My name is Elizabeth Pearson I have lived and worked in Cape York since 1980. I was given an opportunity to work at Apunipima Cape York Health Council between 1996 and 2007 in multiple roles - two of those roles were in the capacity of Family Develop Unit Manager, and Health Policy and Planning Manager.

It was then that I had the privilege of meeting Lorian Hayes a leading Indigenous Researcher of Foetal Alcohol Spectrum Disorder who shared her knowledge, and provided education and training to the team I managed at Apunipima. The Report submitted was a result of that work; the recommendations came about from my work with Queensland Health leading a Reference Group to develop an appropriate Child Maternal Health Service Delivery Model for Cape York.

My role and involvement in Foetal Alcohol Spectrum Disorder education compared to specialist Doctors, health promotion educators and researchers has been peripheral so I will not delve too deep into an area that is best left to people with greater knowledge from their personal investment of years in research and study. But I will share as much as I can from my perspective as a resident and employee working 15 years with Indigenous Organisations.

I moved from Apunipima to James Cook University (2007-2008) supervised by Professor Komla Tsey researching and implementing models of empowerment in three Cape York communities before being employed by Pormpur Paanth in 2009 to establish the first residential rehabilitation centre and community-based Alcohol and Drug Service Area in Cape York Peninsula. Queensland Health has always provided outreach work in ATODS and Mental Health to Cape York communities.

Pormpur Paanth Aboriginal Corporation (PPAC) is an aboriginal community controlled service that was established between 1991 and 1992 as a vehicle for providing resources to women and children of Pormpuraaw in Western Cape York experiencing a variety and varying degrees of domestic violence; and to provide adequate social emotional wellbeing services, including safety and protection.

It primarily focusses on family-based interventions, culturally appropriate counselling and support services, family and social emotional wellbeing; dependency, residential and substance use services. The secondary role is advocacy relating to those socio-cultural determinants in low socio-economic environments that impact on and relate to poor health such as lack of appropriate housing, employment opportunities, education and increasing welfare and Justice Issues.

The Organisation provides upstream health promotion strategies as a means to enabling people to increase control over improved health outcomes. PPAC provides counselling support and referral pathways to services that address mental health and associated illnesses, co-morbidity and substance use and provides primary health care functions and linkages to specialist services outside of the community with Allied Health and Chronic Disease Management services and specialist staff and Doctors visiting the Primary Health Care Centre through Royal Flying Doctors Service and Apunipima Cape York Health Council.

Pormpuraaw is home to the Thaayorre and Mungkan Aboriginal peoples who are separated geographically into the two clan groups, and separated by cultural practices and spiritual taboos. There are historical families in the community outside of these clans who live on either side of the Housing Divisions.

Pormpuraaw people continue to practice their cultures and traditions. Elders, adults and young people speak traditional languages as their first language and English may be a 4th or 5th language. There are more than 14 dialects are known to local people.

An active cultural life is maintained when possible. Oral traditions and storytelling, gathering bush tucker, traditional cultural practices and custom are passed on to the younger generations by the Elders of both clan groups.

There are 750 people living in Pormpuraaw. It is situated on the western shores of Cape York where fishing and netting for prawn are favourite pastimes for everyone; and inland are the wetlands which is the setting for hunting and gathering. The Wet Season (December-May) is when the community is isolated by flooding. The only way into the community is by air. During the Dry Season (June-Mid December) roads are open and the drive to regional centres is 9-10 hours by road. It is during this time the greatest risk of binge drinking takes place and sly grog is brought into the community and consumed under various conditions and nocturnal activities.

The Alcohol and Drug service works with individuals, and family groups of any gender, age and race denomination. However, primarily clients are Aboriginal and or Torres Strait Island populations. It has associated links with Primary Health and Allied Health Services that fly in from regional areas to support the work we do or advocate for:

Alcohol and Other Substances
Domestic Violence and Anger Management
Child Maternal Health Care
Social Emotional Wellbeing and Mental Health
Allied Health Care and Chronic Disease conditions
Nutrition
Self-care, Hygiene and Dental Care

Being the only community in Cape York with an Alcohol and Drug Service in a community-controlled non-government organisation we are well positioned to take up the challenge as a pilot site within North Queensland and remote health care when developing a national approach to the prevention, intervention and management of FASD.

It is also the only community in Cape York that has service delivery in alcohol through a Sports Club operating five evenings a week and affiliated with Brothers League Club. There is an opportunity to establish a partnership using prevention strategies including trialling product warnings to raise awareness of the harmful nature of alcohol assumption during pregnancy; and other mechanisms such as re-creating coasters, stubby holders, and posters to display at the Club.

In the foreword of the Apunipima Cape York Health Council report *Creation of Life: Foetal Alcohol Spectrum Disorder Report 2000-2006* it is written that *we need to be efficient in utilising different political strategies, including advocacy, thus initiating action, cooperative strategies ensuring* ***working together to plan action****, maintain communication to* ***recruit others to join the fight, be innovative*** *and pass on maintenance strategies to other organisations* so I have to acknowledge the House of Representatives, its Standing Committee and Australians who have worked for decades to get to this stage in our continuing History in improving Health.

During the time that I managed the FASD Project there was specific funding for FASD education in Cape York communities but since then there has been less funding primarily for FASD and therefore limited access to the same level of education in FASD as the previous years. This has created a lapse in information and FASD education reaching a critical mass in communities.

During the past six years substantial funds have been invested in Regional Organisations undergoing transition to different models of services. This will continue for some years as health services evolve under concurrent initiatives relating to *Closing the Gap*. This may mean regional organisations will be depressed or hyperactive during change management trends. We see this every time a government department re structures and reviews its governance systems.

It is during this phase of change that communities may experience a trough. Momentum slows, or stops. This has also been true in the past when the governments funded programs that were a short term solution to entrenched issues. In order to become more empowered and mobilised bottom-up (grassroots) solutions to issues need to be initiated and appropriately funded. The six strategies in the *Cape York Substance Misuse Strategy*, the first being the restoration of social and cultural norms, are most appropriate when leading an Inquiry of this magnitude.

It is in the context of this strategy that we have to raise the social and socio-cultural consciousness. Collectivistic education on FASD should be the emphasis "the social constellations of which individuals are part" (Nijhuis HGJ, Van der Maesen LJG). It is also in this construct that educating community people of the harmful effects of drinking during pregnancy will create a unified force who shares the beliefs and moral attitudes of community wellbeing.

If the AOD residential service was to undertake a randomised controlled trial versus business as usual (community life) research it would provide details from clients relating to euphoric expression of peace, and desire of never wanting to leave. It provides a setting for a captive audience massaged by increased well-being and knowledge framed in the Health Literacy Model. However, the community is where they return and this is where the work is required.

So the five remaining strategies: availability and access, managing time, and money; rehabilitation and pride of place are all relative to increasing individual, community and environmental wellbeing if implemented within an empowering framework that promotes bottom-up solutions, upstream health promotion education, prevention, intervention and increases employment and Vocational Education outcomes.

The social and environmental determinants are equally important to the social emotional wellbeing and health of the individual, family and community as a whole. Family breakdown, abuse and isolation, loss of safety, fear and loss of respect, violence and grief, alcohol and alcoholism, housing constraints and noise pollution (aggressive arguments and loud music) are major contributing factors in the disruption of the individual and people's ability to build healthy communities in this Nation's future.

The Executive Summary says that exposure to alcohol during pregnancy leads to defects in the following neuro-developmental aspects of life. It is likely that children will experience early inconsistent memory and short-term memory loss; they may show poor understanding of instructions and language; they may show evidence of hyperactivity leading to early school failure and social isolation. They may show intrusive behaviour, and episodes of victimisation. It also states that young people and adults with FAS may experience difficulties including: mental health problems, been found to be more aggressive in the School setting, lack reasoning skills, and are unable to act reasonably in social settings. They are also at increased risk for drug, alcohol and other substances abuse, gambling problems, legal problems, confinement, inappropriate sexual behaviours and employment problems. The transition to adulthood may lead to increases in family and lateral violence issues including self-harm.

Having lived for more than 30 years in Cape York I tend to think about the cycles { (some being 10 years) but again researchers and epidemiologists can produce trends and quantitative data that will either support or diffuse my thinking} of self-harm and suicide attempts in young adults. Ten year age span covers the life of a minor - the resilient child not in control of the social conditions in which he or she survives (including the womb) until 10 years pass and the impacts of poor diagnosis, anxiety, depression, anger and attention seeking behaviour on the young adult trying to struggle with the low socio-economic disadvantages could result in suicide. During my past working life there have been clusters of youth suicide in a number of communities in Cape York.

The FASD Adult by definition has no freedom to choose a greater life for his or herself because by description employment opportunities, social cognitive behaviours and parenting abilities are reduced. The child-youth-adult may become a victim of abuse and neglect, experiencing early removal from their family homes and communities resulting in multiple foster care scenarios.

Only Child Safety can report on how many FASD affected newborns, or failure to thrive children have been remove from a community in Cape York.

It is integral that the relationship between alcohol use and pregnancy be explored both from the viewpoint of health but also within the boundaries of a socio-cultural context that this relationship plays in women's lives and its impact on the day to day life they lead in their community, and how these patterns are sustained by the men and extended families considering most are living together in overcrowded housing.

The extent to which people have control over their lives is a crucial determinant of personal and population health. Public health policy needs to create supportive environments that strengthen community action and community ownership of health.

Behavioural change strategies (like the Family Wellbeing Program highlighted in AIMhi action research projects as a way forward in Indigenous social emotional wellbeing), behavioural health promotion, and upstream health promotion strategies need to be funded, implemented and supported to facilitate the change process.

At all levels we need to lead in planning and communicating the harmful effects of drinking and drug taking, and specifically for today's inquiry the effects of drinking, smoking and drug taking on the unborn child during pregnancy, and the rights of the unborn child to be born free of disability.

Family-based interventions, health promotion and education enable the appetite for change to reach the critical mass. The vision must be shared by people and leaders at multiple levels of democracy (government and aboriginal society); successes will pursue and ongoing reflection required reducing desensitisation to information as dependency battles with social consciousness and behavioural change.

Community people being educated in Foetal Alcohol Spectrum Disorder, vulnerability of the foetus and risks of maternal use and childhood development, then becoming critical change agents, community teachers (exchanging knowledge to one another) and researchers utilising Participatory Action Research would necessitate personal transformation based on an understanding and critique of these socio-cultural forces.

We need to revisit outcomes of the FASD Report and increase knowledge of the effects of alcohol on unborn babies; develop appropriate information resources tailored to the community, increase literacy skills, increase participation by community members and engage men in the education process so that Men's and Women's Groups are maintained as vehicles to exchange information and drive family-based initiatives.

The widespread use of alcohol and drugs among young women (and young men), and the links of this use with teenage pregnancy raised community concerns about the long term impact that these patterns of behaviour may be having on an unborn foetus and the new born baby. From the viewpoint 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.

Alternative opportunities to parenthood at a young age need to be investigated. Establish independent learning centres in communities for those disengaged young people who have fallen through the cracks in mainstream education, but may respond to alternative learning methodologies and therapeutic programs (voice of youth-by song and dance, drumming) visual art and visual learning aides such as 3D animated software or You Tube Manuals on how to build, construct, create (something) that leads to sustainable training and employment in a format that suits slower learners immersed in youth culture that includes substance misuse (inhalants, stimulants, drugs and alcohol).

- Recognise Foetal Alcohol Spectrum Disorder as a disability (primary and secondary disabilities) and develop policy and systems that meet the needs of a child at school with FASD by strongly supported infrastructure and resources in the school system.

Generally Cape York schools and communities are under resourced. Child health specialists, counsellors, and creative therapeutic therapies for children whose parents are drinking or drugging must be visiting schools more. FASD Diagnostic teams are required. Communities should be funded to initiate the **purchase provider model** to employ or contract child health therapists as ATOD services work with men, women and families to shift the paradigm. We must move beyond these "downstream" efforts towards a more appropriate whole population public health approach to health policy – what may be termed a social policy approach to healthy lifestyles rather than the current lifestyle approach to health policy (Terris M.)

- Reconsider social welfare measures for carers looking after children with Foetal Alcohol Spectrum Disorders.

- Re consider recommendations in the "National Clinical Guidelines for the Management of Drug Use during Pregnancy, Birth and the Early Development Years of the Newborn' in relation to alcohol consumption during pregnancy given the compelling international evidence that mothers who drink even small amounts of alcohol during pregnancy could unwittingly hurt the unborn child.

- Legislate that all alcohol product labels provide warning messages of the harmful effects of drinking during pregnancy – *mirroring the current practices with regards to smoking.*

- Establish a Health Promotion Fund for Indigenous Communities using an "alcohol content tax" or "alcohol consumption tax". *This could mirror the way the government raises revenue from pokie machine tax in Hotels and Clubs.*

- Invest and build health service capacity, enabling structures and infrastructure around child maternal health through development of a competent workforce, and specialist services needed in child and maternal health and in the delivery of foetal spectrum disorder education and health promotion.

- Continue to develop community capacity using the *collectivistic* philosophies' in relation to promotion, prevention and early intervention strategies to reduce prenatal exposure or exposure to smoking and alcohol in the period between conceptions to birth.

- Invest in the Family Wellbeing Program, highlighted in AIMhi action research projects as a way forward in Indigenous social emotional wellbeing.

Family Well-being as an empowering tool capturing *Individualistic* and c*ollectivistic* philosophies and views of health which manifest themselves in participatory action research practices in everyday life. The Family Well Being Program is an empowerment and engagement tool that will enable people to take responsibility and make decisions to change unhealthy behavioural patterns such as drinking while pregnant. It is a tool that has the potential to effect social reform. When delivered in group environments enhances discussion between people, provide opportunities for broadening understanding, reinforces family connections and minimise division where people feel safe to

interact and share experience, learn, support one another, build confidence to plan and work together in the reduction of negative issues in their lives

- Policy should build up national health capital through investment in physical assets most obvious ones being the health care system infrastructure, school support systems for children, housing and social services; dependency and substance use facilities and services that relate to Foetal Alcohol Spectrum Disorder and Child Maternal Health.

- The COAG Reform Council: National Healthcare Agreement (NHA) 2008-09 highlights objectives that should be adapted when considering a national approach to FASD. Some are listed: the need for appropriate data, the inclusion of appropriate measures, the availability and accuracy of survey collections to report data; improve the accuracy of data; improve comparability of data. Consider the appropriateness of the output—number of young people with disabilities that may be a consequence of FASD. Consider broader measures of social inclusion for reporting equity in health outcomes; Improve ability to disaggregate data by Indigenous status, socio-economic status and remoteness

Physicians should be better able to identify at-risk pregnancies and alcohol-affected individuals and address foetal alcohol exposure in the clinical setting.

- Fast track policy development and policy implementation that encompasses mid-stream actions impacting on living and working conditions and behavioural risk factors that provide positive and constructive government-supported initiatives to reduce Foetal Alcohol Spectrum Disorder and strengthens community mobilisation establishing 'change agents for health' from within in order to raise the communities' social consciousness.

- *Community development: A three dimensional approach*
    - Women (and men at Men's Group meetings) at the community level and raising awareness through workshops. A community development approach respected that women and men in communities lived the problem of alcohol abuse but needed the appropriate information, resources and support to begin the process of change. Using this approach community participants are encouraged to design and develop culturally appropriate information and support mechanisms to bring about sustainable change.
    - Local service providers in communities – developing simple communication strategies and collaborating with other service workers like nutritionists, GAA and ATODS, to develop workshop content; and the delivery of FASD education to the community members
    - Regional service providers – information sharing, and encouraging collaboration through the Child Development Working Group hosted by Queensland Health and the development of the 0-4 and 5-14 child health screening tools. The Model involved interaction, networking and collaboration between services at all levels and enabled gaps in service delivery to be readily identified but not necessarily addressed for optimum outcomes.

The following points came out of the 2006 Report:

- It was suggested that a ***Health in the Hands of the Family Program*** be developed and implemented to improve health management capabilities, and health care plans. What could this look like?
- Regional health-related agencies should have a brief that extends beyond clinically based issues into social justice (holistic models of health care), legislative and human rights areas (rights of the unborn child) and the social determinants that impact on health.
- Effective community organisations need to promote an inter-sectoral focus and foster individual and community mobilisation that provides enabling structures for the delivery of programs such as Foetal Alcohol Syndrome and Foetal Alcohol Education.
- Education Queensland to provide training to all teaching staff, especially those working in Cape York communities
- FAS/FASD should be one of the modules in medical training (doctors and nurses), and Indigenous health worker training
- The importance of Indigenous Health Workers to the delivery of primary health care cannot be over-emphasised. Their significance lies not only in being at the forefront of health delivery, but also in the fact that they are part of the people they care for; sharing in the general health of their communities
- A need to reform workplaces and workplace practices to empower Indigenous Health Workers
- The need for Health Workers to establish and maintain regular contact with their local Remote Indigenous Media Organisation (RIMO) to promote and inform on health issues, especially Foetal Alcohol Syndrome and its relation to Chronic Disease, and mental health in adults. This could be done where appropriate in language therefore equipping staff with social marketing skills (community BRACCS).
- Accessible rehabilitation services planted in family and culturally appropriate lands across Cape York for detoxification purposes from alcohol and other drugs

To be effective we know we need to:

- Be client focussed and forge strong relationships with our clients and help restore a belief in themselves and their future because we know learning to trust again is the essential step in healing
- Stick with our clients through the ups and downs, outreach, provide education and intervention strategies, and advocate
- Help individuals, families recover from trauma of abuse, neglect or violence because we know that with support and opportunities individuals and families can reach their full potential
- Look beyond challenging behaviour to identify and build on strengths because we know every person has strengths and resilience that, if acknowledged, will provide a platform for healthy development
- Include family members and other significant people in planning and caring because we know it is critical to strengthen connections and build positive family relationships

- Respect people's culture and spiritual beliefs because we know how important these can be in developing identity and a sense of self
- Involve our clients in planning, decision-making and the way we help meet their needs because we know that taking control of their lives builds resilience and independence
- Acknowledge and promote the human rights of children and young people because we know that a good childhood is every child's birth right and that this means the future of Indigenous people, and restoration of culture and social norms

Research

Undertake scientific experimenting on the brewing stages of alcohol to extract the process that creates the harmful toxins or poisons that affect the unborn child during consumption by the adult and isolate it.

Undertake research that investigates a wide range of behavioural issues in children i.e. Attention Deficit and Hyperactivity Disorders and whether it is located in genetic and generational conditioning relating to the family history of consumption of alcohol.