"Broken Arrows"

A Parliamentary Submission for the inquiry into FASD

"FASD Children are like 'broken arrows', broken before they have even had a chance to fly"

> Written by Warren 'Wazza' Harvey—

(Contents may contain confidential information)

Broken Arrow

My wife and I began our adoption journey shortly after our first biological daughter was born....it began by making a few enquiries. Our desire was to adopt from Ethiopia after we had three biological children.

The adoption process was very long and lengthy. We were considered unsuitable to adopt for three main reasons;

- 1. **Low Income:** My salary as a full-time school Chaplain & choosing to be a one income family, was deemed to low by the Department of Child Protection. (DCP)
- 2. **Insecure employment**: I had recently been made redundant from my employer of 7 years and was working on various farms. At this stage of Adoption we were only in the screening stage and still several years away from adopting
- 3. **Isolated Community:** The small rural community that we were living in at the time was considered too small and too far from Perth!!

After we were informed that the DCP were not going to allow us to adopt, we were very surprised to receive a letter dated 5 September 2006 saying that we had been approved.

The adoption process is a long and lengthy emotional roller coaster ride. In January 2007 we moved to Esperance.

Then in 2007 still several years away from adopting from Ethiopia, DCP phoned and informed us that there was a child in Perth needing adoption. I informed them that we were not on the local list.

They explained that our profile 'matched' the desire of the biological parents. Since I was travelling to Perth for my Father in-laws funeral, I thought I would meet the child—who is now our adopted son.

Our son with his foster mum came to visit Esperance with his foster mum a few times before being placed with us officially on the 15 August 2007. During placement we observed some unusual incidences for a 2.5 year old boy. Of particular note was his seemly inability to perceive height and danger. On one occasion he was climbing on some play ground equipment and he just kind of walked off the edge and collapsed in the sand.

There were many other incidences that appeared to indicate some sort of developmental delay. We asked our DCP Case Worker about these issues and we were informed that he did have failure to thrive when he was born but 'had met all his mile stones' and that he was not developmentally delayed.

Many of our concerns were explained away—maybe his foster mum had never taken him on a climbing gym before so he simply hasn't learnt about those experiences or developed those skills etc..

At first these reasoned responses seemed to make sense, however my wife especially would notice lots of little things and would raise these observations with our Adoption Case Worker.

Mainly due to my wife persistence, DCP referred our son to a Paediatrician to check him over. A letter is sent to us which states. "I have been reviewing all the notes on young xxxxx and I do not believe that his biological mother had illicit drugs during pregnancy etc. As the assessment from State Child Development Centre really says there is little known about xxxxx prenatal history and no history of substance abuse or illness during pregnancy. So I think this little lad is normal and certainly I would be very happy with his development at the present time" Dr Scurlock

We were still not convinced and DCP sent several independent Psychologist to reassess our suitability to adopt. During this time our focus shifted from trying to ascertain 'what is wrong with our son?" to "what is right with us!"

We decided in the end the best way to find out "What is wrong with our son" was not to raise anymore concerns or issues about him with DCP.

The adoption went through on 5 January 2009 and DCP were now out of the picture my wife could proceed with her investigation. She read books on ADD on ADHD and then on a adoption newsletter she found out about FASD.

She ordered several books about FASD. Then one day she showed me a drawing and asked me what I thought and I said 'that looks like xxxxx!'

A simular picture is inserted bellow, illustrating the facial features of a FASD Child.

We asked our doctor if he could give us a referral to the visiting paediatrician to diagnose FASD.



By this time our son had grown out of some of his facial features so we brought a photo of him when he was about 2.5 years old, when his flat philtrum was very apparent.

The Paediatrician that had previously saw our son saw him again but this time specifically asking to consider FASD. She said quiet frankly that she 'was not into diagnosing things like that—after all if he has it—what can you do about it!!'

Being dissatisfied with her response we asked our Doctor if he could refer us to another Paediatrician Dr Lindsay Adams who states in his letter "xxxxx strikes me as a young man who was exposed to alcohol inutero. He does not have the full facial features of FAS but does have behaviour issues consistent with FASD"

Since then we have obtained written confirmation of alcohol consumption during pregnancy by his birth mother.

We are still on our journey of trying to obtain a complete diagnosis as living approximately 750 km away from Perth has proven to be rather difficult.

Doctors at times like to re-schedule which is not a simple task when family and work events have been work around you either being there or not being there over weekends. In sufficient notice for tele-health conferences has also been an obstacle.

We have had one attempt at obtaining Carers Allowance but have been declined. Respite is limited as FASD is not registered with as a disability.

"Children are a gift of the Lord, the fruit of the womb is a reward Like arrows in the hand of a warrior, so are the children's of one youth" Psalm 127: 3—4

Children are like an arrows in a warriors hands....and one of my children is already a 'broken arrow'; he was broken in the womb......we hope that with the right support we can shoot our son in the right direction but because he is a 'broken arrow' he will need extra guidance along the way.

Secondary Symptoms of FASD

- → Disrupted School Experience (60%)
- → Mental Health Issue(90%)
- \rightarrow Trouble with the law(60%)
- → Alcohol & drug problems (30% 40%)
- → Inappropriate Sexual Behaviour (40% - 50%) (Streissguth 1997)

"FASD Children are like 'broken arrows', broken before they have even had a chance to fly" Warren 'Wazza' Harvey



The Information Vacuum

Being fully convinced that our son has FASD and frustrated by the lack of information available in the community, amongst medical and health professionals. I began strategising.

On the 9 September 2009 which is international FAS-Day and has been since 1999...but to this date is still not on the WA Health Promotions Calendar, I held a community workshop for any anybody who was interested in learning about FASD.

This workshop was attended by approximately 50 people of community members and various health professionals, it was an interactive workshop.

The activity that I called "The Information Vacuum" impacted many participants. I had borrowed pregnancy books from the library and took some from my own book shelf. Then in small groups they had to discusses the following questions.

- 1. Who wrote and endorsed this book and what impression does that give the reader?
- 2. Does the book provide any information about alcohol and pregnancy and if so what information?
- 3. What information does it give about FASD?
- 4. What do you think or feel after doing this activity?

All the random sample of books were found inadequate when it came to informing women about the risks of drinking alcohol during pregnancy. But one of particular note was one found on my own bookshelf that my wife and I purchased for our own pregnancies.

The book is called "The Girlfriends Guide To Pregnancy" written by Vicki Iovine. (1995) "It's everything your doctor won't tell you"

In her introduction Vicki writes "I have given birth to four children in six years, two boys and two girls and no twins in the lot, and the lesson I have learned (aside from not to trust the rhythm method) is this: Ninety percent of the information I needed to get me through these pregnancies



came from my Girlfriends who already had children. Sure there are a lot of books about pregnancy that you could read." (pg xv)

This book was promoted on the "Today Show" and gives readers the impression that because Vicki Iovine is and 'experienced' mother who has lots of 'Girlfriends' with experience then the information in her book can be relied on despite a little disclaimer found hidden in fine print on the inside cover which 'disclaims any public liability arising directly or indirectly from the use of this book'

So what information about alcohol and pregnancy does it provide? Here is a direct quote from page 64 in her book.

"If my beauty salon story sounds extreme, just wait until you run into the Pregnancy Police at a party or restaurant. God forbid if you should have a glass of wine with dinner or participate in a champagne toast, even with a notarized letter of permission from your doctor. The P.P. will either look witheringly at you or actually lecture you about fetal alcohol syndrome. Almost all of the Girlfriends—none of whom, I hasten to add, drank a total of four of five glasses of wine or champagne over the course of their entire pregnancies—found themselves lamely trying to defend their imbibing to total strangers more than once.

Naturally, doctors will have their opinions about drinking during pregnancy, and I am neither condoning nor condemning drinking. I am just saying pregnancy is hard enough; what with the societal stigmas against hot tubs, aspirin, coffee, and artificial sweetners, not to mention your own compromised sex life and your comical physical proportions, a single drink once every couple of months seems allowable, if not outright deserved. But, hey, I'm no doctor. Life is a series of calculated risk, and you and your doctor should work together to chart a coarse of behaviour that is healthy for the baby *and* liveable for the mother"

So much for 'calculated risk'! When this book gets down to Alcohol and pregnancy and Fetal Alcohol Syndrome. That's where it starts and finishes.

The Girlfriends' Guide To Pregnancy boasted that it would tell me all the information that my doctor won't! So lets look at what Doctors are telling pregnant women about Alcohol and FASD

"Western Australian research has shown that 97% of health professionals thought that women should be informed about the consequences of consuming alcohol in pregnancy. However, about 55% of health professionals caring for pregnant women did not routinely ask about alcohol use in pregnancy and 75% did not routinely provide information on the consequence of alcohol in pregnancy.

Australian women consider health professionals to be the best source of information about alcohol use in pregnancy. A survey of Australian women of child bearing age, showed that over a third were unaware of the consequences of prenatal alcohol use on the fetus. In this survey, women may not ask about alcohol consumption in pregnancy as the expect important issues to be raised by health professionals"

(Alcohol and Pregnancy Project. Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals (1st Revision). Perth Telethon Institute for Child Health Research; 2009)

Health professionals have been failing to provide information, leaving the majority of women to suck up any information they can find, which is usually in books that are <u>unreliable</u>, <u>uninformative</u>, <u>and understate the living reality of FASD</u>.

Therefore, when it comes to information regarding the potential consequence of consuming alcohol during pregnancy we are currently living in an information VACUUM

- Variable
- Absent
- Confusing
- Understated
- Uninformative
- Misleading



Filling the Void

In 2010—my wife and I with a long term foster mum with a FASD child booked a site at the local shopping centre and set up a display we made Information Kits for schools and health professionals.



Inspired by a "Don't Snicker at FAS" that I found surfing the net I made up some of our own chocolate slogans. We gave away over 1 000 chocolates and distributed around 20 FASD Info Kits to Schools and

Doctor Surgeries.

People were very happy to receive a free chocolate stapled to a matching flier with some brief information about what FASD is as illustrated bellow.

I phoned and emailed the WA Health Department to see if FAS – Day could be included on their Health Promotions Calendar.

I was very surprised at their response. In short, I was informed that. I had to have an organisation, an activity, a logo, resources etc before having FAS-Day listed on the Health promotions calendar!

www.nofasard.org.au drinking during pregnancy. Timeout from drinking will last only 9 months; FASD last a lifetime!! Parents with FASD kids struggle to take When you drink alcohol, timeout. your unborn child drinks it, too Be a smarty at a party. When offered drinks Say 'no thanks..... I have a baby inside!' These Smarties won't last long; neither will the party but FASD will last a lifetime! www.nofasard.org.au FETAL AL ALCOHOL HOL JL SYNDROME OME ME Parenting a child with FASD = Fetal Alcohol Spectrum Disorders Parental exposure to alcohol can cause brain damage FASD...is no picnic!! to the unborn child, which will last a lifetime. This Picnic will be gone No amount of alcohol is known to be safe during pregnancy. Alcohol causes more damage to the baby than in a minute but FASD is permanent. FASD is permanent brain damage and causes serious

Take timeout from

Don't Drink Alcohol During Pregnancy!

www.nofasard.org.au

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Fetal Alcohol Spectrum Disorders is 100% preventable.

any other drug.

behaviour and social problems.

Surely it IS the Health Departments role to do Health Promotion!!

It is great that various organisations such as the Cancer Council has Daffodil Day and Australia's Biggest Morning Tea that raises funds and awareness of various health issues. Jeans of Genes Day, Red Nose Day for SIDS in order to raise vital funds and create awareness....I support many of these activities.

However there is fundamentally something wrong when our state Health Department is either unwilling or unable to do health promotion especially when there is no non-government organisation able to do so at that time in relation to new issues coming to the fore like FASD.

Has our Health Promotion Calendar become more of an event calendar to raise funds for non-government organisations than for genuine health promotion by our Health Departments??

I believe non-government organisations should be able to raise funds and awareness of various health issues, and utilise the Health Promotion Calendar to do so.

The issue is that the Health Department should not rely on individuals or non-government organisations unequipped or under resourced to do Health Promotion in areas that require government leadership!

NOFASARD the National Organisation for Fetal Alcohol Syndrome And Related Disorders is a national leader on FASD—however currently they are still a fledgling organisation in terms of infrastructure and financial backing.

I am a volunteer representative for NOFASARD and am on a number of work groups relating to FASD in WA.

I am pleased to now add that the Health Dept of WA have just recently formed several working groups to develop strategies in the prevention and awareness of FASD.

Australia's First (Twin) Pregnant Pauses!

Each year I have attempted to build on last years achievements—in 2009 we had 50 participants at a FASD Workshop then in 2010 we gave out over 1 000 chocolates at our local shopping centre..

Then in 2011 thanks to the Esperance Local Drug Action Group and especially Jill Fitzpatrick, Kylie Ryan and Drama teacher from Esperance SHS Kathy Bowering We managed to organise Australia's First (twin) Pregnant Pauses. One organising group—one town—two locations!

At 9 to 9 am as students were walking from their form room to class when approximately 50 students stuck a balloon up their shirt and paused in a pregnant pose for 90 seconds while their drama teacher beated on a bongo drum.

Then at the traditional time 9.09am a flash mob invaded a local shopping centre an paused for 90 seconds.

The Local Drug Action Group had just successfully organised two flash mobs making Australian history in this vital public awareness campaign—and where were the media?

Despite a number of efforts on our part even paying a freelance cameraman to produce TV quality video footage, we were still unable to make to the news. The media did however have news footage on FASD on the 9 November with the focus on FASD and indigenous people. Enabling the common myth that FASD is only an indigenous issue.



Every year on September 9th, International FASD Awareness Day is observed. Proclamations are issued in countries, states, provinces, and towns all around the world. Bells are rung at 9:09 a.m. in every time zone from New Zealand to Alaska. People all around the world gather for events to raise awareness about the dangers of drinking during pregnancy and the plight of individuals and families who struggle with Fetal Alcohol Spectrum Disorders (FASD). The first FASDay was celebrated on 9/9/99. This day was chosen so that on the ninth day of the ninth month of the year, the world will remember that during the nine months of pregnancy a woman should abstain from alcohol. Anytime is a good time to raise awareness about Fetal Alcohol Spectrum Disorders (FASD).

Participants in the flash mobs were given wallet size business cards based on the previous years slogans but due to funding from Heathway we were able to have them professionally printed.



The flash mob was a success and it is anticipated that there will be several Pregnant Pauses organised around Australia in 2012 using face book and other social mediums.

FASD pervades many places, many races, many faces.
FASD does not respect culture, class or race;
FASD is not just a concern for indigenous communities.
Wherever alcohol is consumed, FASD has the potential to raise its face.
With all pregnancies there is a man involved.
Let's face it; FASD is a concern for all Australians.

Warren "Wazza" Harvey

Watch Australia's First Pregnant Pause on Youtube

http://www.youtube.com/watch?v=deFwszdxKTM

http://www.youtube.com/watch?v=T25_78VF8qs&feature=related

Poisson in a Bottle

Alcohol is a teratogen, in other words to the developing baby it is poisonous. The alcohol passes freely to the fetus through the placenta. The Blood Alcohol Concentration (BAC) of the fetus is as high as the mothers maybe even higher. However the developing baby has limited ability to metabolise alcohol and can disturb the development of the baby.

The developing baby, depending on gestation stage, urinates the alcohol into the embryonic sac and continues to reabsorb the alcohol through the lungs. The developing baby struggles to metabolise the alcohol.

Prenatal exposure to alcohol can cause the following to the unborn infant.

- \rightarrow Death (Miscarriage and stillbirth)
- \rightarrow Malformation
- → Growth Deficiency
- → Functional Deficits



Teratogen: Any agent that can disturb the development of an embryo or fetus. Teratogens may cause a birth defect in the child. Or a teratogen may halt the pregnancy outright. The classes of teratogens include radiation, maternal infections, chemicals, and drugs.

(medicinenet.com)



Other drugs known to be teratogenic are often prescribed and are labelled with appropriate health warnings such as "DO NOT USE IF PREGNANT OR SUSPECT YOU ARE PREGANT OR ARE BREAST FEEDING"

Often prescribed drugs are discussed with their doctor, only accessible to those who require them therefore access is limited and are appropriately labelled. However when it comes to alcohol which is more readily available, and due the information vacuum, is not being discussed by doctors and other health professionals and neither does it have any health warning despite the fact that alcohol is a teratogen. According to the "Woollard Report" or the Education and Health Standing Committee . Alcohol: Reducing The Harm And Curbing The Culture Of Excess. Report No. 10; 2011

The report states that "research shows that a voluntary labelling system is ineffective" and that this system of labelling "is counter intuitive, falls short of government's expectations and does not sufficiently protect public health"

However the Standing Council on Health—whom this report was written for have advised "that pursing warnings about the risks of consuming alcohol while pregnant is prudent but, noting the voluntary steps industry has already taken in this area, has suggested that industry should be allowed a period of two years to adopt voluntary initiatives before regulating change" according to Ian Wight-Picken Chief of Staff writing to me on behalf of Hon Dr Kim Hames MLA who is

a member of the Standing Council on Health.

In efforts to prevent FASD all alcohol needs to be labelled, and clear warnings where ever alcohol is sold, "a survey of Australian women of childbearing age, showed that over a third were unaware of the consequences of prenatal alcohol use on the fetus" (Alcohol and Pregnancy Project. Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals (1st Revision). Perth Telethon Institute for Child Health Research; 2009)

The "Woolard Report" also states that there is "strong evidence that warning labels can be effective not only in increasing information and changing attitudes, but also changing behaviour. The successful use of tobacco warning labels suggest that alcohol warning labels should;

- \rightarrow be graphic and attention getting
- → Occupy a considerable portion of the package surface, for example at least 25% of physical space
- \rightarrow Involve rotating and changing messages"



The report also states that "in light of the high levels of public support for the concept of warning labels, action by State Government on this issue would be well received. Changing the text of the labels on bottles and cans would not be a particularly expensive undertaking for the produces of alcoholic beverages if they were given notice of the change (Education and Health Standing Committee . Alcohol: Reducing The Harm And Curbing The Culture Of Excess. Report No. 10; 2011)

Since this report was compiled for the State Government—I do believe that the Federal Government would also get much support for from the general public.



When you drink alcohol, your unborn child drinks it, too

Thank you for the opportunity to share some of my experiences and insights into FASD for this Parliamentary Inquiry.

FASD is 100% preventable—lets do everything in our power to prevent this disability through public awareness.

FASD is 100% permanent—lets ensure that children and adults with FASD get all the support they need in our schools and justice systems. And that women who drank during pregnancy get the support they need with out blame and shame.

I hope my submission meets the necessary requirements and terms of reference.

If you have any questions regarding my submission then please do not hesitate to contact me on **equivalent**.

Yours sincerely,

Warren "Wazza" Harvey