members, including women of all ages, health professionals, teachers and educators within the community and then expanding to the Australian population will make an important contribution to improvement to mental health in childhood that includes intellectual disability, cognitive impairments, learning difficulties, speech and language delay, and behavioral and emotional problems.

1. **Primary prevention**

The first component of any intervention should target the community as a whole.

Raising awareness

Develop a capacity building intervention focused on women who may become pregnant or have already had a child who has been prenatally exposed to alcohol.

- To increase literacy skills in relation to health promotion materials.
- To identify and develop appropriate FAS/FAE resources to use during the community events and activities.
- Increase the awareness and knowledge of the effects of alcohol and other drugs on the developing fetus and how it impacts on the newborn infant.
- Facilitate the development of a sustainable health education ethic within the community.
- Reduce the risk factors that compound the effects of using alcohol and other drugs in pregnancy, including family violence and poor nutrition.
- Contribute to the development of supportive environments through public policy that is conducive to good health and encourages healthy children, families and communities.

As a result there is little attention given to the prevention of secondary disabilities for affected children and youth within the health and education sectors. Community health workers, nurses and other allied health professionals express concern and frustration about responding to the birth defects that they are observing are as serious health problem that has continued to be ignored in Aboriginal communities and the broader communities within Australia.

2. Secondary prevention or risk reduction

Reaching those at risk,

When planning prevention programs it is critical to understand the nature and scope of the problem; in this case the rates and circumstances of alcohol use by women of child bearing age, pregnant women who have given birth to a child affected by Foetal Alcohol Syndrome (FAS). Accurate information concerning alcohol use by women, particularly pregnant women is often limited due to a lack of routine screening and under-reporting of alcohol use by women in clinical interviews.

3. Tertiary prevention or minimizing complications and chances of recurrence.

Whole of community approach

The third component of the research will be to identify the prevalence of Fetal Alcohol Syndrome (FAS). These will achieved by adapting and using an existing screening tool and identifying individuals who are affected by exposure to maternal alcohol exposure.

By raising the awareness of Fetal Alcohol Syndrome (FAS) amongst community members, including women of all ages, health professionals, teachers and educators within the community and then expanding to the Australian population will make an important contribution to improvement to mental health in childhood that includes intellectual disability, cognitive impairments, learning difficulties, speech and language delay, and behavioral and emotional problems.

NICFASEN's principles provide cultural capacity to ensure that Cultural Respect, Cultural Safety and recognition are applied to all areas of diagnosis, feedback to families and all service delivery to birth mothers, carers, families and community where a child has been given a diagnosis of Fetal Alcohol Syndrome (FAS).

- **Public Education** is focused on educating the public at large about the dangers of drinking alcohol during and even before pregnancy. Public education can take many forms such as educational campaigns relating to product warnings, ie posters, lectures, brochures and media attention are all forms of public education.

- **Professional Training** is focused on teaching healthcare, child care and community service workers and medical professionals about Fetal Alcohol Spectrum Disorder (FASD). Beyond that, teaching them how to discuss with women about the effects drinking can have on the fetus. Professionals should be given concrete suggestions for introducing the topic of drinking during pregnancy and they should be familiarised with ways to help women stop drinking.

- **Public Policy** refers to the way government on every level deals with the issue of drinking alcohol during pregnancy. Public Policy is seen in warning women to stop drinking while they are planning to become pregnant.

- **Programs and Services** refers to programs which intervene – even briefly with women who are drinking during pregnancy and services which support the women while they are pregnant and after. Provision of Fetal Alcohol Spectrum Disorder (FASD) diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of Fetal Alcohol Spectrum Disorder (FASD) on affected individuals.

- **Parent and Community Activism** is simply what its name says. Parents and Community members taking an active role in the prevention of Fetal Alcohol Spectrum Disorder (FASD).

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KOWANYAMA
FOETAL ALCOHOL SYNDROME
HEALTH LITERACY PROJECT

BACKGROUND

The use of alcohol, tobacco and other drugs during pregnancy continues to be a leading preventable cause of mental, physical and psychological impairment in infants and the older child (May, 1995). It is obvious that the duration of one's pregnancy is a very important stage for the development of both the mother and infant. Moderate to heavy alcohol consumption by a pregnant woman can result in her child being born with Foetal Alcohol Syndrome, which is considered to be the leading known environmental cause of mental retardation in the Western world (Hayes, 1998).

There is little knowledge about congenital malformations but it is know that the environment affects at least one third of infants born with problems, especially Foetal Alcohol Syndrome. The birth defects caused by alcohol abuse by the mother and father before pregnancy and by the mother during her pregnancy are together called Foetal Alcohol Syndrome.

When maternal drinking is heavy the effects in decreased fetal growth are marked (Little & Wendt, 1991). Lower levels of drinking are also reported to cause significantly lower birth weights in many studies, with as little as two drinks daily being associated with decreased birth-weight (Kuzma and Sokol, 1982, Wright et.al., 1983; Streissguth, Barr and Martin, 1984; Little, Asker, Sampson and Renwick, 1986).

CONCERNS OF COMMUNITY

The widespread use of alcohol and drug use among young women, and the links of this use with teenage pregnancy, raised the communities concerns that the long term effects of these habits may be having a significant impact on the unborn foetus and the new born child.

Where there is clear evidence of family breakdown, abuse and isolation, fear, loss of respect, violence and grief, alcohol and alcoholism is a major contributing factor in the disruption of the individual as well as healthy communities.

Aboriginal people living in Kowanyama and Wujal Wujal have identified the overuse of alcohol by youth and pregnant women in their communities as a major concern, and believe that there is a direct link to a large number of health and social problems associated with their alcohol misuse. From the view-point of health, there is a significant risk attached to the relationship between alcohol and pregnancy. For many Aboriginal women alcohol is a normative part of their social and cultural environment and lifecycle as is pregnancy.

OBSTETRIC OUTCOME

A previous study undertaken by Humphrey, 1995 which explores pregnancy risk scoring in Far North Queensland revealed that low birth weight babies, birth interventions and pre-term births were more likely to occur in women with a high risk categorization. Categories of risk are subjective and flexible rather than fixed. Different approaches to risk categorization are appropriate in different contexts.

Teenage births and particularly young teenage births are commonly regarded as at risk groups (Queensland Health, 1997).

The median age of Aboriginal and Torres Strait Islander mothers across Australia is 24.6 years. As a result of research undertaken by Hayes (1999) in a rural indigenous community, the mean age of birth mothers was identified as being 23.27 years. While this age is lower than that for the Australian population at large, it is not so low as to place women in a risk category (ABS, Births, Australia, 1998).

Another commonly considered risk factor for poor obstetric outcome is parity. Generally perinatal statistics tend to indicate that grand multi-parity is associated with mothers from remote area, and with Aboriginal mothers from remote areas (Queensland Health, 1997).

DRINKING HABITS OF WOMEN

A study examining the drinking habits of women attending a health screening centre in Sydney between 1975-1981, found that not only were more women drinking, but those women who did drink consumed more alcohol (Corti & Ibrahim, 1990). The argument of the changing status of women has made it more acceptable for women to drink socially has been put forward by Corti & Ibrahim (1990). The changing behavioural patterns and the continuation of alcohol consumption by women may be seen as a direct result of the social acceptance of women drinking and combining their drinking activities within the boundaries of the home and family environment. The idea that alcohol is portrayed as fashionable, socially acceptable and a desirable product is true for Aboriginal women who are acutely aware that any stigma associated with he behaviour of White Australian women will count ten fold. In Canada, 25% of women, reported drinking alcohol during pregnancy, with 5% of those women reporting binge drinking. (NPHS).

Alcohol as well as other drug use during pregnancy is an important issue in Indigenous mothers and babies' health. It has been identified in many studies that children born to mothers who drink alcohol will be more severely damaged, as the mother's alcoholism depletes her body of nutrients to nourish the foetus, (Barker, 1998; Nathanielsz, 1999). Again in the event of poor nutritional status, mothers who are undernourished can attain higher blood alcohol levels and decrease their capacity to metabolise alcohol. Short intervals between births, is also associated with an increased risk of congenital malformations and severity of foetal alcohol syndrome (FAS).

The risks of prematurity, small for gestational age, and miscarriage as well as congenital abnormalities are three times higher in drinkers. The identification of alcohol use by pregnant women requires an in-depth understanding of how the history of use relates to

relationships, conception and childbearing (Russell M, 1985; Burd, 1994). (See appendix 1 Screening tool proposal).

Learning disabilities in the child have also been associated with alcohol consumption throughout the term of the mother's pregnancy. The amount of alcohol consumed during the first trimester has a substantial affect on the unborn child and is related to the frequency and timing of the use of alcohol, (Little & Wendt, 1991:181). However, it is suggested by Barker (1998), that there are no safe limits of alcohol consumption by pregnant women. In the early stages of pregnancy just one session of five glasses of alcohol or two drinks per day in the later part of the pregnancy has shown to cause alcohol related disabilities in the newborn, (Hayes, 2001). The risks of prematurity, low birth weight, failure to thrive, small for gestational age and miscarriage as well as a wide variety of congenital abnormalities are all trebled in drinkers, and these should be regarded as non-specific risks of alcohol consumption (Sayers and Powers, 1997:524).

A study carried out by Bower (Bower et el.,1989:248) noted, *a high occurrence of foetal alcohol syndrome amongst Aboriginal births*. Lancaster (Lancaster,1989) postulates that malformation rates are higher among Aboriginal people than non-Aboriginal people. Significant differences were noticed for some congenital malformations including *misrocephalus; several types of congenital heart defects; cleft lip with or without cleft palate and talipes* (club foot) (Lancaster, 1989:241).

Alcohol increases the incidence of abortion, still birth and prematurity. The most severe effects of alcohol abuse on the foetus occurs in the 1st Trimester, this being the most dangerous time for women as many are not are that they are pregnant. During these early stages of pregnancy is when the damage is done. Large prospective epidemiological studies leave no doubt that a significant decrease in infant mental and motor development is associated with maternal alcohol use at even moderate levels (Streissguth et. Al., 1980).

The population-based prevalence model used in Canada uses pre-existing data of a population to estimate the incidence of FAS. 46 per 1,000 Native Canadian Yukon, 25 per 1,000 British Colombians, 51% to 66% children in special Education were exposed to maternal alcohol use, (Habbick et al. 1996), unfortunately there is no data available for Australia.

It's now well established that the health of the indigenous people of Cape York communities cannot be determined only by medical or biological factors. Measuring economic and social determinants can be just as important. For example, the health and life expectancy of Australia's Indigenous people is far worse than for the rest of the population, Ring, 1996 (*Trends in Estimated Mortality Cape York 1976-1994*).

It has been suggested by Ring, 1996 that overall mortality levels for indigenous people of Cape York are still more than three times higher for Aboriginal and Torres Strait Islander people than for the total of Queensland. Ring also suggests, that the death rates related to alcohol misuses are over 21 times higher than for the total Queensland population.

Education across all levels of community is therefore an urgent need, as is a good, comprehensive data collection system to measure the actual prevalence of alcohol and drug use by pregnant mothers and to monitor the efficacy of intervention programs.

A health literacy program has been carried out in two Cape York communities.

Health Literacy Program

METHODOLOGY

AIM: To decrease rates of maternal alcohol consumption and consequently the incidence of foetal alcohol syndrome and foetal alcohol effects in the community

To increase community awareness of Foetal Alcohol Syndrome and Foetal Alcohol Effects and to inform community members of the dangers of maternal alcohol consumption during pregnancy as an important health issue.

OBJECTIVES:

1. To increase community people's awareness and knowledge of the effects of alcohol on unborn babies
2. To increase literacy skills in relation to health promotion materials

- To identify and develop appropriate FAS/FAE resources to use during community events and activities.
- To facilitate the development of a sustainable health education ethic within the communities

BACKGROUND:

Health Literacy is a terminology that is rapidly gaining popularity in the medical and health promotion literature. As with most new labels, Health Literacy has a broad range of definitions. Many of these labels are purely functional in their approach. For example, "Health Literacy is a constellation of skills including the ability to perform basic reading and numerical tasks required to function in the health care environment" (Parker et.al.1999:53).

This definition focuses on the skills necessary to perform certain tasks. It is an entirely functional perspective with the aim of equipping individuals simply to function within the health care environment. This means equipping people to be able to find the health service they need, know who they should see, read labels on medical containers and so on.

Other definitions are broader and include skills such as interpretation and understanding with the basic competencies necessary to follow instructions. One such example is supplied by the American Cancer Society (2000), "Health Literacy is the capacity to obtain, interpret and understand basic health information and services and the competence to use such services in ways that enhance health".

Broader still are definitions incorporating the potential for people to make their own health decisions. For example: "Health Literacy is the degree to which people can obtain, process, and understand basic health information and services they need to make appropriate health decisions" (The National Library of Medicine, in Osbourne, 2000).

Equipping people with the necessary skills and understanding to actively participate in their own health care is a primary objective of the new public health. Yet, in the United States it came as a shock to the Government when the National academy on an Aging Society reported in 1998 that over 90 million adults in that country had low literacy skills and were consequently unable to read and understand the instructions contained on prescriptions or medicine bottles, appointment slips, informed consent documents, insurance forms, and health education materials (Osbourne, 2000). The majority of the 90 million people with low literacy levels were from various minority groups: African American, Hispanic and Native American, most significantly. These groups are also the people with the highest mortality and morbidity for most diseases.

Over the last 15 years researchers have provided extensive evidence of the link between low literacy skills and poor health (Clenland & Van Ginniken,1988; Grosse & Auffrey, 1989; Weiss, Hart, McGee & D'Estelle,1992; Tresserra, Canela, Alvarez and Salleras,1992). As the major component of the new public health is health education, it became apparent that the people with the greatest need to access health information are also the people least likely to be able to read or understand it in its current form. Health education and health promotion are primarily reliant upon print materials, most of which are written at tenth grade or higher reading level (Drew Hohn, 2000).

As a result of this realization it became a health promotion priority to make health information materials easier to read (Dowe, Lawrence, Carlson, and Keyserling, 1997). It has become increasingly evident however, that simplifying the language of health information materials does not necessarily lead to better outcomes in relation to positive health behaviours (Rudd, 2000). In fact, Plimpton and Root (1994) found that easier to read materials had a greater impact on highly literate patients than they did on low literate, at risk patients. Indeed, Greenberg (2001) suggests "…it may be that the effort spent creating and distributing written educational materials for low literate audiences may do little more than foster a false sense of security among health care providers".

Some reasons for the failure of this approach may be that not only are the current materials beyond the reading capacity of many people most in need of the information, they are also presented in a way that focuses on individual behavioural change dictated from the top down. Cultural differences are treated as educational barriers to be overcome. People who deviate from White middle class norms are encouraged to make individual changes in their lives to comply with mainstream expectations (Zambrana & Ellis, 1995).

Rather than simply "dumbing down" the language used in health materials, it seems more prudent to engage groups in the development of health materials, *while at the same time* increasing their literacy levels and critical thinking skills to encourage lifelong interest in gaining, sharing and acting upon, health knowledge. The combination of these two elements is the key to effectiveness within health literacy. Experience within the field of education has demonstrated the value of context based learning, "inviting learners to be active participants in the learning process, and providing opportunities to work on identifying problems and constructing solutions (Fingeret, 1990; Horseman, 1990; quoted in Drew Hahn, 2000). The community's own issues, problems, aspirations, skills become the basis for learning as well as the tools to engage in it (Fingeret, 1990). As Drew Hahn (2000) points out, "Learning together has the potential to honor the perspective of local communities and different cultural perspectives, and to entail an exploration of the inherent diversity and structural equity issues. Learning together also has the potential to develop an informed community of adults who feel empowered to address the issues of health and well-being in their own lives and to confront a health care system that ignores their informational needs." By contextualizing literacy learning within health learning we move beyond the development of discrete literacy skills, or even advocacy for health behavioural change, to strengthening people's capacity to think critically about information leading to a greater sense of power and control in their lives.

Consequently, this project has as a working definition of Health Literacy:

A model to engage groups in the development of health materials,

while at the same time

increasing their literacy levels and critical thinking skills to encourage lifelong interest in gaining, sharing and acting upon, health knowledge.

Finally,

There is absolutely no doubt of the low literacy levels among Aboriginal and Torres Strait Islanders, particularly in remote communities. It is also evident that conventional health promotion activities have not been effective. The Health Literacy approach we suggest differs from the conventional in two ways: Firstly, the people themselves create their own learning environment and learning materials; and secondly there are strategies built into the process to simultaneously increase literacy levels while increasing health awareness.

STRATEGIES:

- A Health Literacy Program will be carried out in four communities. This program will be implemented over three months in each community. This program will increase awareness of the effects of alcohol on unborn babies and facilitate the development of appropriate FAS/FAE resources within the community setting. In addition the Health Literacy Program will increase literacy skills among participants empowering them to continue the process of lifelong learning in relation to their health. The program will be implemented by Aboriginal Facilitators trained in Health Literacy and supported throughout by a Public Health Researcher experienced in Health Literacy and Action Research Methods.

- Liaison will be carried out with community health action groups, local medical officers, nurses and allied health professionals to establish a strategic approach to sustaining information gathering and information dissemination activities in participating communities.

PERFORMANCE INDICATORS

1.1 Capacity participation rates in the Health Literacy Program

1.2 Increased knowledge among participants of the effects of alcohol on unborn babies

1.3 Development off appropriate information resources on FAS.FAE to be used in the community.

- Increased literacy skills among participants

- A commitment among participants to further disseminate their knowledge of the effects of grog on babies.

- Increased awareness within the broader community about FAS/FAE

- An increased sense of control over their own health decisions among participants.

- Participation of a broad range of stakeholders in the liaison process

- A workable strategic plan on dealing with FAS/FAE for each community participating in the project.

EVALUATION

At the beginning of the Health Literacy Program, two baseline surveys have been carried out:

- To measure the literacy levels of participants in the Program

- To measure the level of knowledge about the effects of grog on unborn babies among participants (some behavioural variables will also be included relating to substance use during pregnancy).

At the end of the Health Literacy Program, literacy levels will be again assessed, as will levels of knowledge about the effects of grog on babies (some variables will also be included relating to intended maternal alcohol use in the future).

The entire process of the health Literacy Program will be fully documented resulting in an extensive report intended for use in future program development. It is envisaged that this process will result in a Health Promotion Model that is useful for a range of health issues within a broad range of Aboriginal and Torres Strait Islander communities.

At the beginning of the liaison with health professionals and community health action groups about developing a strategic plan for sustaining health promotion in relation to the effects of alcohol on unborn babies, a baseline survey of current knowledge, attitudes and perceptions will be recorded. The process of community negotiations and negotiations with professional staff will be fully documented providing a detailed account of the development of the strategic plans and MOU's.

Six months after the development of the MOU's; strategic plans and the completion of the Health Literacy program, a follow-up evaluation will take place. This will include;

- documentation of activities in the community compared against the strategic plan
- review of health service data relating to alcohol use during pregnancy over the preceding 12 months. (If antenatal information does not already include information about alcohol use, then this is something else that will have to be initiated).

TIMEFRAME

The timeframe for this project will be ongoing over a period of twelve months.

CONCLUSION

One of the major barriers to the success of health promotion material in general, and the types of materials mentioned above, are the extremely low levels of literacy within many Aboriginal communities. Low levels of literacy and numeracy skills, re-enforce feelings of hopelessness and low self-esteem which contributes greatly to the alcohol problems. In addition, low levels of literacy and numeracy skills make it difficult for people to participate in the development of health promotion materials that are meaningful to them.

In order to address this issue, it is proposed that a health literacy approach be taken to meet the strategies outlined above. This approach is based on the belief that people's literacy and numeracy skills can be raised at the same time, and in the context of, their increased awareness. To this end, programs developed within the communities to increase awareness of the dangers of alcohol use during pregnancy will also be embedded with literacy and numeracy building strategies. This approach will provide long-term outcomes as participants will increase their initial knowledge of the topic as well as their ability to access, understand and critically assess health information that they come across in the future. This approach is part of a life-long learning strategy, which not only provides information, but also encourages a lifelong approach to seeking health advice and modifying behaviour accordingly.

An initial pilot for the Health Literacy program is envisaged in involving two communities within the Cape. This Program would assist in meeting the objectives outlined above through involving community members in the development of their own resources, while at the same time increasing their knowledge of FAS/FAE and increasing their literacy and numeracy skills particularly in relation to understanding health information.

The Health Literacy Program will span ten weeks with the FASET team visiting each of the communities. During these visits the team will facilitate problem-based learning workshops with community participants and health workers. These workshops will systematically work through the development of resource materials on FAS/FAE specific to each individual community.

Literacy and numeracy skills which are relevant to the development of these materials will be practiced and improved in a systematic way and from a Problem Based Learning approach (PBL):

1. reading and comprehending simple texts
2. association between known and unknown concepts
3. writing simple texts
4. understanding the structure of health information
5. thinking through the presentation of health information
6. critical evaluation of information.
7. understanding of alcohol use and misuse and the effects on the body
8. Foetal Alcohol Syndrome

9. reproductive health
10. childhood development as it relates to FAS

Those participants involved in the pilot series of workshops and the development of health information relating to FAS/FAE, will be encouraged to continue the process of learning in the context of their communities, and to become involved in training others, both formally an informally. It is imperative that one way of breaking the cycle is through education and training for re-empowering the individual as well as the community.

RESULTS TO DATE

KOWANYAMA

A twelve month program was initiated in Kowanyama on May 21, 2002. The community council, Justice Group and the Mothers & Babies Center was contacted in writing re preliminary visit to community (appendix 1), to inform about the profile of the team and the type of service it will provide. It was envisaged that the team would stay in the community for two-week blocks, return to Cairns for two weeks and then return to the community for the commencement of the second block. The FAS team will make twenty visits (ten blocks) to the community throughout the year.

Preliminary Visit

- The FAS team entered community to discuss the community needs re alcohol misuse in depth.
- The consultation process began by introducing the team to the various organizations in the community.
- It has been a major concern that too many external service providers do no stay in the community for very long. It became a priority that the team spend considerable time in the community to engage with community members during their time and space.

- Community meetings and informal discussions were held with pregnant women, their families, women who are in their reproductive years, partners and young women and men.

- Discussions were held with health staff, community workers, and other relevant government agencies such as education, police, and community groups, mothers and babies centers, kindergartens, CDEP gangs/workers, to encourage their support and cooperation with the development and implementation of the FAS strategy.

The first workshop was held on the 17/06/02. A meeting was held with the women's group at the mothers and babies centre re recruitment for the 2 week workshop, a list of names was given to us by the Coordinator. This will be very much a community owned program for sustainability.

A series of FAS presentations were and still are carried out to ensure the broadest possible coverage of the community. These presentations served to introduce the community members to the basic facts surrounding FAS and assess their awareness of, and concern regarding the issue. The sites concentrated on are: The Community Justice Group; The Mother's and Babies Center; the CDEP workers; and the School both teachers and students, Police and Council.

Results from these initial presentations follow:

KOWANYAMA FOETAL ALCOHOL SYNDROME PROJECT FIELD NOTES

MAY 21, KOWANYAMA

Justice Group

Participants – 12 women, over 45 years. This session was held in the Court House.

At first the women were not keen to proceed as women were pressed for time, they pointed out they had another meeting to go to as we were setting up all the equipment.

Lorian began with the egg in a glass of vodka. (The team use a raw egg cracked into a clean, dry, and clear glass with usually two nips of vodka or any type of clear alcohol, it makes it easier to see what effect alcohol has on the egg. The egg has similar properties as a developing embryo). She handed the glass around. The women were interested. One woman said, "It's cooking, Look! They killing that kid eh".

All the women are very concerned and attentive throughout the rest of the presentation. They said, “girls should know and stop drinking grog”.

FAS babies (dolls) were shown around the room and the women said “they felt real sorry”.

They all agreed that “People need to know that to drink alcohol, what damage it does to them.” Lorian explained the effects of alcohol on the foetus and the women said they understood. They were very strong women in their views and they were knowledgeable of events in the community. Very early in the presentation comments were: “These young ones drink and smoke every day. Even pregnant they drink.”

They were having a discussion in language among themselves very animated.

“ Young people don’t know this.” Nodding their heads in agreeance.

An elder stated “‘ Young people don’t know this”.

Lorian told the story of a14 year old boy who has FAS, is now on a disability pension as he cannot continue with school and cannot work as a result of his brain damage. This had an impact on the group with one lady indicated to another and made reference that she knew someone who is like that in Kowanyama.

Lorian stated that everyone has to know about FAS/E and understand the damage alcohol can do- services need to be set up to deal with these children.

People shouldn't feel shame it is too important an issue. Lorian shared information about a family she had identified where there was (3) three generations in one family with FAS. There was lots of talking among themselves "Shouldn't be drunk alcohol at all."

When the indications of FAS were described, one lady indicated to another and made reference that she knew someone who is like that in Kowanyama. One woman pointed out that some of the kids expelled from school were not naughty but had this health problem. One woman said, "I didn't drink". "My mother didn't drink." In the 70's it started too much drinking. Women worry about the young mothers and the children. Women know the signs and symptoms of alcoholics they identified those in the community

Gradually women became more and more interested and all agreed that the power point presentation was the best way to give the community the message-better for them to understand (the community). Lorian explained that Natasha an Aboriginal Health Worker in Kowanyama would be doing training, which would keep it in the community.

The women were saying that kids are expelled/ suspended from school. They were at this stage relating it back to FAS that these kids were not naughty but had a health problem because their mothers drank during pregnancy. They felt that the kids could be sent out to the outstations and teach the old ways and take teacher out there also to understand. They also said that parents should be part of their kid's education, but these are modern times!

There was talk about the Education Department and that parents can write letters to the dept. regarding remedial teacher to care/teach our kids. Set up some sort of orientation for all new teachers re cultural awareness an introduction to the community and our ways.

Apunipima staff member preparing for a FAS/FAE workshop

CDEP WORKERS AND COUNCIL STAFF

May 22, Kowanyama

Participants 46. (4 women)

The FAS workshop was held at the Council Training Centre.

Workers were told they would have their pay docked if they didn't attend. Bob Sands said, "At least I can create a captive audience for you".

As the room was crowded men found it easy to wait outside without actually coming into the training room at first. Lorian simply began her talk. At first the egg in the glass of vodka did not show any interest. I was holding the screen, which was put up upside down 1/2 way through the talk, the screen fell down making a loud bang.

Everyone jumped then silence they were pretty intent with the subject.

Bob Sands organized for all Council workmen to attend the FAS presentation at 8 am on the 22nd May. Participants 46. (4 women)

Workers were told they would have their pay docked if they didn't attend. Bob Sands said, "At least I can create a captive audience for you". The FAS workshop was held at the Council Training Centre.

As the room was crowded men found it easy to wait outside without actually coming into the training room at first. Lorian simply began her talk. At first the egg in the glass of vodka did not show any interest. However when the egg began to cook the men started to become interested. The men outside the room were soon edging in so they could hear.

Information from Bob Sand, Council CEO, Kowanyama

The Justice Group is now responsible for the new alcohol regulations in Kowanyama.

Lorian gave an overview of what the FAS presentation is about and wanted to do a session with the CDEP workers. She spoke of what the FAS workshops would entail and that it is a 12 months program working with a support group of community members and staying in the community for -2 weeks each visit.

Council workmen attend the FAS presentation at 8 am the next day.

A representative from Kowanyama spoke about a program offering a support system to families when the husband gets home from prison relating this to FAS. The early option group recognise the need and looking at programs to help our kids.

We have teachers blaming the kids (disruptive)

the discussion and see the demonstration.

Interested community and CDEP workers listen intensely

No one left the session before it was over and the men were keenly interested in the information provided. After the session, there was much discussion in the community about the issue of FAS.

Question time

Kowanyama State School.

May 23 Kowanyama

John Baskerville School Principal:

Meeting with John to arrange a FAS presentation with the teachers-arranged for the 19th June.

Also mentioned that we would be at the schools Career Expo working in with the Sexual Health team who are doing "theatre" workshops with the students and they would incorporate FAS/ alcohol etc.

May 30 Kowanyama

Kowanyama School's Career Expo

The School Principal arranged a FAS presentation with the teachers for the 19th June.
Arrangements were also finalized for the FAS TEAM to be at the schools Career Expo working in with Apunipima's Sexual Health Team who were doing "theatre" workshops with the students.

Kowanyama school expo – students showing interest in the Grog Babies

FAS team member with Kownyama school children

The first session of the day was spent with the younger students. The girls all enjoyed handling the dolls and having their photos taken. They understood what the session was about, one girl saying, "This one's mum had too much grog Miss. And Cigarettes too. All that."

Girls interested in handling the dolls

One little girl was very concerned about the FAS doll. She said, "Who is that one's Mum? Which of you is the mum? She was angry that the mum had been drinking and thought it was one of the presenters.

A staff member from Apunipima Cape York Health Council who has experience with drama, dance and theatre worked with the girls to create a theatre dance relating to FAS. The girls all sat in a circle as the staff member asked them to pass the bub around and talk about how she might feel. How would you be feeling? The staff member asked. The girls wrote on the board how the bub might be feeling – sad, cold, angry, scared. One girl explained, "That baby sick. He cry for a long time. Hold baby properly and even then he won't stop crying. Cuddles won't help. He's not angry. He's not hungry. He needs grog Miss".

The staff member asked the girls to think about that baby in the womb. A question was asked for them to think about the mother drinking grog and how she might feel. Two girls pretended to be the women who were drinking. They were dizzy, wobbly, feeling sick. One of the women was pregnant. Two kids were sober women sitting by watching. The pregnant woman felt shame. The drunken woman fell down and her friend helped her up. The staff member from Apunipima then turned the movement into a dance step.

The girls where then asked to focus on the baby in the womb. Pink jersey fabric was used to cover the two girls who were acting out as a foetus in the womb. They acted out how the babies were feeling. They were shivering, afraid and cold. They cried out pushing out against the jersey. A scene was established in dance that came from the girls exploring their feelings and acting them out with the staff member assisting them to put these to music in the form of dance. The children were extremely proud of what they had achieved.

Later in the day the older class joined the Team and the scene was expanded. The staff member taught them some choreographed steps that led on from the morning's session. The girls worked hard to develop a routine. When boys were allowed into the room to watch the girls became shame and no longer worked on the dance.

Banners

The Grog Babies banners were placed on the wall to assist in setting the scene, the banners were then later used by the girls as a shroud draped over their shoulders as they performed in their presentation of Grog Babies to the rest of the school.

Commencement of the FAS Workshops

Day one of the FAS workshop:

Participants: 6

- Irene Mayor
- Louisa Daphney
- Shirley Victor
- Donna Brumby
- Cecilia Sand
- Louise Daniel

All women were asked if they were okay with writing their names on a list for our records, all agreed and a book was passed around.

An introduction of the FAS workshop was given including what the participants could expect from the sessions and what would be covered. Group rules were drawn up and all were asked to add throughout the session if they thought of any thing further.

The two younger ladies commented that they knew of some kids around who they thought would be FAS/ E kids. The miracle of life slides (see appendix 2) elicited a lot of interesting questions regarding damage to the embryo. One asked “How long does it take before the organs form? Can doctors test if the pregnant mum is drinking alcohol?”

A Baseline Literacy assessment was carried out (see appendix 3). The baseline assessment revealed that most of the women in the group had sound writing skills and were well able to understand the questions. Prompting was needed to encourage several of the women to participate in each question, with some questions being left unanswered by a few women. Half of the women present were able to read the questions independently of support strategies and answer all the questions. The remaining half were able to read the questions and answer them with some support from the presenters. Some of the women had beautiful handwriting. All the women were aware of the health issues covered. Some women struggled with recognition of percentages and their depiction in graph form.

During the discussion, there were varying degrees of understanding. Some participants had a very good idea and did not require prompting, others understood when further explanation was given. Nobody was off track with the topic, the group certainly have a grasp that alcohol was being consumed at a high level in their community and the effects were being felt in families and the community, the most effected were children.

I believe this group had a very good understanding of the language used and were very interested in the subject, also recognising and relating it to individuals in the community. They recognise that the effects of grog are felt by many in the community and were very interested with the Miracle of Life (appendix 2).

Three of the women were quite comfortable and participated at the start. Two younger women were very quiet at the start of the session though they did relax and were involved as the session progressed, participating well and asking questions. One lady was a non-participant initially. She did come and go out of the room several times during the session (smoker?).

She was very reluctant to participate, appeared shy and was prompted a couple of times to participate and would comment appropriately. I would suggest that she was probably asked to attend the workshop. All other participants were very interested and took part in discussion and at this early stage voiced that they knew some kids around who would have FAS/E. One woman spoke of her adopted child in great detail who she believes is a FAS child and described his behavior, and how she is able to manage him. She says to get through to him, she has to work one on one with him in a quiet area to settle him down. " I get him to look at my face and talk to him then".

Oriel began the session with a mind-mapping exercise with the group. This exercise

encouraged a lot of interaction. (see appendix 4) [attach Oriel's mind mapping stuff.]

For the purpose of this report, using codes will protect participant's names as confidentiality is a priority.

W1 stated, Women's Shelter (not working well) see better use of the centre."

" Community Police and Commonwealth Police bring women to the centre or they walk down themselves."

" Sick female friends and family getting bashed by their partners to."

" How the children are affected and they don't go to school"

W1 said" Women's Shelter caters for ALL women"

As a response to family violence and community violence,**W2** said," Drive the kids to drink themselves to dull it all out". This was supported by **W1** who also stated that

" Women leave shelter to go home to man thinking he might change in the time she's been away, not so" " Children starving and go to alcohol"

W3 asked " How can you stop that from happening?" " Drinkers get their money and go straight to grog."

W4 felt that the" Attendance at school getting better more outside things happening" All agreed and believed that this is true.

A suggestion was made by **W2** " Alcohol→sell only mid strength –light beer no limit people can drink as much as they want"

A response was made by all participants that "Take away is limited to three days per week" and that a "Takeaway food outlet is open same time as canteen- this is good -saves the man going home and annoying his woman about food at home."

It was stated by one woman that "Sexual abuse victims go to clinic but no follow up"

Baseline literacy assessment (appendix 3)

All women did well with the reading

One woman asked "Passive smoker-is baby affected?"

W2 spoke about her experiences raising a FAS affected child," Cannot control FAS in them, talk to them in a calm manner one on one tends to let them cool down." I make them sit down and look at me until they cool down".

POEM: Don't Ask My Child To Fly which is taken from the FAS work-book developed by the Coordinator of the FAS program and Apunipima staff with the advise from a consultant was Read out by the group. Two stanzas were completed end of day.

Group comments from the days proceeding:

Educational

Help to be strong to work with child with FAS

How to settle child down
Interesting

Interesting

Good day with more information to learn -man's business as well

June 18 Day two

W4 and **W2** were only participants so we postponed the day activities and did a planning day with Apunipima staff.

June 19 Day Three:
Participants: 6
Cecilia Sand
Louisa Daphney
Donna Brumby
Clarita Frank
Debra Yam
Shirley Yam

Three women from the previous day didn't attend. Three new ladies came along today. All three participated, though one needed more encouragement she was shy and maybe not feeling confidant enough (shame).

Went over yesterday's activity to bring new ladies up to date, which worked well as it gave the attendants from the previous day to reflect and comment, they also assisted in getting understandable information across to the new ones.

New people were asked to read out a question from the Baseline Health Literacy form prior to filling it in which they were all able to do and continued to re-read to other each other a few times to understand what was required of them. Two of the new ladies were able to perform the reading task well and one young girl was shy and needed to be coached through- it was allowing her the time to read at her own pace on a one to one basis.

W5 was very nervous and shy about reading out aloud so I sat with her and did one on one and she then completed the task…had some problems with some words but encouraged her to break the word up and sound each section.

An Alcohol session was held in a Problem Based Learning (PBL) format. A scenario is below, the women had to read out the scenario, and then decide what issues they knew what was fact from their readings, what issues they felt they did not know about and what information they assumed they knew. We then worked through the issues they identified as not knowing anything about and then working on the issues they assumed they had knowledge about ie what is a dialysis machine and how does it work? Who uses a dialysis machine and why?

SCENARIO

Tom age 50 and Sylvia age 45 and their four young children, and older son and his pregnant partner, moved to a bigger town from the community.

Tom had to move to "bigger town" so he could go on the dialysis machine

Because he use to drink heavily and his kidney is not working properly.

Sylvia drinks on her pension and family allowance supplement days. Sylvia drinks a lot of VB (binge drinks).

Sylvia and Tom's younger children all go to primary and high school, two of their children are not doing well at school, children' ages are 8,10, and 11 they are going to primary school. The other child is 14 and is at high school.

Eldest son age 19 and his pregnant partner age 17 drinks alcohol, smoke cigarettes and gunja (marijuana), she is 2 months pregnant.

Began with a scenario

The question was asked by an Apunipima staff member Oriel Murray, " What do you understand from this scenario?" " What do you think is happening in this story:"

Participants replied with " No support network for Sylvia in the new environment"
" Children homesick starting in new school"
"19year old son and wife smoking and drinking"
" Didn't know his heavy drinking would lead to kidney illness"
" Tom keep on drinking to get rid of himself"
" Murri drink with friends"
" Lots of responsible"
" Mum gambling fathers drinking -not looking after their children"
" Children forgotten"
" Tom loves friends more then his family"
" Parents may have been drinkers"
" Children maybe experiencing lots of problems e.g. not going to school. Not getting enough sleep."
" Doing poorly at school due to parties happening at home"
" One lady did not offer any suggestions, she appeared shy, she may have asked the question
" baby of the pregnant woman what happens to the unborn baby"
" Happens when mother is smoking yandi."

Dolls used as a visual aid

One woman asked " Can smoking can be passed through sweat to baby."

Apunipima staff members discussed issues relating to alcohol and marijuana use, sharing this information with the new woman in the group.

An enquiry made by another participant was " What happens to the body when you smoke yandi and drink alcohol?" Mouth swab taken for yandi.

The Poem

This activity was to get the group to read the poem and the authors meaning of each stanza, plus get the group to offer comments or what they think the each stanza mean in the own words. People were rather shy at first but were able to perform the task. Comments were written on butcher's paper and these are below.

THE POEM- THE GROUPS INTERPRETATION OF EACH STANZA

1.

- Not expect your child to achieve higher then what their capabilities are.
- A healthy child- our expectation of that child to success e.g. Education
- FAS child will be difficult- their learning capacity

2.

- FAS problem with eyesight
- Eagle and what it symbolises
- Education to assist parents of FAS children

3.

- Trusting with 'high risk' to predators

4.

- Normal v FAS →inability to focus if everyone is talking at once he/she cannot filter 'workout' what is being asked of them
- Brain goes into sensory overload →confusion

5.

- They have to march to their own drummer and sleep their own cycle

6.

- A routine- that is continual for the FAS child- schedule which can/will take time

7.

- Teachers in the school need to know about FAS to understand better how to set programs for the FAS child
- Orientation regarding FAS included for new teachers

8.

- FAS child is unable to do what a small child can do-due to the mother taking 'grog' during pregnancy

9.

- Denied 'the 'potential'capabilities' due to 'grog'
- A journey with FAS awareness and education could prevent 'prenatal exposure' mothers become aware regarding the effects of alcohol

10.

- Community commitment regarding FAS for our children's health
- Support group to help mothers and dads of children with FAS

June 20 day Four: 11am
Participants: 4
Debra Yam
Shirley Yam
Cecilia Sand
Louisa Daphney

Family roles: Lorian drew a diagram regarding the roles in a family and went through the different roles people can be recruited into to drink alcohol.
These were:
Chemical Dependant –the alcoholic
Caretakers - co-dependant

Group discussions were held around a person trying to get off the grog and the co-dependant family member trying to pull them back into the alcohol scene as they themselves may not be ready to admit they need help also and are not ready to receive help for their issues.

Discussions regarding children from this group and how they have different roles within the group

- Hero- can't do wrong, play up to the parents, become the attention seeker, could be the one who actually trains to make something of his/her life
- Scape goat- angry self-destructive
- Lost children -loner
- Mascot-make others happy

June 24 Day Five: Morning session

Participants: 4

Debra Yam
Shirley Yam
Cecilia Sand
Louisa Daphney
Rosemary Henry (new lady)
Shirley Victor

Going over same material for two ladies to catch up from last week. The ladies found the slides interesting.

W1 suggested that " Smoking dope, can that affect the baby, but not as much as the alcohol?"

W1 explained " how the Mother can sober up but baby's still drunk"

W6 began to nod her head and hmm agreeing –not sure if she understand. She has nodded throughout the presentation, maybe shy. Her young child distracted her, as she was checking that he didn't touch anything, which would account for her appearing disinterested.

W1 again took the lead and stated "We have one drunken woman and we tell her that alcohol can affect her baby- I can tell them that and show movie/video. **"**To protect our family just to encourage them – I can help them in the women's shelter". She also stated that it was important to **"**Get to school kids before they are pregnant- teach them in school".

Afternoon session

Below is a table of phrases developed with FAS symptoms, the bold print is Kokoberra language explaining the symptom

Participants: 4

TABLE OF PHRASES-RESPONSES	
LOSS OF INTERLECTUAL FUNCTIONING	MILD TO SEVERE VISION PROBLEMS
• Slow in spelling-hard to find sentences • Ability in expressing yourself • Not functioning well for them ***LM*=bung gai**	• Cannot see properly • Very bad eyesight • Cannot see what you want them to see with their eyes **LM=*chelkampar*** Small eyes Sore eyes

HIGHER THEN NORMAL PAIN TOLERANCE	SEVERE LOSS OF INTERLECTURAL 'POTENTIAL'
• Don't feel pain much • Can tolerate pain more then normal • Hit them-they do same thing (no effect) • More accidents than normal kids • Strong head-hard head they don't know • We don't know another word • **LM=*Poet ian***	• Very very slow at learning • Damage memory • Not well in the mind • Short term memory • Don't have the ability to do things eg.fulfil a dream of e.g. becoming a doctor or do every day living skills • **LM=*ChoKont Poet On* Gort**
MENTAL RETARDATION	DYSLEXIA
• Brain damage • Imbalance brain • Slow timing • Smaller brain • Slow brain **LM=*ChoKont Tiki Pir***	• Read back to front • Imbalance in the brain • Haziness
SERIOUS FACIAL DEFORMATIES	CLEFT PALATE
• Funny looks on their faces • Different sizes • Fas c kids eyes smaller • Nose broader • Fold of skin around the eyes-P • Bone not formed to push skull out-P • Top lip thin-P • Top lip is flat rather then having a "tramline"	• Cleft means=gap/split • Gap in the roof of the mouth-top • Nor feeding properly-P • Sounds are different
IMMUNE SYSTEM MALFUNCTION	BEHAVIOURAL PROBLEMS
• Pick up "things 'very quick • Pick up colds • Runny nose • Chest infections • Test for parasite –Is it done in the community/schools? • GAA training-when that is done we could pick up a lot of these things that the children may have	• Behave yourself please • Not normal • Talk a lot • Very friendly-P • Not sitting still-P • No fear-P • Not frightened-P • Being a bully • Not scared of anybody
ATTENTION DEFICIT DISORDER ADD	IMPULSIVENESS
• A child diagnosed with ADD without knowing the underlying causes *eg*.FAS (could be) • Hyperactive= can't stop still, jump from high places that they are not scared • Keep on keeping on • Hyperactive=fast action-P	• Quick to do things without thinking 9 of the consequences) • It someone-throwing something at someone • Jumping into the water –river- without thinking of the consequences • Tunnel vision-P • Not aware of danger-P • Run across the road- not worrying about a car

• Eye flicker=hyperactive even in sleep=REM	coming • Having to be reminded everyday about road rules *etc*
POOR JUDGEMENT	LITTLE RETAINED MEMORY
• Don't know how far a car is –distance • Tell a *strong* child not to try and beat the car • Don't understand or grasp what you say	[When asked 'who would like to have a go at this one' answer: No thanks} • Remember little bit of things but not for long • Remember 'short time span' so not for long-P
DEAFNESS-HEARING DIFFICULTIES	TREMORS
• Can not hear people talking-P • Cannot hear sounds	• Got the shakes • FAS withdrawals-P • FAS child when the cry
NO CAPACITY FOR MORAL JUDGEMENT	NO CAPACITY FOR EMPATHY
• No conceptions for wrong or right – especially with teenagers • Don't have the capacity to judge good from bad-P • Connect to impulsiveness-P	• Empathy –your feelings –showing • Not showing feelings-P • Don't feel sorry
HEIGHT AND WEIGHT DEFICINCIES	
• Short in size- FAS • Light-low- in weight FAS	

June 25 :

Participants: 4

Shirley Yam
Shirley Victor
Cecilia Sand
Lousia Daphney

The table of phrases was completed with the group.

June 26:

Presentation to Kowanyama Community Council female workers

Participants: 6

Andrea Andrews

Rosyland Gilbert

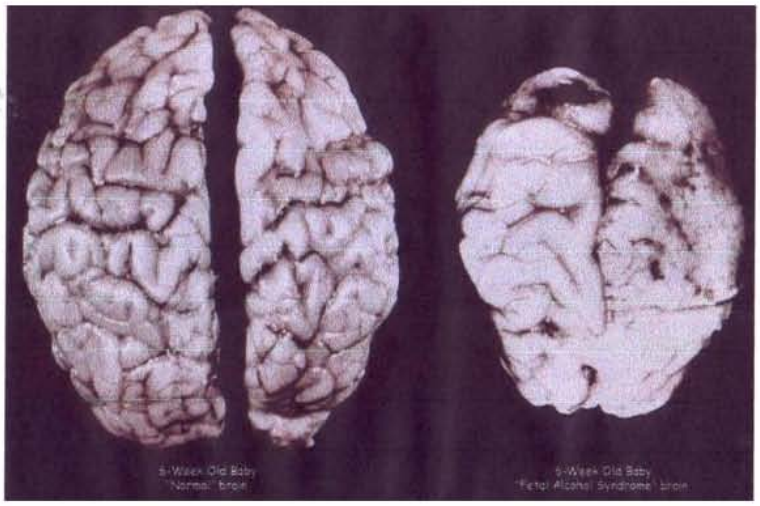
Bernice Daniel

Shenane Gibo
Judith Brumby

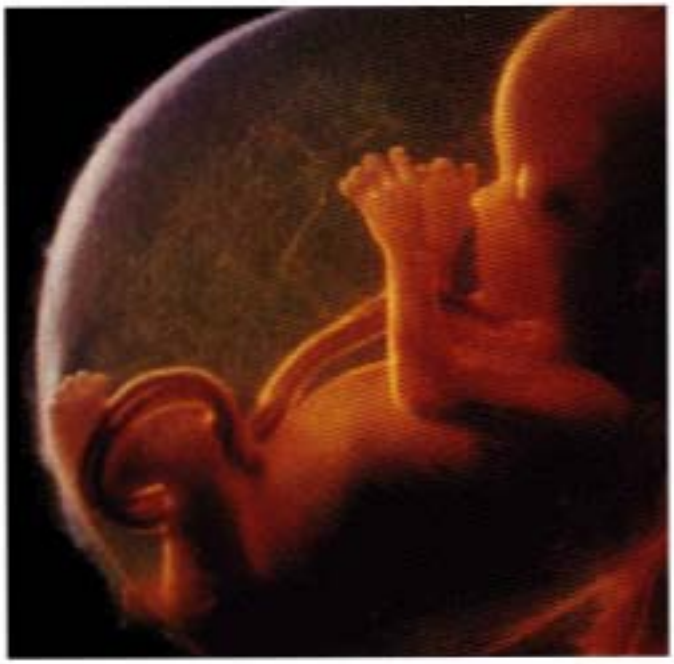
Maxan Brumby

W7 asked **"** When you get a baby from a drunken mum does their brain go back to normal if she stops drinking?" an interesting question which raised general discussion, especially when they saw the baby's brain.

Baby's Brain at 6 Weeks (the large is a healthy brain from a baby born to a mother who did not drink alcohol, the smaller damaged brain is from a baby born to a mother who did drink alcohol during her pregnancy and the baby had FAS)



The slides of the developing embryo was shown everyone was very intent agreeing with what was being said when the lifecycle was put up they appeared to be understanding that this happens in their community.



One lady was distracted as she had her young child with her. The little boy held one of the teaching dolls and wanted to undress it.

These were the responses from all the ladies.

" Black mothers don't listen to advice from others" "They say, Don't tell me what to do"

Three of the ladies agreed to be part of a support group-the workshop and training sessions.

One lady picked up the doll and really looked at it touching it.

All appeared to be affected by the presentation, the two younger ladies were chatting together and indicated they would be like to attend the workshops.

Planning day for the trip out by the river with the workshop group

June 27:

Participant 4women 6 children 1 man (bus driver)

Shirley Yam

Shirley Victor

Cecilia Sand

Louisa Daphney

Arrived at the river and a site was chosen everyone contributed to collecting the fire- wood. The ladies shared their expertise in fire making, made the fire then put the billy on for a cuppa.

On of the ladies made a damper cooked in the coals of the fire. yum!

Stories were shared between the group the young girls sang songs of their favourite

" Girl Band", they were shy at first. They also taught us games that were mainly about teenage boy/girl stuff a lot of fun and laughing.

The two young boys played with toys and also bush games pretending to hunt that "big ol' crocodile". Some went fishing and caught a fish and freshwater turtle, the latter was cooked and eaten for lunch by the ladies (we were not offered any of that food). Chicken wings were wrapped in foil and cooked for lunch.

An elder of the group said, " I will sing a song for you." Her adopted daughter accompanied her it was really beautiful.

This turned out to be a great day we did not have a formal day of the workshop but a lot was achieved in terms of the relationships formed between Apunipima staff and the group. I believe we (Apunipima staff) were the recipients of much more then a day on the river. Our class room for the day was a beautiful calm and peaceful spot by the river under a canopy of trees that gave shade for the entire time were we there. The ladies local knowledge of the different trees and shrubs with their medicinal uses (what was poisonous) were shared with us. They were very generous in sharing

their culture and stories which was so interesting talking about the history of Kowanyama. Talking about how different their community is today compared to when they were young.

Cecilia Sand, Coordinator of Mother's and Babies Centre:

Four women attended:

A list of names was given for the interested people for the workshop.

How to approach mothers with FAS babies-we would be sharing the information through the workshop and awareness program throughout the community and this would allow people to identify if their child has FAS/E.

Comment: "How will mother accept?" "Could be in denial about her FAS child".

It was stated by the FAS Coordinator, that the team will be working solidly with one person for 12/12 period and hopefully they will then accept and seek solution about how to best manage their child.

It was noticed by the team that W8 was really only the one lady who was reluctant to be an active participant…I would suggest that it was due mainly to not wanting to be there…when prompted for an answer she understood what the topic was about. Not sure why she was reluctant to engage in discussions, she appeared to been interested in the sessions.

There was varying degrees of understanding some participants had a very good and didn't require prompting, others understood when further explanation was given.

Nobody was off track with the topic, the group certainly have a grasp that alcohol was being consumed at a high level in their community and the effects were being felt in families and the community, the most effected were children.

I believe this group had a very good understanding of the language used and were very interested in the subject, also recognising and relating it to individuals in the community. They recognise that the effects of grog are felt by many in the community and were very interested with the Miracle of Life.
W4 "Alcoholic man has low sperm count?"

Three of the women W2; W1; and W4 were quite comfortable and participated at the start. Two younger women W3; W2 were very quiet at the start of the session though they did relax and were involved as the session progressed, participated well and asked questions. One lady W8 was a non-participant initially (history-staying for a short time at workshops in general) she did come and go out of the room several times during the session (smoker?).

She was very reluctant to participate, appeared shy and was prompted a couple of times to participate and would comment appropriately. I would suggest that she was probably asked to attend the workshop. All other participants were very interested and took part in discussion and at this early stage voiced that they knew some kids around who would have FAS/E.

W2 spoke of her adopted child in great detail who she believes is a FAS child and described his behavior, and how she is able to manage him. She says to get through to him, she has to work one on one with him in a quiet area to settle him down. " I get him to look at my face and talk to him then".

Slide 1:

The Miracle of Life slides (see appendix 2) were used which shows how conception occurs-with the sperm attaching to the ovum. W4 asked questions about how an"Alcoholic man has *low sperm count*?"

Slide2: The zigot second day after conception

Slide 3: Eight-week W4 asked "How long does it take for before the organs form?"

Slide 4: tenth week

Slide 5: Damage to embryo W4 again asked"Can doctors test if the pregnant mum is drinking?" LH explained that a urine test can be done.

Slide6: Development stage

Slide7: Takes longer for foetus to get rid of alcohol liver too immature, whereas the mother gets rid of the alcohol quicker- but that leaves the toxins in the sac and the foetus drunk. The dolls were then shown and discussion but did not elicit much from the group. W4 was called away who has led most of the discussions and comments.

Everyone was asked to read out a question from the Baseline Health Literacy form prior to filling it in which they were all able to do and continued to re-read to other each other a few times to understand what was required of them. All became less nervous therefore able to read

End of first session

THIS FORM TO BE USED TO REPORT EVERY SESSION

Date 24/9/02 **Venue** Mother's & Baby's Centre **Number Present** 4

Time Began 2pm **Time Ended** 4.30pm

Topic Alcohol & Drugs

Activity Review of last session-Video The Honour of All

Did all in the group present participate?

All in the group were very interested in the video the Honour of All that was shown and commented on the similarities of the community and the alcohol issues. "That's what is happening here in our community."

When reading was involved, how many were able to read out loud?

This session did not require the group to read.

How many seemed unable to understand?

The group were very interested in the process taken in the video to clean up the community –getting people off the grog. All present understood.

Why do you think anyone in the group is not participating in the above activities?

All present were participating. They are all aware of the alcohol use and abuse, as it is all around them in their community, see it every day. So the strategies that they used in the community (video) needed people who were very strong and committed.

Does the activity seem at an appropriate level of language/understanding for the group?

The video show how a Native Canadian community were successful in getting people off the grog. The group (Kow) identified with that community and understood the issues of violence, child neglect etc. They were very interested to see the strategies that were put in place to address the issues and they were most impressed with the outcome albeit it was a long process.

Anything else?

At the end of the video there was a discussion about the video and people were very vocal in how this is important information to them and how it could be used in Kowanyama. They were wanting to get a copy of the video to be able to show it to the community, hoping that by showing it some people might be motivated into taking action.

When writing was involved, how many were able to write legibly?

NA
When oral discussion was involved, how many were confident in speaking up? Though one lady led the discussion all participated. They were impressed that the story was from an indigenous community in another country and how they could perhaps do something similar in Kowanyama. They were considering some names of local people who probably could coordinate this with support from the relevant services in Cairns.
How many only took minimal part? All participated equally.
Of those who took part, did they seem off track? People were very aware of the issues in the video and demonstrated their understanding by saying, "The same things are happening here all of what they are saying in the video." "It's right here in this community no different." "If they can do it we should be able to do it to." "Too many people drinking all the time."
Anything else to add?

THIS FORM TO BE USED TO REPORT EVERY SESSION

Date: 25/9/02	**Venue:** Mother's & Baby's Centre	**Number Present:** 4
Time Began: 2pm		**Time Ended:** 4.30pm
Topic: FAS Workbook & Reproductive Health		
Activity: Reporting (brainstorm) Inside the Womb		

Did all in the group present participate?

All in the group were very interested and wanted to know how **do** doctors diagnose. What is the process of getting kids diagnosed particularly here in Kowanyama. How do we get them to diagnose so we know what we are dealing with in the community?

When reading was involved, how many were able to read out loud?

Like all first sessions we usually have a pause when a request for someone to read a sentence to the group. Everyone drops their head and hope someone else will do it. There was not a lot of reading this time and SY did it.

I introduced the Macquarie and a Medical dictionaries to the group. This created a lot of interest although there were two people using them the others in the group would ask "Go on look that one up for me" or "What does that word mean" This interaction continued throughout the whole session. All participants have read out loud during the sessions.

How many seemed unable to understand?

- All present understood and were interested to contribute to the session, especially regarding pregnant women having the urine test for alcohol, should be included at the first antenatal visit.
- There was a lot of interest in the reproductive health *looking inside the tummy and also what goes on in there- the role of the four players.*

Why do you think anyone in the group is not participating in the above activities?

- All present were participating and contributed to the brainstorming session regarding diagnosing FAS children and the urine testing for alcohol in pregnant women.
- A lot of discussion regarding the developing baby. They were able to make the connection regarding FAS and what would happen with the developing foetus if the mother was drinking during the pregnancy. The role of the Umbilical cord and the placenta was of great interest of how whatever the mother takes in the baby does as well. "If the message can get to the mother the responsibility she has to the foetus inside her she might take some notice and do something about it, if she wants a healthy baby"

Does the activity seem at an appropriate level of language/understanding for the group?

- Yes people's knowledge of the Foetal Alcohol Syndrome allows them to articulate and contribute to discussions. They are especially interested to get their message about FAS/E through to young people. The group have become very passionate about the issues and want to stop more babies being born to alcoholic women.
- The reproductive health

Anything else?

When writing was involved, how many were able to write legibly?

At the start of the session someone was needed to scribe on butcher's paper for the brainstorming-SY was nominated and elected, with the promise we would all help out. Very good writing skills. So while all was not required to write- everyone takes personal notes down in their folders.

When oral discussion was involved, how many were confident in speaking up?

The women all tend to have their say, did not require prompting. Sometimes someone might answer a question and will ask the group for their opinion (back up).

How many only took minimal part?

All participated equally.

Of those who took part, did they seem off track?

All had some knowledge (acquired from sessions) and would ask questions that were very relevant to the activities.

Anything else to add?

THIS FORM TO BE USED TO REPORT EVERY SESSION

Date: 26/9/02 **Venue:** Mother's & Baby's Centre **Number Present:** 2

Time Began: 2pm	**Time Ended:** 4.30pm
Topic: FAS workbook cont. & Reproductive Health	
Activity: Diagnosing **&** OHTs	

Did all in the group present participate?

For reasons that were unavoidable there were only two participants today. This of cause made it rather difficult but both women were active participants.

When reading was involved, how many were able to read out loud?

Both women are quite competent readers. They were encouraged to read out the information from the OHT regarding the diagnosis of FAS children and Reproductive Health session.

How many seemed unable to understand?

They would ask for an explanation if unable to understand either from the facilitator or each other. This did not occur in this activity.

Why do you think anyone in the group is not participating in the above activities?

Both were active participants.

Does the activity seem at an appropriate level of language/understanding for the group?

Yes they followed and participated well, again each took on the responsibility and interacted by asking questions and offering suggestions, that indicates it was pitched at their level.

When writing was involved, how many were able to write legibly?

Writing was not required with this activity- however I have glanced at the folders on occasions and all participants take their own notes. Very neat and elegible.

When oral discussion was involved, how many were confident in speaking up?

Both women participated equally and were very concerned about the diagnosing children with FAS.

How many only took minimal part? Shared equally.
Of those who took part, did they seem off track? Both ladies' *learned* knowledge of the subject was good and very strong about the need to have a screening program/session for FAS in Kowanyama to find out what the numbers of children with FAS.
Anything else to add

THIS FORM TO BE USED TO REPORT EVERY SESSION
Date: 27/9/02 **Venue:** **Number Present:**
Time Began: **Time Ended:**
Topic:
Activity:
We did not have a session today all Council employees work half days on Friday which included the Training Centre and M&B Centre
THIS FORM TO BE USED TO REPORT EVERY SESSION
Date: 30/9/02 **Venue:** Mother's & Baby's Centre **Number Present:** 5

Time Began: 2pm	**Time Ended:** 4.30pm
Topic: Early Childhood Development	
Activity: 0-6months milestones	
Did all in the group present participate? All ladies were active participants. One of the ladies needed to be prompted, this could be due to her not starting at the beginning with this group and may lack some confidence.	
When reading was involved, how many were able to read out loud? Used this activity to involve the group this included reading out from the OHT, sorting pictures at different milestones and ages, so it was very interactive and all participants were involved.	
How many seemed unable to understand? All in the group understood as they were all mothers and used their experiences to explain and discuss the different development stages.	
Why do you think anyone in the group are not participating in the above activities? As above. One of the ladies needed to be prompted, this could be due to her not starting at the beginning with this group and may lack some confidence, otherwise all participated.	
Does the activity seem an appropriate level of language/understanding for the group? Yes I believe so. All contributed to the discussion by using their own experiences with their children's development. What ages their children were when the reached a milestone. Some comments: "This will be useful to help mothers with their FAS child." "Also helping teachers in the school when setting programs for kids who have FAS."	
Anything else?	
When writing was involved, how many were able to write legibly? All were taking notes. A scribe was not required for this activity.	
When oral discussion was involved, how many were confident in speaking up? Two ladies were very confident and always led the discussion, sometimes this inhibits others from participating but the ladies would also encourage others to lead with comments: "You know about this, go on you can say something."	
How many only took minimal part? Possible the one lady mentioned earlier she needed to be prompted quite a few times just to ask her opinion give a comment regarding if she agreed or disagreed. Wanting to involve everyone, one has to be aware of those who are passive participants and use gentle persuasion to include them so they also feel that their input is important.	

Of those who took part, did they seem off track? No. Everyone knows the subject and were able to answer or lead a discussion.
Anything else to add?

THIS FORM TO BE USED TO REPORT EVERY SESSION

Date: 1/10/02	**Venue:** Mother's & Baby's Centre	**Number Present:** 4
Time Began: 2pm		**Time Ended:** 4.30pm
Topic: Early Childhood Development		
Activity: 9-12 months milestones (*some of these may be repeated from yesterday's session*)		

Did all in the group present participate?

All ladies were active participants. One of the ladies needed to be prompted, this could be due to her not starting at the beginning with this group and may lack some confidence. The group were very competent using the dictionaries whether physically or calling out a word to be looked up, so there was participation from all in the group.

When reading was involved, how many were able to read out loud? *Used this activity to involve the group this included reading out from the OHT, sorting pictures at different milestones and ages, so it was very interactive and all participants were involved.*
How many seemed unable to understand? *All in the group understood as they were all mothers and used their experiences to explain and discuss the different development stages.*
Why do you think anyone in the group are not participating in the above activities? *As above. One of the ladies needed to be prompted, this could be due to her not starting at the beginning with this group and may lack some confidence, otherwise all participated*.

Does the activity seem an appropriate level of language/understanding for the group? *Yes I believe so. All contributed to the discussion by using their own experiences with their children's development. What ages their children were when the reached a milestone*
Anything else?
When writing was involved, how many were able to write legibly? *All were taking notes. A scribe was not required for this activity.*
When oral discussion was involved, how many were confident in speaking up? *Two ladies were very confident and always led the discussion, sometimes this inhibits others from participating but the ladies would also encourage others to lead with comments: "You know about this go on you can say something."*
How many only took minimal part? *Possible the one lady mentioned earlier she needed to be prompted quite a few times just to ask her opinion give a comment regarding if she agreed or disagreed. Wanting to involve everyone, one has to be aware of those who are passive participants and use gentle persuasion to include them so they also feel that their input is important.*
Of those who took part, did they seem off track? *No. Everyone knows the subject and were able to answer or lead into a discussion.*
Anything else to add?

BASELINE LITERACY ASSESSMENT

Date:17/06/2002

Venue: Crisis Care Centre

How many present?

There were six female attendants at the first day of the workshop

How many filled in literacy assessment?

All the participants filled out the Literacy assessment form.

How many did not take part in the discussion/ Why?

CONSULTATION PROCESS
Date: 30/7/02 Meeting: Aurukun Justice Group Present 11(7F-4M)
NOTES: *Notes from the FAS Awareness Presentation*
We were booked to do a presentation but on arrival at the appointed time there was a Justice Group meeting and the coordinator denied that there was such a meeting booked. Needless to say we were not impressed having traveled so far to be told that he knew nothing about a meeting with the FAS team. Eventually we were invited in to do the presentation following the *court proceedings* that the Justice Group were conducting. This was a *shame job* for us to be present when people were being given *sentences* community law way. Lorian made the introductions and what would be presented at the session. The women were rather impressed with the dolls and kept pointing at them and making comments among themselves. They recognised how serious FAS is and that the young girls should hear about Foetal Alcohol Syndrome. The women were very intent during the session. Alan asked: "If there was any data regarding FAS children in Aurukun?"

No was the response.

White lady: “If I could arrange for a group of young girls would you do another presentation?” this comment was five minutes into the presentation that was the impact it was having on the group.

Alan: “FAS cause problems in the school?” “What programs in the schools?” “Are there any screening tests that kids could be tested?”

Lady: “Excuse me can they (kids) be treated?”

Three ladies left the room. One man left the room. Young girls came into the room.

Lorian did the egg test and used the dolls to explain the effects on the baby if the mothers is drink and continue to drink alcohol during pregnancy.

Lorian: Have you heard the term ‘failure to thrive’ some discussion and people answered in the affirmative.

Alan: “ Could medication help kids at school?” “Do they need one on one teaching?”

Lorian: “They need a structured environment”

She also informed the group that ultimately following the training support group will be set up in the Cape communities.

Alan: “No resources to do it”

White lady: “If male and female with Foetal Alcohol Syndrome have a baby well the problem would be exacabated.” She was quite shocked and visible stressed. It was impressed upon people that FAS is 100% preventable, therefore It was very important that everybody knows that alcohol can cause damage to the unborn baby.

Alan; “ What is Government doing?” “Are they supportive?” “What about if these young people with FAS are sniffing as well they would be doing double damage”

Lorian: “ Grog has the worst effect on the unborn baby, other drugs do not have the same extent of damage.”

Young girl: “Foetal Alcohol Syndrome sufferers drinking alcohol and smoking yandi, people believe-don’t understand.” “Hard for people in the community to understand.” “Growing up in a good home, clothes with everything….you know.”

The group were asked if they had alcohol problem in Aurukun all in the group knodded in the affirmative.

White lady: “What resources do you have?” When she was told that we have not developed any at this time due to lack of funding. She shook her head in despair!

White lady: “Can foetal alcohol syndrome be detected in the uterus?”

Alan: “Resources are given by Government.” “Can a FAS mother have a FAS baby, is it genetic?”

Young girl: “ Hard for mother to give up drinking…change environment”

White lady: “Can it (FAS education) be done in the schools?” She was horrified when told that we were speaking to students in grade three in another community.

Young girl: “The pop festival next year.dancers come along…kids learn from kids”

Session ended 11.40am.

Date: 30/7/02

Meeting: Aurukun Clinic staff Present 9(8F-1M)

NOTES: *Notes from the FAS Awareness Presentation*

Lorian: Did the introductions and explained the presentation and also that it is a pilot program and we were wanting another community to participate. RN: spoke about the questionairre that they use in Aurukun to find out if mothers are drinking for their antenatal clinics.

How many babies with FAS? How many mothers drink? Too many!

The group were very intent and didn’t say very much. But at the end of the session the health workers said they would get together the young girls and bring them in for a FAS session.

Date: 31/7/02

Meeting: Aurukun Teen girls and young women Present 12 and 3 children
NOTES: *Notes from the FAS Awareness Presentation*
Everyone was very intent and appeared very interested in the session. The dolls used during the presentation really has an impact on all those present. The groups comments about the dolls and how life like they are, then when the dolls are used to explain the effect that alcohol use during pregnancy has on the unborn baby, they become very quiet. No questions were asked at this point. A little girl was nursing one of the dolls and was cuddling it very gentle like holding a baby.

Date: 31/7/02 Meeting: Aurukun School Library-teachers Present 17
NOTES: *Notes from the FA S Awareness Presentation .*
The session followed a staff meeting as all would be teachers would be present. The first person to arrive was quite taken aback when she saw the dolls and questioned whether she should be here. “Not for us surely!” Lorian suggested if she s is working with children in the community school it was appropriate that she should be here, that everybody should know about Foetal Alcohol Syndrome. Maybe I was feeling a bit paranoid and defensive but I felt very uncomfortable, I didn’t think the group was very friendly or hospitable towards us. The Principal was welcoming and very interested in the session . During the presentation one lady turned her back and appeared very bored and fidgeted, she then put her head down on her arms that was resting on the table for a short period. Turned completely around from the table and faced the wall. Some comments during and following the presentation. Male: “Even the size is significant.” This comment was prompted when they realised what they could be dealing with in terms of their current students and the alcohol problems in the community. “Going back to apes/devolving.” “We need to jump on to this.” “What do we do in the classroom?”

"What is the life outcome for adults throughout life?" Lorian: It means the carer becomes the external brain for the child with severe Foetal Alcohol Syndrome, the frontal lobe is damaged where the thinking etc takes place. Another comment: "This was more then we bargained for!" The Principal was very positive and is wanting to come on board to set up programs in the school in Aurukun. Unfortunately Aurukun community is not quite ready to take on the program. Male: 'We have to look at working with the family where can go into the future and take a holistic approach… self manage."

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Date: 2/8/02 Meeting: Oriners Present 9?
NOTES: *I didn't actually take notes from the FAS & alcohol talk.*
The plan was to give education to the young men and the coordinators at this outstation. The Foetal Alcohol Syndrome and Alcohol Effects(on the body) sessions were held Friday morning. I was going to talk about Immunisation and Communicable Diseases. However this did not occur.

Date: 5/8/02 Meeting: Kowanyama
NOTES: *Training Workshop Alcohol Effects*
Arrived at the Mother's and Baby's Centre and the staff were very busy with the RDFS visit and the Specialist Team for measuring child development had arrived. Cecelia had not received notice of their visit therefore FAS training was put to Tuesday at 11am.

On our previous visit a FAS Awareness presentation was given to the female staff from Council were interested in the Training program.

Bob Sands was contacted regarding the recruitment from this group and he allocated the times of 3pm to 5pm daily for Council staff to attend over the two week period. We considered this to be very generous and this reflected his commitment to the program

We notified the Council staff of the venue.

One lady arrived at 3pm, she went over and reminded everybody that we were ready to begin. Nobody else came along so we had to cancel the workshop. We were rather surprised as the initial response was very positive from the ladies.

Tania Major the new Coordinator of the Training Centre was approached regarding holding workshops there and also for recruitment for another group. She was also able to get a group of young women and girls together for a FAS Awareness session. It may work well if all notification of training programs comes via the Centre.

CONSULTATION PROCESS

Date: 24/9/02

Meeting: With Cecelia Sands/Shirley Yam/Tania Majors/Judith

NOTES: *Plan sessions*

Met with Cecelia to arrange times to hold the FAS workshop. She suggested the venue to be the Mother's and Baby's Centre that it would suit the staff as all could attend, she said it would be difficult for all staff to attend if held at the Training Centre. The times would be each afternoon from 2pm to 4pm. They would have to close the M & B Centre

I also spoke with Wilma (staff at M&B) who attended a couple of the session last visit, she is keen to participate. She would need to 'catch up' and a suitable time for her was arranged between 8.30am to 9.30am each morning. Wilma would also be attending the 2pm sessions.

I actually spoke to Shirley Yam on our last visit to Kowanyama (former staff at M & B Centre now at Council Office) if she was interested in continuing the FAS training. Shirley did not actually commit at the time. Met with her again today and gave her the details of venue and times of sessions and very positive response when asked if she would continue. Oriel to arrange a time with Shirley to "catch up" with the two sessions of Alcohol and Drugs that she had missed on our last visit.

To meet with Tania Major Coordinator of the Kowanyama Training Centre regarding recruitment for the second workshop. There were some young people who had shown interest after attending an Awareness Presentation about Foetal Alcohol Syndrome given by Lorian at the last visit to Kowanyama. We arrived to find Tania dealing with a personal family crisis. Oriel was able to assist her with advice about how to deal with the situation and the processes. Oriel was very concerned and informed Tania that her brother needed to be airlifted to Cairns to be treated properly. Tania had not slept for days and was exhausted, as were other members of her family.

She needed to be at be at work the next day and would get a list together for us.

Had a yarn with Jenny and Dolly who both work at the Training Centre and explained what the FAS workshop was about. They were both interested in getting more information so that they could talk to their young people about not drinking when they are pregnant. They were keen to start and it was arranged for tomorrow. I will talk with Oriel as it may coinside with the 2pm session with the original group. Both Jenny and Dolly had attended an Awareness Session that Lorian had presented on the previous visit.

Also checked with Judith (Guesthouse Supervisor) if she was still interested in doing the FAS Training and informed her of when these would be conducted. She is still interested but her workload this week is rather busy, guesthouse is booked out for the two weeks.

CONSULTATION PROCESS

Date: 25/9/02

Meeting: With Tania Major regarding recruitment for another group

NOTES: *Plan sessions*

Met with Tania this morning and she wrote down a list of names of the girls who had attended the FAS Awareness Session with Lorian. Dolly and Jenny went along with Oriel to located the girls and gauge the interest regarding attending the FAS workshop. One of the participants was Debbie Yam who had attended some sessions with the original group in May/June. The second group has a total of 5 participants and Oriel will facilitate this group.

Before leaving Cairns we had decided to have a BBQ. We discussed the issue of how to keep people on time and at the session, we considered providing lunch. Taking perishable goods with us wasn't an option and we didn't know if any of the shops would provide cut sandwiches etc. Anthony agreed that purchasing the food at Kowanyama was probably a better option.

Having a BBQ seemed the better plan that would give all the participants the opportunity to come together in a social setting, as they would ultimately form the support group for the community. Spoke to Cecelia she was very supportive and offered the M&B Centre as the venue so it was arranged for Tuesday the following week at 6pm.

Oriel had some time and she organised all stores and ordered the meat for the BBQ for next Tuesday.

We also discussed with two of the girls who danced in Adelaide if they would be interested in performing at the BBQ for the community. They did say yes to the idea.

Oriel had contacted Shaun Edwards and he arranged for three dancers to come to Kowanyama. He believed that it was a good opportunity for the dancers to visit and reaffirm the commitment to the community by keeping that contact and interest particularly with the girls. Also for the Foetal Alcohol Syndrome program.

(CONSULTATION PROCESS)

Date: 30/9/02

Meeting:

NOTES: *Events of the weekend*

Just reporting on an event at the weekend that could have an effect on the workshop. There was a stabbing that the resulted in the death of a male person. This happened at the front of the shop on Saturday morning.

As we were staying at the Clinic dongas I witnessed the proceedings that was quite a traumatic experience. A large group gathered under the tree outside the morgue. Small groups of people then filed into the morgue to farewell the body as it was to be flown out to Cairns for the autopsy.

As to be expected the group were very traumatised. What I thought was interesting once they came out of the morgue they appeared to be on auto pilot, which was probably their way of coping with the situation. Business goes on as usual. There did not appear to be any effort made to have counselling available for the groups.

2pm: Melissa had attended a session on the last visit and was encouraged to come back by her mother – in –law. She is keen to continue with the training although she is rather shy and reserved and does need some encouragement to interact. I think it could possibly be that she did not attend at the beginning and still feeling her way.

Wilma did not attend any of the session last week. She was the support for her sister who is the partner of Tania's brother and they travelled to Cairns at the weekend. I would like to get Wilma and Melissa into the second group but it could be difficult as the hours Wilma work at the M& B Centre are around meals times. She does the cooking at the Centre.

Brainstorm Session 25/09/02

We do not know how many babies and children have FAS/E. Why?

Discussion:

- Children not being diagnosed
- Parents don't know about FAS
- Doctors don't know about FAS
- Nursing staff don't know about FAS
- Teachers don't know about FAS
- Doctors don't know how to diagnose FAS
- Doctors and nurses don't learn about FAS in their training
- Alcohol can cause damage to the developing foetus
- You are drinking so is your baby
- Your baby not getting nutrients and won't grow

Doctors could use urine alcohol test strips to screen for alcohol use when pregnant women come to antenatal care

Would this be a useful strategy for early diagnosis?

Or is it too invasive?

What list of recommendations could you make to the Health Department about this?

DIAGNOSIS: we want:

Doctors to use urine alcohol test strips at first antenatal visit-it is a none invasive test which can be done when other tests are done

Doctors would need to inform/offer the client that this test is available-would permission from the client need to be done?

By doing this test will prevent FAS

TO BE SURE THE SAFEST ADVICE IS:

NO GROG IF YOU ARE TRYING (FOR A BABY)TO GET PREGNANT!

NO GROG IF YOU ARE PREGNANT! **NO GROG WHILE YOU ARE BREASTFEEDING!**

Diagnosis Criteria FAS;

Rewriting the TOOL in everyday language. Group activity.

FAS- Diagnostic Tool	FAS- Tool rewritten
Confirmed maternal alcohol exposure	Mother drank during pregnancy
Evidence of facial anomalies	Proof of facial features with that of a FAS child
Evidence of growth retardation • Low birth weight for gestational age • Decreasing weight over time • Disproportionate low weight to height	Proof of slow in growing • Baby too small • Losing weight • Low weight to how tall the child
Evidence of brain abnormalities • Microcephaly • Decreased cranial size at birth	Proof that brain has not grown properly • Brain is not fully grown • Small head when born

Diagnosis Criteria FAE;

Rewriting the TOOL in everyday language. Group activity.

FAE-Diagnostic Tool	FAE-Tool rewritten
Confirmed maternal alcohol exposure	Mother drinking during pregnancy
Heart defects	Heart not working properly
Shortened fifth digit	Short little finger
Renal problems/ kidney problems	Trouble with kidneys

Hearing problems	Cannot hear well
Brain abnormalities	Brain is not fully grown properly
Behaviour problems	Playing up

BASELINE LITERACY ASSESSMENT

Date:17/06/2002

Venue: Crisis Care Centre

How many present?

There were six female attendants at the first day of the workshop

How many filled in literacy assessment?

All the participants filled out the Literacy assessment form.

How many did not take part in the discussion/ Why?

WHAT HASN'T BEEN ACHIEVED

- MOU'S have not been completed, it is envisaged that they will be completed in the next stage.
- FAS specific strategic plan – next stage
- Review of health service data relating to alcohol use during pregnancy over the preceding 12 months

WHAT NEEDS TO HAPPEN

- Keep up the momentum of FAS/FAE awareness – keep community interest
- Funding for local support worker position
- FAS/FAE education/training to this position
- Ongoing support for the FAS team at Apunipima and externally
- Roll out of health promotion programs – Kowanyama to whole of community particularly young women of child bearing age

- Qld Health staff to be given education re FAS through the program, it has been very hard to engage with staff from Qld health, they have not shown any interest in the program, they are suggesting they are too busy
- FAS/FAE resources developed for the wider community
- FAS/FAE resource funding for Kowanyama FAS group to complete their development of resources
- Police to be given education training through their system re FAS/FAE
- That all external servicee providers to come on board and include FAS/FAE as their core business

The use of alcohol, tobacco and other drugs during pregnancy continues to be a leading preventable cause of mental, physical and psychological impairment in infants and the older child (May, 1995). Moderate to heavy alcohol consumption by a pregnant woman can result in her child being born with Fetal Alcohol Spectrum Disorder, which is considered to be the leading known environmental cause of mental retardation in the Western World (Malbin D. 2005.

It is obvious that the duration of one's pregnancy is a very important stage for the development of both the mother and infant. From the view-point of health, there is a significant risk attached to the relationship between alcohol and pregnancy. For many Aboriginal and Torres Strait Islander women alcohol is a normative part of their social and cultural environment and lifecycle as is pregnancy. Where there is clear evidence of family breakdown, abuse and isolation, fear, loss of respect, violence and grief, alcohol and alcoholism is a major contributing factor in the distribution of un-wellness of the individual as well as the communities. Fetal Alcohol Spectrum Disorder has been identified at the community level as a priority health issue for both Aboriginal and Torres Strait Islander people as well as non-indigenous people throughout Australia. The FASD workshops that the National Indigenous Corporation for FAS Education Network is a community based initiative. It is expected that as a result of the regional working groups a series of Fetal Alcohol Spectrum Disorder workshops will be delivered around the State, and across Australia with an expected outcome informing the planning of service delivery relevant to responding to Fetal Alcohol Spectrum Disorder.

Engaging communities

Raise the awareness of FAS/FAE in the Aboriginal & Torres Strait islander communities.

Establish a sustainable system, to support and monitor awareness raising and the development of educational materials that responds to FAS/FAE

The consultant will work towards engaging communities to build the capacity of the community to address their health needs; facilitate community involvement in health planning and lobbying; assist communities in developing and running health programs, and more importantly increase community awareness of Fetal Alcohol Spectrum Disorder and to inform community members of the dangers of maternal alcohol consumption during pregnancy as an important health issue.

Lobbying & engagement with health agencies

Increase community awareness of FAS/FAE & to inform community members of the dangers of maternal alcohol consumption during pregnancy as an important health issue.

The consultant namely Lorian Hayes has developed and maintained strong relationships with

governments and other service providers, e.g. Q. Health, QATSIH; Dept of Communities; Dept of child Safety (Qld); division of GP's; University of Queensland; Griffith University; Australian Research Alliance for Children and Youth (ARACY); ICHR; Rio Tinto Aboriginal Child Health Program; Child Development Units; Curtin University; University of Washington State USA; University of British Columbia (Canada); FASCETS USA; NOFASARD (AUST); Australian Paediatric surveillance Unit (APSU); Native Wellness Centre University of Washington State; Centre for Human Disability and Development University of Washington State; FASDU(Seattle) USA; Asante Centre (Canada); Juneau FASD Centre, Alaska, AHMRC NSW, Marulu strategy (FASD) Fitzroy Crossing W.A.

Ms Hayes has developed influential presence with governments through membership on committees such as National, State and Local Alcohol and Drug Advisory bodies, National Rural Women's Coalition, Women's advisory bodies and secretariats, Office of Women, Children's Commission. The consultant, through lobbying and engaging with stakeholders has the capacity to advocate that funding is aligned to community needs and is an advocate for communities.

Policy Development

Promote the importance of preventative health care in policy development and service delivery, including the need for increased investment in preventative health

By promoting the importance of preventative health care in policy development and service delivery, including the need for increased investment in preventative health the consultant will assist and support the community to define the components of preventative health care as it relates to Fetal Alcohol Spectrum Disorder, this is achieved by promoting that FASD preventative health focus component be included in any proposed activities by service providers, and to continue to promote, develop an innovative FASD model from the community driven health services and stakeholders. Documented and sharing learning's from FASD workshops with funding bodies, service delivery agencies and community stakeholders. Lastly to work with regional organizations to include a holistic response to FASD relating to the social determinants of poor health and to advocate for preventative health care models with greater community participation.

Linkages and Co-ordination

Provide an advocacy voice for communities to address both regional and community specific FAS health issues

This is achieved through encouraging greater access and use of health services provided by other

health agencies in NSW, educating the community on the role of the health agencies and preventative health education and to continue to promote, develop a model for FASD for community driven services and stakeholders.

Provide resources and ongoing support and educational programs re maternal alcohol consumption

Run FAS Health Literacy Programs in each community on request

Assist communities to develop interventions specifically related to FASD

Develop relationships with community members, community organisations and other external stakeholders who provide services to the communities, community members re FAS presentations, newsletters and introduction letters to organisations.

Objectives of the Proposal

- NICFASEN will develop effective programs to reduce harm related to maternal alcohol use by Aboriginal women and men in such a way as to advocate and promote for the improvement of the life of the child with Fetal Alcohol Spectrum Disorder.
- NICFASEN will train parents, community members and health professionals who work and care for children with suspected or diagnosed FAS.
- NICFASEN will also provide assistance and support for children, their families and to facilitate activities which will respond to the prevention of FASD.

Understanding why a proportion of pregnant Aboriginal women drink alcohol at harmful and hazardous rates will contribute to efforts undertaken to promote healthier communities focusing on primary, secondary and tertiary prevention of the effects of prenatal exposure to alcohol. The greater society's acceptance of alcohol uses in general and in the female population, the greater the incidence of Foetal Alcohol Syndrome in this country. Where ever alcohol is freely used alcohol related birth disorders are a major public health problem, these consequences will inevitably impact on the individual, the family and the community.

When planning prevention programs, it is critical to understand the nature and scope of the problem; in this case the rates and circumstances of alcohol use by women of child-bearing age, pregnant women and women who have given birth to a child affected by alcohol. Accurate information concerning alcohol use by women, particularly pregnant women is often limited due to a lack of routine screening and under reporting of alcohol use by women in clinical interviews.

Benefits of the study:

1. To identify the proportion of children who have been exposed to alcohol during pregnancy and to determine whether these children have Foetal Alcohol Syndrome.
2. To reduce the level of maternal alcohol consumption and to reduce the number of births affected by maternal alcohol consumption.
3. Raise the awareness of Foetal Aclohol Syndrome amongst community members including women of all ages, health professionals, teachers and educators within the community and then expanding to the Australian population.
4. To improve the lives of children with FAS by training health professionals, parents and community members who work with or care for children affected by FAS/FAE.
5. To provide assistance and support for children and their families affected by FAS/FAE and to facilitate activities responding to the prevention of FAS/FAE.
6. To increase community awareness of FAS/FAE and to inform community members of the dangers of maternal alcohol consumption during pregnancy as an important public health issue.
7. Prevention of Foetal Alcohol Syndrome (FAS) could make an important contribution to improvements in mental health in childhood that includes intellectual disability, cognitive impairment, learning difficulties, speech and language delay, behavioral and emotional problems.

Hypothesis:

1. Screening tools that have been used and tested in other countries can be used in population based surveillance of FAS through community health/public health screening programs.
2. As a result of maternal alcohol consumption it is suspected that there is a high prevalence of FAS in the community. Many children with FAS and alcohol related birth defects are not being identified and diagnosed at an early age and therefore are not receiving treatment to prevent secondary disabilities. As a result of maternal alcohol consumption it is suspected that there is a high prevalence of FAS in the community.
3. To prevent FAS births through increasing awareness of the impact of FAS/FAE and to inform the community members of the dangers of maternal alcohol consumption during pregnancy as an important health issue.

Aims and Significance of the Study:

It is envisaged that this study will contain 4 stages;

1. implement an intervention – screening tool (antenatal clinic)
2. identify children who have been prenatally exposed to alcohol during pregnancy
3. ascertain the prevalence of FAS in the community through screening
4. implement the education program (health literacy program)
5. evaluate the intervention of both 1 and 4.

Aim:

To identify the proportion of children in Cherbourg Aboriginal Community who have been prenatally exposed to alcohol and to examine the effects of this exposure on neuro- behavioural indicators and neuro-anatomical indicators in children who are 4-5 years of age.

To identify and understand why a proportion of Aboriginal women drink alcohol during pregnancy and at harmful and hazardous rates

Objectives:

1. Identify the number of women who attend the antenatal clinic and are drinking alcohol

during their pregnancy.
2. To measure the amount, frequency, and type of alcohol consumed by pregnant women in the community. (This tool has already been used a tested in the community)
3. To ascertain the prevalence of FAS in a rural Aboriginal Community in Queensland.
4. Increase the awareness of risk factors associated to alcohol use and abuse which are associated with Foetal Alcohol Syndrome among Aboriginal women living in the community through the delivery of the Health Literacy Program.

Strategies:

1. Work in partnership with staff at the antenatal clinic to identify how many women attend the clinic.
2. To introduce a screening tool to measure the amount, frequency, and type of alcohol consumed by pregnant women in the community. To measure the amount of tobacco used and the amount of marijuana used by the pregnant women. (This tool has already been used a tested in the community)
3. To validate the screening instrument to be used for identifying alcohol consumption by pregnant women.
4. To use the screening instrument to count how many children in Cherbourg have been exposed prenatally to alcohol.
5. Use an existing international screening instrument that will address the physical and psychological effects of prenatal alcohol exposure on intelligence, language, verbal, learning and memory, motor abilities and attention.(i.e. the childhood behavioral checklist)
6. Use the Denver Scale to assess motor abilities, language, fine motor skills- adaptive and personal social skills for children who are newborn infants and 4-5 year olds. (I will probably use other assessment tools as well)
7. To increase community people's awareness and knowledge of the effects of alcohol on unborn babies.
8. To increase the literacy skills in relation to health promotion materials
9. To identify and develop appropriate FAS resources to use during the community events and activities.
10. To facilitate and support the development of a sustainable health education ethic within the community.

Introduction

The behavioral and cognitive effects of prenatal exposure to alcohol may have devastating consequences for the foetus. Evidence pointing to high rates of alcohol use by women in the indigenous community suggests it is likely that many children as a consequence have developmental problems. Outside of the existing data from research undertaken by Hayes 2001, there is little systematic quantitative data on prenatal use of alcohol in the indigenous communities in Australia and efforts to reduce their effects are hampered by this lack of knowledge.

Foetal Alcohol Syndrome is a leading known cause of mental retardation in the Western world (Abel and Sokol, 1987). Although FAS has been extensively studied in North America, Canada and Europe since the syndrome was identified by Jones and Smith in 1973, the only estimates of FAS prevalence in Australia have been based on clinical accounts and unpublished records from obstetric hospitals (Lipson 1994). As a result there is little attention given to the prevention of secondary disabilities for affected children and youth within the health and education sectors. Community health workers, nurses and other allied health professionals express concern and frustration about responding to the birth defects that they are observing are as serious health problem that has continued to be ignored in Aboriginal communities and the broader communities within Australia. This project will significantly contribute to the knowledge of FAS in Australia. It will also address the lack of baseline data in this country for Aboriginal and Torres Strait Islanders who have been prenatally exposed to alcohol by carefully screening the Indigenous populations. It also will raise the awareness of the prevalence and impact of FAS and the health consequences of maternal alcohol use in Australia

Until 1996, efforts to identify children with FAS and prevent its associated secondary disabilities through early diagnosis and interventions were constrained by the lack of efficient and effective surveillance and screening tools. In 1996 the Institute of Medicine released detailed diagnostic criteria for partial FAS/FAE which identifies a complex pattern of behavioral and or cognitive dysfunction that is unrelated to developmental maturity or to family or home environment, and includes:

- Difficulty in learning
- Poor school performance
- Poor impulse control
- Problems in relating to others
- Deficits in language and poor ability for abstract thinking
- Poor arithmetic skills
- Problems in memory, and attention or judgment (O'Leary, 2004)

The teratogenic effects of prenatal exposure to alcohol can have devastating outcomes on the developing embryo and foetus in many different ways causing a whole spectrum of disorders**.** More recently Astley and Clarren (1996) have developed a 4 Digit Diagnostic Code to demonstrate how the two measures of FAS Facial Phenotype correlate with brain function and structure. The Surveillance and screening program devised as part of this project will be based on the proposal of diagnostic techniques which recommends the 4 Digit Diagnostic Code.

When diagnosing children who have been exposed to alcohol whilst in utero, the following criteria should be adhered to:

FAS/FAE *with confirmed history of alcohol exposure;* these patients meet the full diagnostic criteria of:

6. Growth deficiency, prenatally or postnatally, for height, weight, head circumference
7. A specific pattern of minor facial anomalies that includes short palpebral fissures, a complex lower facial malformation that is typified by epicanthal folds, a flat midface, short upturned nose, a smooth or a long philthrum and a thin upper lip.
8. Some CNS damage, including microcephaly, tremors, hyperactivity, fine gross motor problems, attentional deficits, learning disabilities, intellectual or cognitive impairments and or seizures.
9. Alcohol related birth defects to denote the presence of congenital anomalies known to be associated with a history of prenatal alcohol exposure.
10. Alcohol related neuro-development disorder requiring a confirmed history of parental alcohol exposure and evidence of CNS abnormalities.

When diagnosing Foetal Alcohol Syndrome it is important to explore the history of significant prenatal alcohol exposure. As suggested by Stressguth, (1997), and the Institute of Medicine (1996) that two classifications of FAS are evident: one with and one without confirmed maternal alcohol consumption.

FAS/FAE *without a confirmed history of alcohol exposure;* these patients have the same phenotype findings as above, but no history of alcohol can be confirmed due to the availability of the family or origin.

Atypical FAS/FAE is when individuals have a phenotype that very nearly is complete for FAS and has a confirmed history of alcohol exposure, but lack growth deficiencies.

Through the varying techniques used in qualitative and quantitative research, the project will raise the awareness of the prevalence and impact of Foetal Alcohol Syndrome and the health consequences of other commonly used substances. The proposed project will:

1. Determine the prevalence of fetal alcohol syndrome and related syndromes in selected Aboriginal communities.
2. Assess the effects of alcohol use on foetal and child health considering tobacco and cannabis as confounders.
3. Validate a FAS screening methodology to assess children 4-5 years and under who were exposed prenatally to alcohol, tobacco and other drugs.

4. Prevent FAS births through increasing awareness of the impact of FAS/FAE and to inform the community members of the dangers of maternal alcohol, consumption during pregnancy as an important health issue.

1. **Primary prevention**

The first component of the intervention will target the community as a whole. It will involve a Health Literacy Program that the researcher has developed and implemented in another indigenous community.

Raising awareness– Health Literacy Program

Objective 1:

This objective aims to prevent FAS/FAE health problems before they occur by increasing the awareness and knowledge of the general population, particularly young people, about FAS/FAE and the dangers of drinking during pregnancy. This information will target the whole community focusing on women of all ages, health professionals, teachers and educators.

(b) Develop a capacity building intervention focused on women who may become pregnant or have already had a child who has been prenatally exposed to alcohol.
(c) To increase literacy skills in relation to health promotion materials.
(d) To identify and develop appropriate FAS/FAE resources to use during the community events and activities.

In the Framework for Inuit Peoples, it is recommended that health problems relating to FAS/FAE be averted before they occur by increasing the awareness during pregnancy. Recent work that I carried out in North Queensland Aboriginal communities of Cape York has provided evidence that community based health literacy model is successful and will be further developed in Cherbourg.

The Health Literacy Program will:

- Increase the awareness and knowledge of the effects of alcohol and other drugs on the developing foetus and how it impacts on the newborn infant.
- Increase literacy skills in relation to health promotion materials.
- Identify and develop appropriate FAS/FAE resources to use during the community events and activities and in the antenatal clinic.
- Facilitate and development of a sustainable health education ethic within the community.
- Reduce the risk factors that compound the effects of using alcohol and other drugs in pregnancy, including family violence and poor nutrition.
- Contribute to the development of supportive environments through public policy that is conducive to good health and encourages healthy children, families and communities.

At its most powerful health literacy incorporates the potential for people to make their own health decisions. The Health Literacy Program will engage groups in the development of health materials, *while at the same* time increasing their literacy level and critical thinking skills to encourage lifelong interest in gaining, sharing and acting upon, health knowledge. Experience with in the field of education has demonstrated the value of context based learning. Learning together also has the potential to develop an informed community of adults who feel empowered to address the issues of health and well being in their own lives and to confront a health care system that ignores their information needs.

The Health Literacy Program will be implemented over twelve months and it is envisaged that the program will increase the awareness of the effects of alcohol on unborn babies and facilitate the development of appropriate resources within the community setting. The Health Literacy Program will increase literacy skills among participants empowering them to continue the process of lifelong learning in relation to their health. Aboriginal people from the community will be trained by the researcher in facilitation skills to deliver the health literacy program, and supported throughout by the researcher.

Meetings will be carried out with the community health action groups, local medical officers, nurses and allied health professionals to establish a strategic approach to sustaining information gathering and information dissemination activities in the participating community.

2. Secondary prevention or risk reduction

Reaching those at risk, identifying existing data and recruit pregnant women to the study.

The second component of the research will be to identify the number of women who drank alcohol during pregnancy. These women will either be pregnant or have given birth to an infant.

Objective 2: In order to develop an effective intervention it will first be necessary to gather relevant background data.

In order to inform the proposed intervention the recruitment of pregnant women will provide baseline data, as well as the following data:

(i) Level of maternal alcohol, tobacco and illicit drug use, pre-pregnancy, during pregnancy and after pregnancy. It is expected that identifying tobacco and illicit drug use as confounders will be part of the outcomes of the project.
(ii) Qualitative data documenting the reasons for alcohol use again recognizing confounders such as tobacco and illicit drug use.
(iii) Quantitative data relating to knowledge and attitudes to alcohol use and measuring the range of contextual factors relevant to such use.

When planning prevention programs it is critical to understand the nature and scope of the problem; in this case the rates and circumstances of alcohol use by women of child bearing age, pregnant women who have given birth to a child affected by Foetal Alcohol Syndrome. Accurate information concerning alcohol use by women, particularly pregnant women is often limited due to a lack of routine screening and under-reporting of alcohol use by women in clinical interviews.

By raising the awareness of Foetal Alcohol Syndrome amongst community members, including women of all ages, health professionals, teachers and educators within the community and then expanding to the Australian population will make an important contribution to improvement to mental health in childhood that includes intellectual disability, cognitive impairments, learning difficulties, speech and language delay, and behavioral and emotional problems.

Many children with FAS and alcohol related birth defects are not being identified and diagnosed at an early age and therefore are not receiving treatment to prevent secondary disabilities. As a result of maternal alcohol consumption in 92% of pregnant women who attended an antenatal clinic in a rural Indigenous community one can hypotheses that there are a proportion of children in this community that have been prenatally exposed to alcohol in-utero. It has been acknowledged that infants as a result of maternal alcohol consumption during pregnancy can sustain lifelong disabilities. Recent work has provided evidence that community based health literacy model is an effective

approach to increasing awareness of FAS/FAE.

3. Tertiary prevention or minimizing complications and chances of recurrence.

The third component of the research will be to identify the prevalence of FAS. These will achieved by adapting and using an existing screening tool and identifying individuals who are affected by exposure to maternal alcohol exposure.

Many children with FAS and alcohol related birth defects are not being identified and diagnosed at an early age and therefore are not receiving treatment to prevent secondary disabilities. As a result of maternal alcohol consumption in 92% of pregnant women who attended an antenatal clinic in a rural Indigenous community one can hypotheses that there are a proportion of children in this community that have been prenatally exposed to alcohol in-utero. It has been acknowledged that infants as a result of maternal alcohol consumption during pregnancy can sustain lifelong disabilities. Recent work has provided evidence that community based health literacy model is an effective approach to increasing awareness of FAS/FAE.

(Describe what this service is designed to achieve)