

**THE CHURCHILL FELLOWSHIP MEMORIAL TRUST OF AUSTRALIA**

**Report by June Councillor**

**2009 Churchill Fellow**

**The WA Department for Child Protection Churchill Fellowship to study:  
“Prenatal alcohol exposure and the impact on parenting affected children  
especially in Aboriginal communities” in Canada and the United States of  
America (USA)**

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**Dated:** 18 January 2011

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# 1. INTRODUCTION

For the past five years, I worked alongside communities throughout Western Australia (WA) to help raise the awareness of the affects of alcohol on unborn babies. As we now know and research tells us, drinking alcohol in pregnancy puts babies at risk of Fetal<sup>1</sup> Alcohol Spectrum Disorder (FASD) – a permanent lifelong disability from organic brain and structural damage that is 100% preventable. Through my work with these various communities, it became apparent that many parents and grandparents knew very little or had not heard of FASD; Aboriginal Elders however, knew and many times made comments like: *“something not right with these little ones – something wrong, they can’t listen!”*

With the support of my workplace and on one occasion; sponsorship from Gumala Aboriginal Corporation, I was able to attend International and state FASD conferences; to engage in and conduct my own informal research to enhance my knowledge that authenticated the workshops and training I delivered in communities around the state. In 2008, I applied to the Winston Churchill Memorial Churchill trust for and was successful in getting a 2009 Churchill Fellowship to further increase my knowledge on FASD; hear personal stories from parents and carers of loved ones diagnosed with and/or affected by FASD and to learn from the international FASD experts about the conditions.

As well as learning more about FASD, my Churchill Fellowship study aimed to look at traditional Aboriginal ways of parenting; how alcohol has impacted on Aboriginal child rearing practices and what it means for parents and carers, parenting children prenatally exposed to alcohol. It is commonly known that Canada and the United States of America are the leading countries in FASD research, prevention and intervention strategies, so I travelled (alongside my husband)<sup>2</sup> to these countries to learn from experts in the field and look at the similarities of the cultural and social impacts between the Native Indians, First Nations and Australian Aboriginal peoples. I hope that what I’ve learned and am about to share with you in this report will be of interest and as beneficial to you as it is to me.

Note: This report does not contain statistics eg: prevalence of FASD in Australia etc, however it does outline in story form; my Churchill Fellowship Journey and FASD learning experience.

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<sup>1</sup> Fetal’ rather than ‘Foetal’ is used to be consistent with International language use on FASD

<sup>2</sup> Places in this report where I refer to ‘us’ or ‘we’ it includes myself and my husband

## 2. ACKNOWLEDGEMENTS

My 2009 Churchill Fellowship is sponsored by the Western Australian, Department for Child Protection (DCP). I would like to take this opportunity to extend special thanks to:

- The Winston Churchill Memorial Trust National Board; for awarding me the 2009 Churchill Fellowship and the Western Australia Regional Committee for their great support.
- Mr Terry Murphy, Director General, DCP for departmental sponsorship of my project;
- Hon. Minister, Robyn McSweeney (Minister for Child Protection, Community Services, Seniors and Volunteering and Women's Interests) for endorsing my original application and to the Department For Communities, Executive staff and previous work colleagues for their ongoing encouragement and support.
- Mr Chris Field, WA Ombudsman; for supporting a prior commitment and allowing me to take the time from office to fulfill my duties of the Churchill Fellowship; and to all Ombudsman WA staff and colleagues, thank you for your invaluable support.
- The mothers that shared their moving stories about their child/children living with FASD and the challenges you endure on a daily basis; you are all very special and amazing people with incredible stories and passion; my heartfelt thanks to you all.
- The wonderful people that hosted my visit to your countries, your communities and your homes: Carolyn Hartness, Suzie Kuerschner, Nancy Poole, Joanne Nelson, Hanna Scrivens, Deborah Kacki, David Gerry, Janet Christie, Liza Miles and Linda Dano-Chartrand.
- Last but not least, my beautiful family; for their undying love and support; for forgoing 11 weeks (and more) of family time to allow me the space to do this study. Without your support, I would not have been able to stay focused and be away from home for this lengthy duration.

This study would not have been possible or as successful as it was without the invaluable support and time you all afforded me; for this I am eternally grateful.

### 3. EXECUTIVE SUMMARY

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#### **3.1 Project Description**

My project was to study “Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities in Canada and the United States of America”. To learn this I visited the states of Washington and Oregon in the USA and British Columbia and Manitoba in Canada.

#### **3.2 Highlights and Lessons Learned**

The highlights were: Aboriginal, First Nations and Native Indian Cultural Exchange; Meeting people diagnosed with FASD and observing their challenges and successes; Meeting FASD experts whose research and materials I've read (eg: Professor Susan Astley); attending the FASD Diagnostic Clinic to observe two real assessments and visiting programs that work with and support women with addictions to achieve better outcomes for their children.

I learned that Native Indian and First Nations people alike develop their programs on the concept of the Medicine Wheel;<sup>3</sup> it includes traditional ways of healing using language, medicine and spiritual teachings. They don't focus on the deficits of people affected by alcohol but find, build on and nurture their strengths. Their programs (including that of Child Welfare) are women centred; they work with improving the life outcomes for the mother to achieve the best outcomes for the child. The consistent messages across the two countries was that people from all disciplines who work with families and individuals with FASD need to be FASD trained (including professionals) and that people with FASD are 'our teachers'. FASD cuts across all disciplines including health, education, child protection – fostering services, adoptions, in-care accommodation, disabilities, justice, correctional services, parenting, police services and employment. There are FASD diagnostic clinics in the states and provinces; some provide mobile and regional services supported by provincial government. Their FASD programs and campaigns are strongly supported by the provincial governments and in some places from what I understand, by the Liquor industry. Pregnant women with older children in care are still drinking during pregnancy – where in society lies the responsibility of the 'duty of care' to the unborn child?

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<sup>3</sup> Medicine wheels –a Native Indian & First Nations traditional approach, based on the four directions, to guide life's learning, healing etc. websites show examples of two different Medicine Wheels, see References 1 & 2.

### **3.3 Implementation**

I am hopeful this report will influence change in relation to FASD. The information and knowledge I gained during this study will be used to benefit my work at OWA particularly, in the Child Death Reviews Team and the Western Australian communities with which I work. I anticipate this report will be used to complement the existing FASD projects, research and Model of Care to inform government and help instigate training for parents, carers, service providers and professionals; initiate services and supports for people living with or suspected of having FASD in WA. The information and experience will be shared with Aboriginal people and communities in order to encourage others to consider doing a Churchill Fellowship to engage in further study to help close the gap on Indigenous issues.

### **3.4 Recommendations**

1. **Training** - a FASD training program is developed or adopted from Russell Family Fetal Alcohol Disorders Association for use by government departments and other services and that the FASD training is incorporated into Induction and/or Professional development training within organisations.
2. **Family Support** – women on drugs and alcohol are strongly supported to overcome their addictions to improve their lifestyle; gain positive skills and establish safer, stable home environments, which leads to better outcomes for their children; and that children with FASD or FASD like behaviours and symptoms be supported through implementing relevant strategies in schools, fostering services, home care etc.
3. **FASD Partnerships & Collaboration** – identify lead FASD agency; to build partnerships between government, non government and the private sector to address FASD; that government and other relevant services with a responsibility to people with this disability, work collaboratively to achieve the best possible outcomes for people with FASD: and that the FASD assessment, resource and workforce development and diagnostic projects be supported and where necessary be expanded to benefit the broader WA community; and establish a state funded FASD coordinator to coordinate FASD partnership initiatives and training in WA.
4. **Traditional Ways of Parenting** - Aboriginal teachings to be acknowledged, respected and further explored to find out if it fits with the current research, if so Aboriginal people be encouraged and supported to continue that practice where appropriate eg: Aboriginal birthing centre that is Aboriginal controlled with support from hospitals and health services etc.
5. **State FASD Conference** – A state conference for individuals, families, service providers and professionals be held in Perth to share and exchange knowledge, bring together the supports and build a stronger community around those affected by FASD.
6. **Reclaiming Our Voices** – That the invitation from the First Nations women in the West Regions of Manitoba for five Australian Aboriginal women to attend one of their ROV gatherings is accepted, supported and honoured.

## 4. PROGRAMME

Attached as an Appendix to this report is the dates and names of people and agencies I pre-arranged to visit during my Churchill Fellowship trip. There were some appointments for various reasons did not eventuate however, listed in the table below are the people I met and who so kindly contributed to my study and includes the places I visited on my Churchill journey. Some people opened their homes to us and others provided us with significant exposure to their cultural beliefs and practices. Carolyn Hartness (a Native Indian – Eastern Band Cherokee woman with whom we spent a majority of our time in the USA) was extremely resourceful and had immense knowledge and connection not only to community, but to FASD experts as well. Carolyn so graciously arranged the USA component of my journey and linked me to the FASD families and experts.

### 4.1 CANADA CONTACTS

Nancy Poole	Director, Research and Knowledge Translation BC Centre of Excellence for Women's Health in Vancouver: (Vancouver, BC)
Joanne Nelson	A/Epidemiology and Research Officer, Health Canada BC Region (Vancouver, BC)
Willow Allen	Program Consultant, Aboriginal Head Start On Reserve Program, First Nations and Inuit Health, British Columbia Region Health Canada, (Vancouver, BC)
Paulena McKeller	Aboriginal Support Worker, Sheway - A Community Program for Women & Children (East Vancouver, BC)
Hanna Scrivens	FASD Coordinator Soar Mentoring Program Inter Tribal Health Authorities, (Nanaimo, BC)
Janet Christie	Moms Mentoring Moms Program, Victoria, BC - (Victoria, BC)
Liza Miles	Art Therapist Moms Mentoring Moms Program, (Victoria, BC)
David Gerry	Beacon Community Services, Victoria, BC)
Deborah Kacki	Interagency FASD Program, (Winnipeg, Manitoba)
Linda Dano-Chartrand	Reclaiming Our Voices; West Region Child & Family Services (Winnipeg, Manitoba)
First Nations Communities	Rolling Rivers Reservation, West Regions Manitoba
Family Homes	Linda & Miles; Vern & Tracey, Winnipeg, Manitoba <sup>4</sup>

<sup>4</sup> Full names withheld for confidential reasons.

## 4.2 UNITED STATES OF AMERICA (USA) CONTACTS

<b>Carolyn Hartness</b>	FASD Educator & Consultant and Member of FASD Native Expert Panel, SAMHSA. (Kitsap County, WA)
<b>Suzie Kuerschner</b>	Strategies for Prevention, Intervention & Resilience in Teaching for Success (SPIRITS) (Portland, Oregon)
<b>Professor Susan Astley</b>	Professor of Epidemiology/Pediatrics and Director, WA State FAS Diagnostic & Prevention Network University of Washington, (Seattle, WA)
<b>Tom Stokes</b>	Area Administrator Department of Social and Health Services Children's Administration Region 5 Centralized Services, Pierce and Kitsap Offices
<b>Barbara Smithson</b>	
<b>Therese Grant</b>	Associate Professor - Department of Psychiatry & Behavioral Sciences; Director of Fetal Alcohol Drug Unit (Seattle, WA)
<b>Kathryn (Kay) Kelly</b>	Project Director - FASD Legal Issues Resource Centre Department of Psychiatry & Behavioral Sciences
<b>Heather Carmichael-Olsen</b>	"Families Moving Forward" Faculty, Psychiatry and Behavioral Sciences Research Affiliate, Center on Human Development and Disability (Seattle, WA)
<b>Deborah Robinson</b>	Sudden Unexpected Infant Death Investigation (SUIDI) Infant death Investigation Specialist and NW Infant Survival & SIDS Alliance (NISSA) Program Director (Seattle)
<b>Vicki McKinney</b>	Adoptive Mother (Mossy Rock, State of Washington)
<b>Lorri (Carolyn's Friend)</b>	Adoptive mother (Seattle, WA)
<b>Dr Sheri Hills (PhD, LLC)</b>	Early Childhood Policy Specialist Developmental Psychology, Speech-language Pathology and Infant Mental Health,
<b>Lenora Lee</b>	Advocate & Case Manager Kitsap Parent, Child Assistance Program (PCAP) Kitsap County, WA
<b>Ginny Wright</b>	Co-Chair, Hawaii FASD Taskforce and Adoptive mother 6 <sup>th</sup> World Indigenous - Healing Our Spirit Worldwide Conference Presentation, (Hawaii, USA)
<b>Nicola McDonald (New Zealand)</b>	Sudden Infant Death Syndrome (SIDS), NZ 6 <sup>th</sup> World Indigenous - Healing Our Spirit Worldwide Conference Presentation, (Hawaii, USA)
<b>Native Indian Community Visits</b>	Indianola, Kitsap County Suquamish Reservation Unofficial visit – Coushatta Reservation, Louisiana

## **5. MAIN BODY**

My personal interest in FASD came about when I attended an Aboriginal Health Workers Conference in Adelaide around 2002, where I heard presenter Lorian Hayes speak about the ‘Grog Babies’ Program; a Fetal Alcohol Syndrome (FAS) educational program developed for the Aboriginal communities in Queensland. I was astounded by this new found knowledge [FAS a serious health condition that will potentially destroy our children, families, communities, our language and culture; and until then I had never heard of it; even though I had worked in the health field for a number of years prior to this learning]. As Lorian further raised our awareness of the effects by showing us the FAS manikin (doll) with distinct facial characteristics; my heart sank – I saw the face and the small framed body of my little niece in that doll; it brought tears to my eyes. There were so many of my own family members and friends that were drinking through their pregnancies and were unknowingly putting their children (our future) at risk of permanent damage. This was to mark the beginning of my FASD journey.

### **5.1 ABORIGINAL PARENTING PRACTICES**

To set the scene I'll start with the Aboriginal perspectives which forms the basis of this report.

#### **5.1.1 Aboriginal (Australia)**

Information in this section relates to my own knowledge and experiences, which spans over 40 years including stories told to me by my grandmother. Birthing and nurturing babies was always the responsibility of the women and strictly considered “women’s business”; the fathers weren’t involved but were alert and stayed close by. Aboriginal women in communities were skilled traditional midwives (unqualified by Western standards but very skilled in the Aboriginal ways). They performed deliveries in the birthing place usually under shady trees sometimes near a river. Although this is no longer practiced there are communities especially in the remote regions who are keen to have their own birthing centres to support the women in their communities and prevent anxiety, loneliness, isolation etc that mothers-to-be endure when having to give birth in rural towns sometimes 300 kilometers away from home and family. A documentary on Halls creek women in 2004 and the comparison model of the Inuit people in Alaska named ‘Birth Rites’ is one that tells this story<sup>5</sup>. In terms of nursing; mothers would breastfeed the babies and if for any reason a mother was away working or had passed away whilst still nursing (breastfeeding), another breast feeding mother/relative would nurse the child and

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<sup>5</sup> This documentary was shown on SBS, 2004 and is also a video; reviews from some viewers:

<http://www.essentialbaby.com.au/forums/lofi/version/index.php/t97127.html> . See also recent article on similar topic in reference number 39.

the responsibilities were shared among the family to raise the child. Aboriginal babies and children were often nurtured not only by the parents but their extended family (biological and through kinship – information on the Pilbara kinship system<sup>6</sup> can be found on the DIA website at [www.dia.wa.gov.au](http://www.dia.wa.gov.au)). Babies would be carried in a long oval shaped, hand curved, wooden dish lined with paper-bark, known as the 'coolaman' so they were safe and to keep their backs strong. In the Pilbara where I was born and raised; the 'yandy' (a multi-purpose apparatus, similar shape and size to the colaman generally made from tin or aluminum), was used to also carry young babies; although their main purpose was to separate the minerals from the dirt eg: gold, tin etc. As the child grows and becomes a toddler (and older) they are carried in the mother's arms or on the back with the mother's arms and hands as the secure seat; this is probably better known in general as "piggy backing". Fathers and the men would take up their roles and responsibilities once the boys grew a little older (the age varied); the men would then begin their teaching to pass on their hunting skills etc.

In terms of sleeping babies – In Aboriginal families, babies sleep with or close by their mother (in or near parent's bed) for monitoring, easy rousing, easy feeding, nurturing and bonding. I remember an elder (my aunty) saying if a lactating mother needs to be away from her young baby for a lengthy period; the baby will be calmed by having a piece of her recently worn clothing (a blouse, dress etc) nearby; the baby smells the mothers scent and is calmed by it. As a mother of four children I found this piece of advice to be absolutely reassuring and true. I was told by a FASD expert and Foster parent also, of a real life story in the USA, where this also worked for a child with FAS – in this case, the carer (who was an older adult sibling of the baby with FAS); wore the mother's blouse, sat in the same chair and nursing position, while bottle feeding the baby. In the current climate though, this teaching or advice (leaving the garment in the cot or bed with baby) may be challenged especially given the Sudden Infant Death Syndrome (SIDS)<sup>7</sup> research and messages from SIDS experts and educators.

As an Aboriginal person I am fully aware of the difficulties experienced by Aboriginal people that have large families and our requirements to honour cultural responsibilities eg: caring for extended family if and when the need arises. This almost always means living in overcrowded conditions and having to share home space eg: children giving up bedrooms to adults while children share makeshift beds in the lounge. Many Aboriginal people have more than two children so even without extended family, the children are required to share rooms and beds. Parents may not be able to afford cots for babies so babies sleeping in bed with mum, is still and will probably remain common practice.

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<sup>6</sup> Kinship Systems – Australian Aboriginal structure determined by descent for marriage relationships. See Reference.

<sup>7</sup> See SIDS and Kids Reference number 5.

I acknowledge that in other parts of Australia, other ways and means may have been used to birth and parent children however, due to time and resource constraints I was not able to research and gather additional information or stories from other areas.

### **5.1.2 Native Indian and First Nations**

On my trip around the United States of America and Canada, I was met consistently with the common stories about the importance and significant use of the cradle board (layered with soft cushion known by the Ojibway nation as 'Tikkanaagan')<sup>8</sup> is used to carry and sleep the baby. The baby is swaddled securely and strapped to the cradle board to keep their legs and back straight. It provides a great opportunity for enhancing their vision, hearing and stimulates their senses; it also helps strengthen their neck muscles. It is also the Native Indian and First Nations people's belief that the baby in this position views the world through similar eyes to their parents and family; they are never unhappy or stressed; and babies are known to sleep longer, snuggled in their cradle boards. As I travelled and had the privilege of going into people's homes, I was excited to see (in one home in particular in the US), two cradleboards hanging on the wall in the lounge room; made specifically and used for twin boys who are now of pre-school age. To me this signified the pride of these culturally significant boards.

## **5.2 Cultural Practices/Experiences**

I had the privilege of seeing first hand some of the strong spiritual and cultural practices of the First Nations and Native Indian peoples in Canada and the United States of America. Soon after we arrived in Washington state (USA) we were taken to the Suquamish Reservation to see the local POW WOW where many beautiful dances, drumming and songs were performed by not only the local tribal members but visiting competitors from other parts of the US and Canada. The days were structured as such that they had native memorabilia and native foods for sale; a massive feast of salmon and wild rice (free of charge) to share with the people; a canoe race for the men; various competitive categories of dance (in full regalia) eg; toddler, young children, youth, adult and an elders category. There was the Intertribal dance where everyone was invited to participate in a fun dance. It was amazing to witness the amount of respect displayed for each others stories and songs. Although they shared the same spiritual beliefs (that everything starts with and is given by the Creator), their stories, songs and artwork varied to tell their individual tribe's stories. The men took turns in drumming for their tribal groups and the ceremonies were extremely harmonious. It was at this particular gathering that I first

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<sup>8</sup> See Reference number 6; pronunciation of 'Tikkanaagan' sounds like 'tikanogan'

witnessed the use of the cradleboard – a grandmother (whom we met and had spent much valuable time with) had handmade this board for her new grandchild (whilst awaiting the baby’s arrival into this world). On the day of this ceremony, the baby was one week old and she was taken onto the floor, strapped securely to the cradleboard and in her grandmother’s arms for her very first intertribal dance; baby slept peacefully throughout the whole process despite the loud singing and heavy drumming – which in their culture is likened to the heart beat. According to this grandmother, it is tradition for the children to start their learning journey and have a significant place in ceremony as early as possible. Without question, the grandmother gracefully assumed her teaching role which was one she noticeably enjoyed. Overall, it was great to observe the importance of early teachings and how precious the children were to these Native Indian tribes at this magnificent cultural event; even significantly so, those that carried obvious scars of the affects of alcohol. People including the children participating in the dance event were treated with utmost honour and respect.

While in the USA I learned of another spiritual significance; first from Carolyn Hartness and then others, that there is a council of ‘Thirteen Indigenous Grandmothers’ from various parts of the world. Each of these Thirteen Grandmothers received this same ‘vision or dream’ which weighed heavily on their hearts: *‘the earth is in trouble, she is crying - the earth and her children are suffering great pain’*. Carolyn mentioned that the Thirteen Indigenous Grandmothers came together at a recent gathering to speak of their dream, share about their concerns and seek guidance and healing from the creator. I was very interested and wanted to learn more about this gathering. I searched the internet and found additional information regarding their progress: a book recording their narratives and a movie documentary titled *‘For the Next 7 Generations – 13 Indigenous Grandmothers weaving a world that works’*, which records their travels and information on the gatherings; both of which I have not yet viewed.<sup>9</sup>

In Canada we were treated to a more intimate welcome ceremony by an Ojibway family. After we arrived in Winnipeg, Manitoba I was met by Linda Dano- Chartrand (an Ojibway woman), who was my key contact in Winnipeg. We visited various places in Winnipeg including Ka Ni Kanichihk Inc, (a First Nations Resource and training type centre),<sup>10</sup> where I met Executive Director, Ms Lesley Spillet (a First Nations woman). Ka Ni Kanichihk Inc., provides Aboriginal specific programs and services to First Nations people, focusing on their overall wellbeing and building on their strengths and resilience – ‘to help them to help themselves’. Program types provided include: youth, women’s, children’s,

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<sup>9</sup> See References number 7.

<sup>10</sup> Ka ni kanichihk (pronounced Ga Ni Ganichick) means ‘those who lead’. See Reference number 8.

employment, training, courses etc. Lesley said: *“we look after our own people, including the ones that everyone else gives up on; we [Ka Ni Kanichihk staff and council] never give up on our people”*.

It was while we were having a guided tour of the Ka Ni Kanichihk centre that Lesley presented me with two long plaits of ‘sweet grass’ (a sacred plant) and a beautiful ‘eagle’s feather’. Lesley explained that sweet grass has many traditional uses such as medicine, tea, binding for baskets etc). Linda said *“to receive an ‘eagle feather’ as a gift is the highest gift one can receive in First Nations culture; many people go through life without receiving one; to receive it, it is considered by the First Nations people to be of high class honour”*. Linda congratulated me on being a recipient of this significant gift.

Linda took us on an outreach trip to the Rolling Rivers Reservation in the west region, three hours from Winnipeg, where she had arranged for me to meet with First Nations women - the committee of the ‘Reclaiming Our Voices’ program (ROV). On our way to the meeting, we stopped at the Buffalo (Tatonka) pound where she told us the significant stories of this magnificent beast. Linda also shared Ojibway stories with us about the medicine trees and animals; Linda handpicked two fresh branches of sage (another sacred plant) from the bush and handed them to me, she said, *“this is medicine for women, I [Linda] picked one for you and one your daughter, you take it home for her [I felt very privileged – again to receive a gift of native significance]; men use sage for smudging (which is now permitted)”*. She went on to tell me that sage has many significant uses: as well as smudging for spiritual cleansing it is a food, a medicine used for healing and a cure for different diseases and health problems.

When we arrived at Rolling Rivers Reservation, the women were waiting for us with the most amazing spread of traditional foods (sweet rice, pink salmon, fish cheeks & Bannock – Indian bread) and a welcoming prayer. As the special guests we were served first and felt very privileged to share in this amazing feast. Before going into the official part of the meeting, I was given a Indian designer skirt and shawl to wear and my husband and I were taken out into the beautiful sunshine with the local lake as the backdrop to our ceremonial meeting place; the women invited me and my husband into the centre as they formed a circle around us. As a group, they agreed to sing us “the bear song”. They drummed and sang harmoniously in unison in their traditional language (I believe to be Ojibway) – to welcome us to their country, into their community and more intimately into their fold. It was the most amazing welcome we had ever experienced. We immediately felt a sense of belonging – a sense of spiritual connectedness. After expressing our (mine and my husband’s) heartfelt thanks for the beautiful welcome, I was taken back in to the room where we commenced the meeting and because the ROV is women’s business, my husband was given a book to read (by Stella, CEO) and invited to settle where ever he felt comfortable – he sat on the outside bench, overlooking the lake. Once our ROV meeting

was over, the First Nations women tried to encourage us to stay the night so we could share in cultural exchange eg: experience sleeping in a Teepee; tell stories (yarns) around a fire and further sightsee around their Reservation. Unfortunately though, due to time constraints and not having our own transport, we were unable to accept their warm and friendly invitation and so returned to Winnipeg.

Another amazing experience we had: on the Sunday before we were due to leave to travel back to the USA, we were invited to Linda's brother's house to share in a feast with their family. Linda picked us up from the hotel and we arrived at her brother's house to find a group of people we soon learned were family relatives, a few family friends including some Native Indian men who were part of her brother's drumming, singing, sun dance and sweat lodge group that performed ceremony in and around Winnipeg. Before going in to share in the traditional feast, we were invited to a room where the group of drummers took their place and we were strategically seated where we could share in the experience. They began with the singing and rhythmic drumming, which was amazing and created a very powerful presence. From the older to the younger men they drummed; each one knowing his place - when to sing their part and when to stop for the others to take their part – it was spiritually and emotionally enlightening. I was fascinated by and learned from this experience: that they had a strong sense of pride in the use of their traditional language and practice of their culture; and how they encouraged and involved the young men as well as welcoming the support of the women with the utmost shared respect especially for the Elders. We witnessed the fun and the seriousness of their actions; being Aboriginal ourselves we could appreciate their times of 'humour' and their timely switch to 'honour' and 'respect'. The women usually play a significant role in these events by dancing to the songs and beat of the powerful drums. However, due to the limited room space were not able to actively participate at this time. After the scrumptious feast and some much appreciated funny stories highlighting the humorous side of their lived experiences (not dissimilar to our own), we were invited to join the group in the front yard of the home where we were again asked to stand together and to our great surprise me and my husband were wrapped in a handmade Indian blanket (featuring bear design) and were culturally welcomed and accepted as members of this amazing Ojibway family. I was left speechless! It brought tears to my eyes as I felt the immediate connection to the very people that until today were total strangers – but strangers to be no more; they called us 'family - we were now a part of them'. Linda's brother explained that he was given this blanket that was made by his older sister and he felt the need to pass it on to me and my husband. This (the giving of gifts) I learned was very common – a spiritually lead practice in First Nations culture. Linda shared with me, a teaching from her grandmother: "*when you are given a gift it is not yours to keep, you hold it for a time and then you must pass it on to another – you will know*" [meaning you will be spiritually lead to give it to the right person] - amazing wisdom and an absolute honour!

During our journey we were able to share our own Australian cultural knowledge and experience with our Native Indian and First Nations brothers and sisters – it was an amazing cultural exchange. We shared stories, including the Aboriginal humour, and presented them with gifts although to us now these gifts seemed less significant; they were not connected to stories handed down etc, they were only what we had purchased for the occasion, prior to leaving Australia. A great lesson learned was that receiving a gift that has pure significance means a lot more than something purchased from a shop; the recipients however, were honoured to receive them (regardless) and shared their appreciation.

### **5.3 Alcohol**

Alcohol as I learned from my own family and community was never a part of our Aboriginal culture; it was first introduced to Aboriginal people in our community in the 1960's when Aboriginal people were awarded Citizenship rights - giving Aboriginal people rights to enter hotels, to purchase and to consume alcohol – this also became the birth of many problems still suffered by our people and communities today. I remember my grandparents (and parents) saying *“our [Aboriginal] people were ‘hard workers’, always clean and dress up; strong family people, until they hit the grog”* a sight I'd witnessed as a young girl growing up in a small country town in the Pilbara, to be the case. It saddens me to see what alcohol is doing to our people, but it makes me proud to see communities in the Kimberley standing up to influence change for the betterment of their people and their community.<sup>11</sup>

Dr Maggie Brady (Social Anthropologist, Centre for Aboriginal Economic Policy Research, Australian National University) researched the history of Alcohol use by Aboriginal people and produced a six part small book series titled *“The First Taste – how Indigenous Australians learned about grog”*, which was launched on 18<sup>th</sup> September 2008. On the afternoon of the launch, Dr Brady presented the findings of this research at the “History & Culture in Indigenous Alcohol use” lecture where she stated that alcohol was given to Aboriginal people during (and possibly prior to) colonization; According to Brady, records also state that Aboriginal people rejected the offer of alcohol at that time in fear of being poisoned. Brady also found during her research, that there is record of fermented drinks being made from native plants by three Aboriginal groups in Australia. These drinks apparently were low level alcohol drinks (lite beer like) that were described in records by non Aboriginal people as having mood changes and that were merry. According to the research too, there is no record of who consumed the drinks and under what circumstances these drinks were consumed. The only place in

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<sup>11</sup> See references 37 and 38.

Western Australia Aboriginal people were found to be making fermented drinks at that time was around Bunbury.<sup>12</sup>

Alcohol is a Teratogen - a toxic agent that impacts on the central nervous system and developing organs of the embryo and fetus; and can cause various forms of 'birth defects' when a pregnant woman consumes alcohol. The level of effects is dependent on the timing of consumption during pregnancy, frequency and the amount of alcohol consumed by the mother. Research experts, Maier S, and West J, state:

*The consequences of maternal alcohol use during pregnancy on the outcome of offspring depend, among other factors, on the amount and pattern of alcohol consumption. Animal studies found that binge like drinking patterns, in which the fetus is exposed to high blood alcohol concentrations (BACs) over relatively short periods of time, are particularly harmful, even if the overall alcohol amount consumed is less than those of more continuous drinking patterns. Long-term studies in humans have confirmed that children of binge-drinking mothers exhibited especially severe cognitive and behavioral deficits. Binge drinking may be particularly harmful because it results in high BACs, may occur during critical periods of brain development, and may be associated with repeated withdrawal episodes (2001).*

Even small amounts of alcohol can cause harm to the developing fetus. Alcohol consumed by the mother-to-be, passes through the placenta into their unborn baby through the umbilical cord. When the mother drinks alcohol so does her unborn baby - at equal levels. Due to the difference in body size (between mother and baby) and the fact baby's organs are not properly developed and unable to metabolise; it stays in the baby's system at elevated levels a lot longer than it does the mothers.<sup>13</sup>

As there is no evidence yet to prove the exact amount of alcohol that causes harm, the key message to promote in our Australian communities in relation to pregnant women and in pre-pregnancy is: “**Not drinking alcohol during pregnancy or prior to becoming pregnant is the safest choice**”. This is a consistent message that is promoted and supported by FASD Experts throughout the world.

The National Health & Medical Research Council (NHMRC) released the 'Australian Guidelines to Reduce Health Risks from Drinking Alcohol' in March 2009. Guideline 4 in this publication refers to Pregnancy and Breastfeeding and states: *Maternal alcohol consumption can harm the developing*

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<sup>12</sup> See Reference numbers 9 and 10

<sup>13</sup> See SAMHSA website Reference number 12.

*fetus or breastfeeding baby. (A) For women who are pregnant or planning a pregnancy, not drinking is the safest option. (B) For women who are breastfeeding, not drinking is the safest option. This guideline applies to women who are pregnant, are planning a pregnancy, or are breastfeeding.*

## **5.4 Brain**

There have been many studies done on the development, structure and functions of the brain. The brain and spinal cord forms part of the Central Nervous System (CNS). The brain is said to be the most complex organ in the body; it starts to develop in the third week after conception and continues throughout the pregnancy and beyond. Various parts of the brain are responsible for different functions; the areas that are most vulnerable and sensitive to prenatal alcohol exposure includes the Frontal Lobe, Corpus Callosum, Hippocampus, Basal Ganglia, Amygdala, Hypothalamus and Cerebellum. The table below shows the parts of the brain, the functions of each part and the problems caused by prenatal alcohol exposure:<sup>14</sup>

<b>Brain</b>	<b>Function</b>	<b>Prenatal alcohol Effects</b>
Frontal Lobe	controls impulse, judgement and executive functions such as inhibitions, thinking, problem solving, timing, planning, sexual urges	Inappropriate behaviour; poor social skills; difficulty with problem solving; unable to understand consequences for past actions; difficulty understanding concepts eg: time and money; poor decision making skills not able to control sexual urges especially in social settings
Corpus Callosum	Coordinates information between the 2 hemispheres of the brain (left and right); left hemisphere responsible for rules and logic, and the right hemisphere is responsible for impulses and feelings	Attention deficits, unable to concentrate or pay attention for too long; psychosocial problems and difficulty with verbal learning, unable to relay or explain messages
Hippocampus	Fundamental to spatial and verbal memory retrieval	Cause chronic stress, anxiety and depression
Basal Ganglia	Controls cognitive processes eg: thoughts, intuition, perceptions; learning habits,	Problems with understanding personal space, make repeated mistakes
Amygdala	Controls emotion and mental state; senses danger, fear and anxiety, recognition of face and facial expressions	Poor impulse control; unable to distinguish between a happy face and a sad face
Cerebellum	Controls balance, coordination and movement	Difficulty controlling movement; maintaining balance and fine and gross motor skills
Hypothalamus	Regulates hunger and feeding reflexes, thirst, body temperature; controls pain, fatigue and sleep	Unable to self regulate; may not know when they are hungry; have problems sleeping etc.

<sup>14</sup> See Reference number 14

FASD experts and families say that people living with FASD requires someone to be their 'external brain' (a term I believe, was first used by FASD Expert, Dr Stirling Clarren). Throughout my journey, I've also heard parents and carers (of children with FASD), say [it to be true] they are their child/children's external brain' – they're required to plan, think for and constantly remind their loved ones of what to do when etc; this is contributed to their brain damage, memory loss, difficulty with problem solving etc. I was in a FASD workshop where I heard an Australian mother talk of how she is required to phone her daughter (who has FASD), every day (sometimes 2 – 3 times a day), constantly reminding her of appointments or to ask if she has fed her baby etc. If mum doesn't ring then the daughter will call her to ask what to do, when to do it etc. This mum [grandma] had to colour code the clock with baby's feed time on it, so the mother knows when it is feeding time etc. Unfortunately due to the organic brain damage, it is the same harrowing experience for all parents and carers of loved ones with FASD.

### ***5.5 Why Women Drink***

Women of all racial backgrounds drink alcohol for many different reasons; be it for fun; to hide or shut out the physical and/or emotional pain from trauma; numbness to cope with abuse; to fit in with the crowd – peer pressure; to simply feed their addictions or to just help them survive everyday stresses. Women in the early stages of pregnancy may not know that they are pregnant and may continue to drink until the pregnancy is confirmed and some will unfortunately continue to drink despite knowing the risks. Women - no matter what their lifestyle or socio economic base, they love their children; they do not set out to deliberately harm their babies. Most women make uninformed decisions to drink because they lack knowledge and are unaware of the potential dangers.

On my Churchill journey, I planned to talk with Birth Mothers, Fostering and Adoptive Parents of children living with FASD and Adults themselves affected by and living with FASD. Unfortunately talking with Birth Mothers and Adults themselves living with FASD did not eventuate (other than my time with a birth mum in Victoria BC, who talked about her professional FASD involvement but not her personal experience). I did meet and speak with Foster Parents and Adoptive Parents, which was still very enriching.

### 5.5.1 Birth Mother's Perspectives

The closest experience I had with learning about FASD from a birth mother's perspective [albeit indirect] was to read books written by them about their personal journeys. A book I read recently called "Cheers! Here's to the Baby – A Birth Mother's Discovery of Fetal Alcohol Syndrome" by Linda Belle La Fever (USA). This book describes her life experience with broken relationships, addiction to alcohol and the struggles and challenges she endured while trying to get diagnosis, help and support for her son, who was born with FAS. Linda wrote:

*"It had been during the course of that failing marriage that I had become well acquainted with the amazing power of alcohol. Such a readily obtainable non-prescription drug with reputation and versatility to treat so many afflictions. Lonely? Have a drink! Nervous? Have a drink! Worried? Have a drink! Sad? Tired? Happy? Bored? Frightened? Depressed? Excited? Confused? Frustrated...? Have a drink! Go on numb those feelings! (pg 9).*

Australian Author (and birth mother), Elizabeth Russell who wrote three books (two of which I've read) titled: "Alcohol and Pregnancy – A Mother's Responsible Disturbance" and "Alcohol and Pregnancy – No Blame, No Shame!" Elizabeth similar to Linda describes her experience and struggles with alcoholism resulting in birth defects from alcohol exposure in-utero of her two sons, diagnosed with a FASD. In brief: the books describe how Elizabeth realized the learning difficulties her sons were experiencing, so set out to find the answers. After not having satisfaction with doctor's decisions etc she embarked on her own research journey endeavouring to get the answers and seek support. Through this, Elizabeth learned about FASD and the FASD work of experts in the USA; she made contact and liaised with these FASD experts and eventually received diagnoses for her sons, through the USA.

All three books are easy reads and give great accounts of the difficulties and struggles for birth mothers and their affected children – they talk of how they live with the daily reminder of the scars (effects) left on their children as a result of their alcohol addictions. Amazingly though, they were able to turn their devastating experiences into positives to firstly help their children live relatively good and stable lives and secondly, through their brave actions and strengths to help the many other women and families who suffer the same demise. Both Elizabeth and Linda are well known and respected FASD advocates and educators. I would highly recommend these books to people interested in increasing their knowledge about FASD (from the lived experience) and to gain an understanding of what it is like for women struggling with addictions.

### 5.5.2 Historical Trauma – Stolen Generation (Australia)

Aboriginal people are still feeling the effects of past government policies and practices that has impacted our families and communities for decades. The 1905 Aborigines Act and the Assimilation policies dictated the practices of removing our children – those that were deemed ‘half caste’, (born to one Aboriginal parent and the other a non aboriginal parent); for the purposes of ‘educating’, ‘domesticating’ and ‘assimilating’ us into Western society; all the while, stripping us of our Aboriginal identity. We (Aboriginal people) were not allowed to speak our language; practice our culture; mix with our own people – especially if we were recipients of the “Citizenship” rights, which was required in order for us to be accepted into society. Our babies were taken from their mother’s arms, picked up and taken to places that would later become their homes – either in institutions or with other unfamiliar families and communities. We’ve heard many stories told to us, of the heart wrenching pain of those directly and indirectly effected by what is now appropriately named the “Stolen Generation”. Reports, such as the *“Bringing them home - Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families”* (1997) by Sir Ronald Wilson; the book written by Doris Pilkington titled *“Follow the Rabbit Proof Fence”* (based on the real life story of her mother’s forced removal),<sup>15</sup> to name a few; tell the stories of these struggles; and among other acts of lobbying, the Aboriginal people who suffered the forced removal of children received the official public ‘Apology’ on 13<sup>th</sup> February 2008 by the then Prime Minister Kevin Rudd.<sup>16</sup> The scars of physical, emotional and sexual abuse; loss of connectedness - language and culture remains; and in many families so does the effects of the alcoholism, drug abuse and violence that were methods often used to medicate the pain.<sup>17</sup>

### 5.5.3 Historical Trauma – Residential Schools (USA & Canada)

I heard FASD Expert and Educator, Carolyn Hartness speak in her presentations and training about the Historical Trauma for Native Indian women who have similarly suffered in Boarding Schools; an experience shared too by the First Nations peoples in Canada in ‘Residential School’. At the Healing Our Spirit Worldwide (HOSW) conference in Hawaii (2010),<sup>18</sup> I attended a presentation on ‘Residential Schools’ (under the ‘Historical Trauma’ stream); that was presented by a First Nations Elder from Canada. He spoke bravely of his personal experience in ‘Residential School’, he said:

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<sup>15</sup> Also available on film “Rabbit Proof Fence”

<sup>16</sup> Unable to find transcript of speech on Prime Minister of Australia’s website, but see Reference number 20.

<sup>17</sup> National Library of Australia - <http://nla.gov.au/nla.aus-vn672744-2x> and the Policy of Assimilation [http://asset0.aiatsis.gov.au/webclient/StreamGate?folder\\_id=0&dvs=1295241291895~247](http://asset0.aiatsis.gov.au/webclient/StreamGate?folder_id=0&dvs=1295241291895~247)

<sup>18</sup> HOSW is an International Indigenous Conference to showcase programs and services that improve Indigenous life outcomes.

*"I was the third generation from my family to go to Residential school. I was a day scholar; I went to the school during the day and then went home at night. I was abused by three men and one was the ...[title given, but withheld here].. during the lunch time; we had to go back to school as if it had never happened; we were told to never tell; no one would believe us; we were no good for nothing; if we told we would go to hell and burn. (Name of Presenter also withheld).*

He went on to talk about how he turned to alcohol, drugs, violence, criminal activity (for which he was often incarcerated); to try and numb the pain. It was an emotional experience for the audience. It brought tears to my eyes to sit, listen and look as he described the sexual and physical abuse (he suffered as a child) and how he and the other boys while hearing the actual abuse on others taking place in one room; prayed in another, that they would not be next. To see this tall, thin framed man, that bare the scars of his past with ill health evident by his small quick breaths between words - the obvious outcome of the 30+ years of hurt and pain from the abuse inflicted upon him (and his body) throughout life; was a real testimony. Although physically frail, spiritually and culturally he stood strong, speaking of his life experiences to now empower others - especially the men and encouraging young people not to make the same miserable mistakes he made; even though he had opportunities to try and improve his life after Residential school<sup>19</sup>, he said he made regrettable choices – ‘a hard lesson to learn’.

The reason I included this story is not only to show the impact of alcohol but to give an example of how difficult it must be for people experiencing trauma to be good parents; to function normally when they are constantly haunted by the past experiences and pain for which they were silenced. Men struggling with past trauma must also find it difficult to be good fathers; to be good role models and teachers for their sons. The men are culturally relied upon to teach the boys especially the young men to be good hunters and providers, a responsibility unfortunately we rarely see now; given the horrific influences of drugs, alcohol violence and sexual abuse in our communities.

## **5.6 What is Fetal Alcohol Spectrum Disorder (FASD)**

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe the four diagnosed conditions of prenatal alcohol effects on the unborn baby when a mother drinks during pregnancy. These are:

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<sup>19</sup> ‘Residential School’ is Canada’s equivalent to Australia’s ‘Stolen Generation’

- **Fetal Alcohol Syndrome (FAS)** – (1) facial abnormalities: small eyes, flat mid face, flat or smooth philtrum (area between the nose and top lip), thin upper lip; (2) neuro-developmental problems: structural brain damage; memory loss; attention problems; problems with judgement, social skills and maths - anything relating to numbers eg: time and money. They will have difficulty understanding concepts. (3) Pre and Post growth retardation
- **Partial Fetal Alcohol Syndrome (pFAS)** – (1) confirmation mother drank alcohol during pregnancy; (2) some parts of the facial abnormalities (as above) and (3) at least one of the following: pre or post growth retardations; structural brain damage or behavioral, cognitive anomalies eg: social problems, problems with maths, memory, attention or judgement.
- **Alcohol Related Neuro-developmental Disorder (ARND)** - (1) confirmation mother drank alcohol during pregnancy (2) at least one of the following: structural brain damage or behavioral, cognitive anomalies eg: social problems, problems with maths, memory, attention or judgement.
- **Alcohol Related Birth Defects (ARBD)** – damage to the skeletal system and the major organs in the body including: heart, kidneys, bones and/or auditory system.<sup>20</sup>

FASD is 100% preventable. The damage to the brain is permanent, it cannot be reversed or cured; these babies will grow up to become adults and unfortunately they will still have the brain damage and experience the same deficits. FASD is often thought to be an Indigenous problem, I've had many people in my four years of delivering FASD community education; say to me "I thought it [FASD] only happened to Aboriginal people". I can assure you FASD knows no boundaries; it can affect the embryo and/or fetus prenatally exposed to alcohol by mothers-to-be from any cultural background be they Aboriginal, non-Aboriginal or Culturally & Linguistically Diverse (CALD); and from any socio economic background including those of high status.

## **5.7 FASD Diagnosis**

At the moment there is no FASD Diagnostic Clinic in Australia which makes it difficult to accurately state the prevalence of FASD in WA. The King Edward Memorial Hospital, *Report of the Birth Defects Registry of WA (2010)*<sup>21</sup> shows there are cases of Fetal Alcohol Syndrome in WA however, no information or diagnosis of any other part of the spectrum eg: pFAS, ARND, ARBD.

Diagnosis for FASD requires a Multidisciplinary team of specialists including a Paediatrician, Psychologist, Speech Therapist, Occupational Therapist, Social Worker, Support worker and a

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<sup>20</sup> FASD Descriptions can be found on many FASD websites; however, see reference number 21.

<sup>21</sup> Recently renamed 'Western Australian Register of Developmental anomalies'

Geneticist. Professor Susan Astley from the University of Washington in Seattle, USA developed the FASD Guide for the 4 Digit Diagnostic Code (2004), which proves to be the most effective tool still being used by Professor Astley and the team at the FASD Diagnostic Clinic in Seattle. The 4 digit code has been adopted by Canada and possibly other countries across the world as the most effective and appropriate diagnostic tool for children with FASD. The 4 digit diagnostic code is a formula used to record the scores of the individual on a graph. The diagnosis is given in accordance with their overall assessment results.

On the 20<sup>th</sup> August 2010, I attended the FASD Diagnostic Clinic at the University of Washington to observe the real FASD assessments of two children (aged 18 months and 6 years). Both these children were in the care of Child Welfare; in separate family homes. It was interesting to observe the assessment process used by the professionals to assess these two children and at the same time; heart wrenching to listen to their devastating experiences and family history. Basically the day started with us (the Observers) being introduced to the Team and then being briefed by Prof. Susan Astley on what the day entailed; they were assessing the 2 young males – 18 month old in the morning and the 6 year old in the afternoon. We received a 30 minute crash course on the 4 Digit Diagnostic Code, to give us an understanding of its purpose and use. We were brought into the main room to hear members of the diagnostic team provide background information on the child, parents and family and the child’s medical and child welfare history. The team then separated and one group worked with the boy while the other worked with the parents; the Psychologist, Speech Therapist, Occupational Therapist each separately conducted their assessments on the boy (using the Bayley Assessment Tool); while two of the other professionals interviewed the parents. Once all was complete the boy and parents were reunited while the team regrouped to share their findings. It was here that they used the 4 Digit Diagnostic Code to map the results. To give you an idea of its use, below is the results of one of the assessments.

	Growth	Face	Brain	Alcohol	Pre	Post
4						x
3				x	x	
2			x			
1	x	x				

(Relates to Environment)

The graph shows he had no growth or facial abnormalities but had moderate brain damage with both pre and post natal alcohol exposure. Outcome: He was diagnosed with ARND. After the team meeting, the parents were brought in to receive the results; each professional gave an account of the tests performed and the outcome; the facilitator then gave the parents the final results and explained what this meant. The parents were then taken out to a separate room by the Psychologist, where they

were able to further discuss their child's situation and set up supports etc. The rest of the team sat around to debrief and expressed their sadness at knowing this child will be another, failed by the system; no physical disability - no supports. The other boy did not receive diagnosis of FASD (due to difficulties with accurately assessing developmental stages due to age); he was recommended for further assessment in the future.

On my visit around Canada and the United States people talked about diagnostic clinics and mobile diagnostic clinics that operate throughout the states and provinces. It is believed that FASD can be diagnosed in any community that has access to a FASD trained team of professionals (as above). Prof. Susan Astley will assess people for FAS (that can't attend in person) at the FASD Diagnostic Clinic in Washington; by using photographs of the individuals face and a detailed record of the person's history including confirmation of mother's drinking during pregnancy (if known). It is proven through recent research that the face is formed on the 20<sup>th</sup> day after conception and there are specific effects that are solely related to exposure to alcohol.<sup>22</sup>

### **5.8 FASD – Primary and Secondary Disabilities**

As mentioned above, any person with FASD will experience various problems depending on the level of damage done and to what part of the brain; the unsettling truth is that they will have permanent irreversible brain and/or structural damage. People with FASD are born with primary disabilities and without early intervention, will later develop secondary disabilities that are linked to primary effects. The table below outlines the primary and secondary disabilities and the environmental factors of FASD.

<p><b>Primary Disabilities</b> include:</p> <ul style="list-style-type: none"> <li>• memory loss,</li> <li>• problems with verbal memory</li> <li>• Problems understanding and expressing emotions</li> <li>• difficulty distinguishing between reality and fantasy,</li> <li>• not understand concepts – they are concrete processors,</li> <li>• a low IQ (although some will have normal to high IQ – and because of this, will struggle to get support services etc),</li> <li>• poor impulse control and</li> <li>• poor judgement.</li> </ul>	<p><b>Secondary Disabilities</b> include:</p> <ul style="list-style-type: none"> <li>• Mental Health Problems eg: depression, anxiety etc),</li> <li>• Learning difficulties in school – don't understand concepts so will struggle with maths, time and money,</li> <li>• alcohol and drug addictions</li> <li>• trouble with the law – commit crimes from petty to serious – again not understanding concepts and that actions have consequences</li> <li>• Repeat offenders</li> <li>• inappropriate behaviour - victim of or perpetrate sexual abuse</li> <li>• difficulty living alone – eg: because of memory</li> </ul>
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<sup>22</sup> See reference number 24.

<p><b>Environmental Factors</b> that also has effects include:</p> <ul style="list-style-type: none"> <li>• Sensitivity to lights</li> <li>• Difficulty with hot and cold</li> <li>• Noise levels</li> <li>• Crowds and lots of movement</li> <li>• Difficulty with changes to their environment</li> </ul>	<ul style="list-style-type: none"> <li>• employment – difficulty getting a job and keeping it</li> <li>• inability to take and respond to more than one or two instructions at a time</li> </ul>
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Children in our communities that display these types of behaviours; and there is knowledge that the mother drank alcohol during pregnancy – even with no diagnosis; should raise alarm bells [for parents, carers and services] that show ‘these children need extra help and support; they will experience learning difficulties’ so the stronger their support, the better their life and learning outcomes. For children already in care with the Department for Child Protection; could more than likely mean that the parents too are, or may be affected; this was consistently mentioned to be the case throughout Canada and the USA. These parents will need the same type of nurturing and support to assist them with parenting.

Despite people with FASD experiencing these difficulties, FASD is currently not included as a disability in the Diagnostic and Statistical Manual on Mental Disorders (known as the DSM-4); a concern shared across Australia, Canada and the USA. The manual is currently being reviewed and Version 5 is due to be released in May 2012 according to NOFAS in the USA and the following submission and support from FASD organization, the committee is deliberating the inclusion of FASD in the new version.<sup>23</sup>

### **5.9 FASD Prevention**

The best form of FASD prevention is that pregnant woman not drink alcohol prior to or during pregnancy. However, we are also aware that many women still do not know about FASD or know that they are pregnant so will continue to drink. Canada and the United States have developed a number of resources to help promote the message in communities about the importance of not drinking during pregnancy etc. The BC Centre of Excellence for Women’s Health, British Columbia, Canada through the BC ActNow, Healthy Choices in Pregnancy Initiative; developed a host of resource materials to promote the prevention messages across the Province. In Australia although we have had the Telethon Institute for Child Health Research ‘Alcohol & Pregnancy Project’ resources promoted in the health sector there needs to be a stronger focus (I believe) on a state and maybe even a national FASD media campaign to help raise the awareness to prevent our children from being alcohol damaged. The WA Drug and Alcohol Office is in the early stages of implementing a state-wide FASD

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<sup>23</sup> DSM 4 is the manual used by American Psychiatrists to diagnose mental health, see reference number 25.

project<sup>24</sup> that aims to address the Indigenous needs however, there needs to be a strategy that will also address the needs of non Indigenous peoples through a large scale campaign – as I alluded too earlier, FASD is not an Indigenous only issue.

## 5.10 FASD Intervention

Carolyn Hartness (with 20+ years of working with FASD) says the behaviours displayed by people with FASD is their way of trying to communicate. It is often misread and labeled as ‘bad behaviour’ or ‘bad parenting’. Carolyn used a great example in one of her education sessions here in Perth when she said: “*the teacher doesn’t ask a blind child to read the blackboard, why do they ask or expect a child with organic brain damage to sit and concentrate through the lesson*”; people with organic brain damage will always experience learning difficulties. I also learned from Carolyn that people often view the behaviours of children with FASD from a negative stand point and she encouraged us to think about what it is like for them eg:

### Negative Stand Point:

- Easily irritated
- Throwing temper tantrums
- Easily distracted
- Repeat mistakes
- Confused
- Memory problems
- Hyperkinetic (Short attention span)

### Think Positive – from their perspective:

- Their brain is over stimulated
- They are overwhelmed; trying to communicate
- They are curious
- They are in the moment
- Again they are overwhelmed
- Again they are in the moment
- energetic

Carolyn developed the *Intervention Mapping – Strategies for Assisting Children Affected by Alcohol in utero (2003)*, which is used as a tool for families and professionals working with children and adults with FASD.<sup>25</sup> Bear in mind though that not all people with FASD have the same identical damage or effects – each person is different and not all strategies will work the same for every person. As Carolyn explains, the parent or carer is the best person to know and understand what works best for their loved one with FASD. The key Elements for Intervention Mapping is:

**OBSERVATIONS** – be a good observer of behavior; they are trying to communicate. Know the environment and what effects this has on them. Observe: the

- Body – (a) clothing people with FASD may experience issues with texture of clothing, tightness, looseness, seams etc. May need to cut off tags, buy clothes with no or small seams etc. (b) Food – textures, colour smell and taste of foods may be unpleasant to them or make them seem like fussy eaters.

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<sup>24</sup> See details in Section 5.20.3 of this report.

<sup>25</sup> See reference number 27

- The Brain – neurological and chemical imbalances may cause overreaction, resulting in violent or impulsive behaviours. Talking to a psychiatrist will rule out other brain disorders that may need treatment eg: medication.
- Physical Environment – overstimulation and distractions can cause behavioural changes eg: (a) crowds - too many people in the room, too many people moving about; (b) furniture – clutter, furniture moved causing disorientation, need order, need to be organised. The best way to prevent overstimulation is to create a quiet space and use soft or neutral colours with no clutter and maintain organisation.
- Colour, sound, temperature, lighting, odors and movement can cause problems so try to reduce the noise level, no flashing or coloured lights, watch and monitor their involvement with hot and cold temperatures. Those with sensory damage may put themselves in dangerous situations eg: touch flames of the fire, drink boiling hot drinks etc and not feel the burning.

STRUCTURE – People with FASD function better when they have unchanged structure in their lives. Structure includes: (a) Physical environment eg: as above – furniture, toys, objects etc can be cues for your child to remain familiar with their environment any changes to the structure can cause confusion and disorientation. (b) emotional environment – people with FASD are very sensitive to their own and other people's emotions. It is important to create a calming and safe environment. FASD educators say that people with FASD function well in prisons due to the regimented environment, set routines etc.

REPETITION – is an important aspect for people with FASD; this helps them to learn. They need to be continually told and shown how to do things, when to do it; this is an ongoing life long action that is required due to their organic brain damage.

CONSISTENCY – environmental consistency – again unchanged physical cues, use of pictures or diagrams help them remember where things go or with matching words eg: put a picture of a sock on their sock draw, put a picture of them on their placemat at the table where they sit so they remember that is their seat at the table etc. Routines are extremely important and must not be changed, otherwise they get confused and will not remember what to do.

BE CONCRETE – people with FASD operate with concrete processing and do not understand abstract concepts. Give them one simple instruction at a time and they will achieve the outcome and find it easier to operate. A very strong piece of advice stuck in my head from a conversation I had with Carolyn last year: she said never start your sentences or instructions with 'no' or don't; she also said

you always tell the child what you 'want' them to do and not what you 'don't' want them to do eg: if they are running in the house – don't say 'don't run' say 'please walk'; they will always remember the last word you said so they will do just that. This takes a lot of practice for parents and carers to remember but it works well with people with FASD.

REWARDS, REDIRECTIONS AND CONSEQUENCES – People with FASD need constant reinforcement to learn good behaviours. Rewards should be given immediately after they achieve; the same with discipline – if a child with FASD has done something wrong that warrants discipline, the consequences should be given immediately otherwise they may forget what they are being punished or disciplined for causing great confusion and a sense of failure on their part etc. If a child with FASD does something that puts them at risk or is repeatedly doing the wrong thing; redirection will help them to learn not to do it; but one must remember that each environment is different for them and what they learn in their home will not make sense to them when they are in another environment or place – eg; grandmas or day care etc. Punishment for bad actions is not always the best way to discipline children with FASD, their actions are always impulsive and their brain damage doesn't allow them to remember the past – **'they [people with FASD] live in the moment'**.

Suzie Kuerschner (USA) talked extensively about the importance of early intervention and how it helped her daughter achieve exceptional outcomes. Although she is still required to provide regular support to her daughter (who is happily married with a daughter of her own) it is from a distance and only as and when required. Through Susie's intervention, her daughter was able to break the cycle of FAS and have a baby that was and is not exposed to alcohol. There may also be other intervention strategies of which I am not aware.

### ***5.11 Child Death Reviews - SIDS and SUDI***

In my current role with the Ombudsman WA, Child Death Reviews (CDR) Team, I am learning more each day about Sudden Unexpected Deaths of Infants (SUDI) and Sudden Infant Death Syndrome (SIDS). Given what I already knew about FASD; that alcohol affected babies have difficulty rousing and now see in some cases (as recorded in departmental files) that the mother consumed alcohol during pregnancy; I was keen to know if there was a correlation between the three (SUDI, SIDS & FASD) or if there was any research that could shed light on the topic and better inform our work.

In the state of Washington USA, I was very fortunate to be linked with a few key people involved with SIDS and SUDI in King and Kitsap Counties. I met firstly with Tom Stokes, Administrator with the Department of Social and Health Services Children's Administration who gave me an overview and the history of the Child Death Review functions across Washington. The Health Dept previously funded

each county to do their own Child Death Reviews but the funding recently ran out so most CDR's ceased. Kitsap County however, is one of the few that is still operating. I explained to Tom that I was interested in finding out if there were any studies to show correlations (if any) between FASD, SIDS and SUDIs. Tom was not aware of any specific research but talked about the Child Fatality Data for the state of Washington – a report on Health Department data pulled together from death certificates etc. He explained that Dianne Pilkey did the state-wide study mapping fatalities and compared it with other counties with similar populations and military bases eg: Pierce County (Suhamash, Spokane), Bextar – Texas Arizona, Kitsap County, and King County. It covers Mental health crisis, substance abuse (although it didn't map what type of substance), addresses, services, prisons, police and domestic violence (not separated out); were some of the key indicators for the data collection.

I later briefly met with Barbara Smithson, Department of Health, Kitsap County and she explained they are now discouraging the use of baby swings and are no longer allowing day care centres to use them. She said they are encouraging parents to bring in and use 'cradle boards' instead; they are introducing the co-sleepers that has a piece that slides under the mattress as an extension to sleep the baby to encourage safe sleeping, easy feeding and mother/baby bonding; she said 'the American Academy of Paediatrics is saying not to have babies sleeping in the bed with you'. Barbara suggested I meet with Deborah Robinson – SIDS Foundation of Washington, who is working with agencies to do better CDR recording etc. There is a focus to get detailed information on SUIDI Form from the Coroner; Emergency Medical Technician, "Scoop and run" – Evidence of the scene; getting protocols in place to keep the scene intact; and how the family becomes a part of the scene. They are linked into the National Database to look at data across the country. Reviews are done monthly in Kitsap County.

Finally, in my brief but very interesting meeting with Deborah Robinson, I learn from a snapshot view, about her involvement with Sudden Unexpected Infant Death Investigations (SUIDI) and SIDS and that she was aware that babies with FASD have difficulty rousing however, was not aware of any research relating it to SUIDI or SIDS. Deborah talked about the "Back to sleep campaign" and the Cradle Board Classes they do (and strongly advocate) with Native Indian communities; she said as well as mothers, they have Grandmothers involved and now dads too are coming. Deborah provides training to professions on effective ways to investigate the death scenes, how the family are a part of that scene, how important it is not to contaminate the evidence of that scene – by removing the baby (known as Scoop and Run) etc, Information about the Sudden Unexplained Infant Death Investigations - *A systemic Training Program for the Professionals – Infant Death Investigations Specialist training and SUIDI* can be found at [www.suidi.org](http://www.suidi.org). Deborah didn't go into too much detail (due to time constraints) but she mentioned briefly, the way they perform an Autopsy has not changed

but how they investigate deaths is changed; there are five aspects which include: Accident; Homicide; Natural; Suicide and Undetermined. Deborah also talked about the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), which according to their website 'is a not-for-profit organization that is leading the world in discovering evidence-based preventive measures for stillbirth and infant death. ISPID is working to promote improved quality and standardization of care for affected parents'. Further information can be found on their website: <http://www.ispid.org>.

Additionally, after an internet search on FASD and SIDS, I found (albeit limited) information on the Prenatal Alcohol, SIDS and Stillbirths (PASS) Network established by the National Institute of Child Health and Development (NICHD) and the National Institute Alcohol Abuse and Alcoholism (NIAAA) 'to develop community linked studies for investigating the role of prenatal alcohol exposure with the risk of SIDS'. PASS consists of a team of world experts in the field of FASD, SIDS and Stillbirth; that contribute their expertise to various research topics. I read briefly of a current study being done by the PASS Network on the 'Safe Passage' a two phase study on two sites including Northern Plain Indians (North & South Dakota, USA) and Capetown, South Africa. Phase two is scheduled to finish in 2011.<sup>26</sup> It will be interesting to find out more about this study to see if there is anything in our Child Death Review field of work that we could learn from it.

Although SUDI and SIDS is relatively new to me and was not the strongest focus of this study, I was able to understand and relate to the issues each one talked about. The points I found most interesting and wanted to learn more about was the national CDR data base, the comparative studies and sharing of information across the counties which is something I believe we don't currently have in Australia or at least WA. It will be interesting to learn from my colleagues back home (WA) if a national CDR database etc would be a useful tool for our work and if so, could potentially put in place.

During my Churchill Fellowship journey I had the privilege of attending the 6<sup>th</sup> International Indigenous Healing Our Spirit Worldwide (HOSW) Conference in Hawaii. At this conference I attended a SIDS presentation delivered by Nicola McDonald from New Zealand. Nicola started her presentation with the Maori history (with fluent use of Maori language followed by an explanation in English); and the struggles they endured as a result of colonization - "*the signing of the Treaty with the British Crown*" eg: not being able to speak their Maori language and how there was corporal punishment for those that were found doing it. She also went on to talk about the spiritual stories of how the Maori 'breath of life' came about and this tied in to her talk about the importance of nurturing their babies and helped set the scene for her SIDS presentation. Nicola was supported by Co-Presenter who weaved a small basket for the 'after birth' to demonstrate Maori beliefs that what you talk about and how you feel when

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<sup>26</sup> See reference number 28

weaving it, is spiritually incorporated in the product and will envelop the baby, their aura and influence their feelings and being. The weaving is again becoming a significant practice for Maori, not only as a teaching tool to pass on culture but to safely sleep their babies to eliminate SIDS. Nicola went on to say:

*“In the 1920’s our mother infant care practice was greatly changed with the introduction of Plunket and the introduction of Truby King who came from the UK. At that time, all mothers were told to sleep their babies face down, and this is a practice that is still prevalent amongst some Maori communities. Also at that time, Maori mothers were told to send their babies down the end of the room and not to sleep with their babies. It is a customary practice for us Maori to sleep with our Pepi [babies]. When we nurture our babies at our breast, our babies hear the heartbeat of mother and know that they are indeed atanga [a treasure to behold]. To actually have practices that cut across that practice meant that babies were sleeping on their own”.*

Furthermore;

*“During the 1980’s and 1994, there was a SIDS global issue; right across the world we are starting to see a huge number of babies dying of SIDS. For non-Maori, you can see here that there were 3.6 per 1000 live births; for Maori, it doubled that number, what that meant was that we needed to look at establishing a Maori intervention program in 1995 to address that; in 1995 and 2005 Maori SIDS launches a mass SIDS local regional intervention”...”and what we can see here is the decreasing of our SIDS rates – 1984 – 2002, we went from 9.9 – 2.34; there was one single thing that we did that changed that rate; there was one message – that message was “Turn you baby over”. We were sleeping our babies face down and we said to all our mothers, our communities, our tribes, you must turn your baby over. In that period of time that was the absolute reduction that we saw. What we also see though, is that from 2002 to now, we are still at 2.3, we haven’t reduced, we’ve plateaued; and there are some key reasons why that is, we are turning our babies over but we are smoking during pregnancy and we are sleeping with our babies”.*

During question time at the conclusion of the presentation, I asked Nicola if there were studies in New Zealand around the effects of alcohol on babies and if there was any correlation with SIDS; her response was that they looked at the research on FASD but found more on smoking and the risks of SIDS which was their main focus - to address smoking and SIDS.

## **5.12 United States of America (USA) – Washington State (WA)**

I arrived in Seattle on the 12<sup>th</sup> August 2010 to start the epic journey of my Churchill Fellowship - my first long overseas study trip. Travelling with my husband (his costs at our own expense) meant I wasn't going to be lonely but I was certain I'd face homesickness and isolation, especially after a lengthy time away from my children (even though they're adults). This however, was the beginning and I was feeling very excited. On our arrival, we were met and welcomed by my good friend and FASD mentor/colleague, Carolyn Hartness. Carolyn insisted we stay with her in Indianola so she could return the favour - in 2009 I had arranged FASD meetings and training for (and hosted) Carolyn in Perth to assist me in writing a FASD manual that could be used within WA to raise awareness and as a training tool for workers. The manual however, was reworked and produced as FASD Resource for parenting rather than a training tool.<sup>27</sup>

## **5.13 Collaborative Circles of Care**

During my time in the USA, Native Indian people (including Carolyn Hartness and Suzie Kuerschner) talked about the 'Collaborative Circles of Care'. It is strongly believed to be an essential and important concept for people with FASD. A Collaborative Circle of Care involves having 'everyone' involved with a child (or older person) with FASD; at the table or on the same page - so to speak. For example: the parents, family members (eg: grandma, aunty etc if they have regular contact with the child), carers, child health nurse, doctor, teacher etc. The Collaborative Circle of Care creates a strong network of people who are (or will become) familiar with and understand FASD; to know what is going on for the child and how best to support them. It also allows people to provide more effective support and services to the family and child.

This is a great concept and could potentially be beneficial to all children who struggle with learning difficulties and behavioral problems regardless of not having a diagnosis of FASD. It would also be beneficial for the parents and carers to know and feel they are being supported. As I learned of this concept I imagined it to be similar to the Stronger Families initiative that already exists in WA, for at risk families, where relevant services and families develop workable strategies to achieve better outcomes for children and the families.<sup>28</sup> I think of the Collaborative Circle of Care concept as being a 'yarning circle' with a wrap around approach.

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<sup>27</sup> FASD Booklet is a product of Parenting WA, Department for Communities.

<sup>28</sup> Stronger Families website <http://www.strongfamilies.wa.gov.au>

## **5.14 The Parent-Child Home Program (Seattle)**

The Parent-Child Home Program is a research based, home visiting program for 2 -3 year olds. It services hard to reach families including those with special needs, migrant families, those in poverty and who have limited access to other services. The program aims to empower the parents at home by the Home Visitors modeling good behaviour in the home; showing mothers (and fathers in 2 parent homes) how to use books and toys to teach their children; how to speak with and treat their child/children (verbal interaction) etc. The program provides early intervention and easy transition for child of the program into school based programs.

I met Annie Soustek, Parent-Child Home Program Coordinator with Southwest Youth & Family Services who invited me to visit the program; unfortunately due to a full schedule and time constraints I was not able to take up the offer. However, I did have an opportunity to be in a home when one of the Home Visitors from the Parent-Child Home Program was visiting the family. I talked informally with the Home visitor and it was interesting to learn that she herself was one of the participating mums in the program previously and after graduating, had taken her learning and experience to mentor other moms now going through the program. I learned that the Home Visitor of the program comes into the home to model good healthy behaviors, show and teach the mums to read books to their young child/children, share in playtime with toys, budget, shop, pay bills, book and attend appointments etc. This particular Home Visitor as I observed, displayed great confidence, competence and pride of achievement and had obviously built a good rapport with her client (mum with ARND).

Sifting through the material given to me by Annie, I found a quote in a Newsletter titled: “Keep our Promises to our youngest learners – Children’s Alliance”.<sup>29</sup> The quote from a participating parent of the Parent-Child Home Program (name not provided); echoed my own words and thoughts about children’s learning; *“I thought kids just learned at school, [but after this program], I noticed that kids learn at home and I can help”*. Prior to me learning about the importance of early brain development, FASD, child development stages and that parents are their child’s first teacher; this too is what I believed. Additional information about the Parent-Child Home [Evidenced Based] Program can be found at [www.parent-child.org](http://www.parent-child.org).

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<sup>29</sup> The Children’s Alliance is the voice and advocate for children in Washington; they ensure policies and programs work for children. Website: [www.childrensalliance.org](http://www.childrensalliance.org).

## **5.15 Parent, Child Assistance Program (PCAP)**

The PCAP is a home visiting intervention program which started in 1991; it is an evidence based research project to assist mothers build and maintain healthy family lives, keep children in safe stable homes and to prevent future alcohol and drug exposed births. The program was originally funded through a federal research grant but is now funded by the Washington State Legislature. The funding is provided to the University of Washington who engages other organisations to deliver the program. The PCAP in Washington State serve almost 700 families in eleven sites within the state. The program goals are:

1. assist mothers in obtaining treatment, maintaining recovery and resolving complex problems associated with their substance abuse
2. guarantee that the children are in a safe environment and receiving appropriate health care
3. effectively link families with community resources and
4. to demonstrate successful strategies for working with this population to prevent the risk of future drug and alcohol affected children.

PCAP has Para-Professional Advocates that are trained and supervised Case Managers; they work with up to 15 families (at a time) over 3 years; women who fail to achieve their goals or relapse are not kicked out of the program. The Case Manager will make every effort to find the woman; encourage her to re-enter the program and start over again with her. Case Managers will help women identify goals, and set steps towards achieving those goals, support them through the process and monitor the progress of each case. The Caseworkers selected to do the advocacy and support work have themselves overcome difficult life circumstances prior to achieving their life changing successes ie; school, jobs and parenting. It was said that 'they' [the Para-professional Advocates/Case Managers] make the best advocates for women struggling with addictions and abuse as they are realistic role models that can influence changes in these women's lives.

I visited the PCAP program in Bremerton (sponsored by Agape Unlimited),<sup>30</sup> where I met the Clinical Director (Charlene Takeuchi) and Para-Professional Advocate & Case Manager, Lenora Lee. Lenora gave us a guided tour of the centre; explained about the program and the roles of the Caseworkers. They have a small 'give away' shop at the centre for parents in need of clothes, blankets etc; a small library (containing FASD materials) that parents can use, books etc on loan; the clients files are not identifiable (no name on file, only a number); kept in centrally located locked filing cabinet; the files contain background information – ie: parent and child history and medical records. As a Research

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<sup>30</sup> Agape Unlimited is an agency to support people who are chemically dependent:  
[http://www.agapekitsap.org/About\\_Us.html](http://www.agapekitsap.org/About_Us.html) .

Program they complete surveys using program casework data to send to University of Washington for research purposes. As they deal with young parents with addictions and child protection matters, the centre has high security (deadlocked front doors etc) for the safety of staff and other clients. The program has 4 Case Managers; they do home visits twice per month at a minimum; they encourage subtle changes and model good behaviour. Caseworkers work closely with Child Welfare, the Courts (re: court orders of parents) and other Services (eg: housing etc) to support the women. The PCAP Case Managers have Mandatory reporting; clients know up front and are encouraged to tell or confess themselves if they have relapsed. If not, the Advocates report to Child Welfare Services, when children are at risk.

I met with Dr Therese Grant and Dr Kay Kelly who provided me with many research papers on PCAP and explained the research behind the program. PCAP has a reporting process through the University Of Washington; Therese provides training to services delivering PCAP and has provided training on PCAP to other countries who have adopted the program; these include NZ, TAS (Hobart) and Melbourne. British Columbia has seven PCAP sites and Manitoba has one site. There are other programs developed in other areas that are based on the PCAP model.

### ***5.16 FASD - Observations (USA)***

We visited a family in Seattle and it was great to meet the people I had heard so much about. It was also very interesting to observe the many things that I heard FASD experts talk about and the way in which people (even adults) can at times revert back to communicating on a child's level. For example, we were sitting in a park one day and a young teenager came by and placed himself in the midst of us; with friendly chatter. It was clearly evident that he had intellectual deficits and was communicating at a much younger age level than that of a teenager of his stature. A mother (with ARND) who was engaged in typical adult conversations with us prior to this young man approaching; instantly switched to the excitement of talking with the teenager about digital video games that she no doubt was very familiar with and could relate too. We watched as they displayed bubbly childlike excitement and hyperactive gestures over this conversation. To me it was fascinating to watch the immediate switch of this young mum from adult to child like excitement and be absolutely comfortable with the process. The minute the young man departed our company, the young mum was again surrounded by adult conversation and had to revert back again; this appeared to be a little more difficult for her; as she seemed far more comfortable in that [childlike] environment or space. Although this was one of her "good, calm" days as her mum puts it; things could change in an instant in terms of her behaviour. We didn't witness any aggressive change this first day but we actually saw the behavioural change on one

other day that we visited her home. Although she was not violent or aggressive towards us, she was very agitated and could not for one minute sit still or hold calm conversation; very different to what we had seen and been a part of just 3 – 4 days before. It was good for me to see in person, all the stuff I had learned about the ARND condition and see first hand, what FASD educators had talked about.

### **5.17 United States of America (USA) - Oregon**

We travelled to the state of Oregon where we visited a Native Indian family and it was great to sit and talk with and listen to the stories of a Native Indian Adoptive mother; about the challenges she and her daughter (diagnosed with FAS as an infant) endured throughout her life. This Adoptive mum is a child development specialist and a well know and respected FASD expert; has written and contributed to many materials based on her lived experiences to help other mothers and families understand FASD. In a FASD information booklet (sponsored by the Northwest Indian Child Welfare Association Inc), written for Native Indians (1993), she wrote as a reflection on her daughter's life with FAS:

*“She is beautiful, bright and generous in her love, way beyond usual. She is full of vibrant energy and spirit. Sometimes her energy seems like it has no limits. Sometimes it seems as though her energy is opposite to my own and everything I am trying to do. Sometimes, my daughter's energy is so quiet, in a sad way. I can tell at these times she feels like a failure. And somewhere in between all this energy, she is cautious and observant of how to “be good.” She has a genuine desire to please those around her....my daughter has to work so hard to learn to be good. She watches, she tries, she asks. And she is broken hearted when she sees herself has having “failed.” Her strength and eagerness to learn and to please, tug at my heart; when she believes she has failed, my heart breaks” (pg 7).*

The stories are too many to record in this report but I had the privilege of meeting two of her daughters including the daughter with FAS. Given what I had learned about early intervention and FASD it was very clear from my observations that this young woman (living with FAS) was coping extremely well in her new home environment. She recently married and had become a mother to a beautiful baby girl. Her mum still provides ongoing support but from a distance, it was great to see the positive effects of early intervention compared to the other young woman who is also a good mum but struggles often, due to her condition and not having had early intervention in her life; prior to being taken in (aged in her 20s) by her adoptive mum.

## **5.18 CANADA - British Columbia (BC)**

### **5.18.1 Sheway**

I had the privilege of visiting the Sheway program in eastside Vancouver<sup>31</sup>. Although it wasn't a part of my original plan I was very grateful for the opportunity. I met with Aboriginal Support Worker (ASW) that talked about her work with the Native Indian women. One of the success stories she shared was about a young mother who lived under a nearby bridge with her baby. The woman never spoke to anyone nor did she access any services, she was extremely withdrawn and would shy away whenever anyone came near her. The ASW visited her persistently taking food and necessities and inviting her to visit the centre where she could access essential health and medical services. The ASW never gave up on her; eventually the young mother began to trust the ASW and started coming to the centre. This young mum is now a mentor for other mothers in the program – a great success story!

Sheway is a program for pregnant women; women parenting children aged under 18 months that live in or frequent the eastside area of downtown Vancouver, BC; is homeless; a street sex worker (prostitute); living in violent relationships and are drug and/or alcohol dependent. These women often lack parenting skills and experience trouble with the law; most of the women have had children removed by the Child Welfare agency due to their homelessness and other serious risks to the children. Sheway works hard to help these women make positive changes in their lives so they can have their children returned to their care.

Sheway is co-located with the Crabtree Corner<sup>32</sup> who also provides much needed services (and who works quite closely with Sheway in order to not duplicate services) to the same client group. Sheway has a number of professional staff based in the centre and when necessary visiting from other services which include: a Doctor, Nurses, Dieticians, Drug & Alcohol Counselors, Social Workers, Outreach Workers, Aboriginal Support Workers, Child Development Specialists etc., It was great to observe the staff on the day we visited, working non-judgmentally with their client group; they have a drop in centre for mums and bubs; washing facilities both for showering and laundry; stocked items such as formula, diapers, clothing for mothers and babies, equipment such as prams, cots, baby seats etc. This not only allows the workers to help meet the needs of these women and children; it also creates an opportunity for them to teach the women how to care for their children and themselves and work towards overcoming the addictions and encouraging them to make better life choices.

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<sup>31</sup> Sheway is a partnership initiative; see Evaluation Report as reference 33.

<sup>32</sup> Crab Tree Corner is a YWCA Family Resource Centre see: [http://www.ywcavan.org/content/Crabtree\\_Corner/258](http://www.ywcavan.org/content/Crabtree_Corner/258)

The ASW took us to meet staff of the various Native Indian Health Society services that are located in close proximity to Sheway that included: the Native Indian Health Service, HIV Positive Program, Drug & Alcohol Program and the Aboriginal Family & Child's Centre; where we received a brief overview of each of these programs.

### **5.18.2 Moms Mentoring Moms Program**

In Victoria BC, I met with Janet Christie and Liza Miles who explained about the 'Moms Mentoring Moms Program' and the use of Art Therapy with their client group. The Moms Mentoring Moms Program was funded for one year through the Victoria Foundation and the Ministry of Children and Family Development. The funding was provided to develop a program for mothers who were most at risk of having children with FASD. The program was developed by Janet Christie who has many years of experience in working with women with addictions and recovery from addictions. According to information taken from her website and the Moms Mentoring Moms Evaluation report, Janet has been in recovery for over 15 years and is a birth mother of a son diagnosed with FASD (as an adult). Janet is working tirelessly to help women prevent having children with FASD.

The Moms Mentoring Moms Program is an initiative of the FASD Community Circle in Victoria; the program objectives are to:

1. support women to reduce their intake during pregnancy, thus improving outcomes for their children
2. empower families by teaching them parenting strategies and life skills
3. reduce unnecessary involvement with the foster care system
4. build positive working relationships within the community
5. to build the capacity of women to mentor other women
6. develop a mentorship package and manual for other communities to use, including a training section for volunteers
7. develop a pool of volunteers to assist mentors

The Moms Mentoring Moms Program engages volunteers and mentors that have successfully recovered from similar experiences to the women in the program. In relation to Art Therapy – Liza works with women (and children) with complex lives, including women in the Moms Mentoring Moms Program. They look at the woman's maximum potential and through Art Therapy are able to take them out of survival mode. Liza talked about a boy she worked with at school who has serious behavioural problems; by using Art Therapy with him, he was able to visualise what was happening to him and this helped him understand and change his behaviour. Liza and Janet both said the mums look forward to

the Art Therapy program and they know it is a success when the mums turn up to do the session even on a pay day; they do 3 hours sessions per week - one week they will have different guest speakers come in to talk with the mums; the next week they have Art Therapy. Information on Art Therapy can be obtained from the website: [www.artsintherapy.ca](http://www.artsintherapy.ca).

### **5.18.3 SOAR (FASD) Mentoring Program – Nanaimo, Vancouver Island, BC**

The SOAR Mentoring Program<sup>33</sup> is provided by the Inter Tribal Health Authority (ITHA) and is based on the PCAP program. This program is for First Nations women (from the six surrounding tribes/nations); who have alcohol & drug addictions; is pregnant (or have children less than 6 months old) and have problems connecting to services. First Nations women living with FASD and/or has a child with FASD is also eligible to access the program. The SOAR Program has Mentors that are trained and supervised Para-Professionals that provide extensive supports to the women to assist them make and maintain positive changes in their lives; make healthy choices and to prevent future births of alcohol and drug affected children.

I met with Hanna Scriven from ITHA, who explained that the SOAR Mentors and other staff receives FASD training through FASD conferences and the Justice Dept in Vancouver. The local college also provides FASD training; Hanna stated that *“Training for everyone working with FASD is Crucial; it gives the workers a greater understanding of the issues for families and provides better practice for programs”*. Hanna talked about how crucial these programs are in order to help women turn their lives around however, she also talked about the huge gap; in this and other FASD programs; they [support programs] are always time limited; she said: *“women with FASD complete the 3 year program with 3 years of intense support and then they go back into crisis mode. There is a need for women with FASD to be referred to another program to continue receiving the support in order for them to better function and cope with parenting”* [again we see the effects of brain damage and the ongoing need for support for people with FASD – needing ‘the external brain’].

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<sup>33</sup> SOAR = Supportive, Optimistic, Advocacy & Restore

## **5.19 CANADA - MANITOBA (MB)**

### **5.19.1 Reclaiming Our Voices (ROV) – West Regions**

In 2007, I attended the International FASD conference in Victoria, BC, Canada where I met a number of world experts on FASD and learned through workshops and presentations about the many programs that are in existence in other countries to address FASD especially Canada and the United States of America. One such program is the ROV in the West Regions of Manitoba, Canada. As I sat and listened to this presentation back then, my mind travelled back to my own country (Australia) and my own community where we could be doing so much more for our women who struggle with addictions and what we could be doing to help them keep their children safe. I was amazed at the information that was being conveyed at that time; from memory, *a third of the children were prevented from going into welfare care and almost a third were returned to their mothers/families because their mothers had turned their lives around as a result of participating in this significant program. The gathering, which was funded by the West Regions Child & Family Services (WRCFS) cost approximately \$60,000 for 200 women to attend a 3 day gathering. According to presenter Dr Kathy Jones (WRCFS), it cost the provincial government over three times that much per year for one child in care*<sup>34</sup>. One of the critical aspects of ROV is that the child welfare workers participate in the gathering with the women as a mentor and role model rather than a case worker; this helps the women to build strong relationships and rapport with the workers (in their community) and to help achieve positive outcomes to start rebuilding their lives. I found this quite interesting so was keen to find out more about the program. The Churchill Fellowship provided the opportunity for me to visit Manitoba and find out more about the ROV program. Fortunately I had kept in regular contact (since 2007), with the key persons involved with ROV, which made it easy for me to arrange the visit.

Manitoba was to be the last province for my visits around Canada and one that I was extremely looking forward too. A few days after I had arrived in Winnipeg and on schedule, we were picked up from my hotel by Linda Dano-Chartrand (ROV Chairperson & West Regions Child & Family Services Officer) and taken out to Rolling Rivers Reservation, which is where the West Regions Child & Family Services main office is located. Linda had arranged for me to meet with the ROV committee and talk with them about my fellowship and hear from them, their perspectives on ROV. As I explained earlier in this report, on arriving in Rolling Rivers we were greeted in the most spectacular fashion – the warmest First Nations traditional welcome! After the cultural aspects were complete, we sat and started to yarn about the ROV. Linda explained to the women that I was here on a Churchill

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<sup>34</sup> 2<sup>nd</sup> International FASD Conference, Kathy Jones Reclaiming Our Voices Presentation, 2007

Fellowship and that I was keen to learn from them about ROV, she also asked the women if it was ok for me use my IC recorder instead of taking handwritten notes – all agreed.

The Reclaiming Our Voices program started in 1999 and was designed to help First Nations women in the West Regions of Manitoba who struggle with alcohol and drug addictions and who need help with ensuring a safe pregnancy; to prevent babies being born in the future with FASD. ROV holds an annual gathering that is only open to women from the West Region communities. Women from other areas of Canada request to come to the gathering (as the word of success spreads) and a few places are made available however; due to funding and venue constraints many are sadly declined. The gathering has a variety of styles to get the message across to women and to assist them with their healing journeys. These styles include workshop presentations; traditional teachings – eg: sacred plants, medicines, sweat lodges, spiritual cleansing; women giving testimony – sharing their personal stories, healing circles – usually run by the elders etc.

ROV is a program that can stand alone or one that can be used in conjunction with other programs such as Mentoring programs already operating in First Nations communities in Canada. ROV is made possible by the staff of the West Region Child & Family Services who attend and participate in the program alongside the women and act as their mentors in a non-judgmental manner. They provide a safe environment and very intense nurturing to allow the women time and space to work through their personal issues. ROV is always exploring alternative methods that work for the women; they listen to and take on board what the women say about the program and make necessary changes to accommodate their needs for healing and change.

*The ROV aims to assist women by*

- *Providing a nurturing environment to help them see themselves as worthy of respect*
- *Giving them valuable information about healthy pregnancies and FASD*
- *Giving them the opportunity to talk or work through difficult issues in a safe, healing environment*
- *Providing a community support and reducing their sense of stigma*
- *Building trust relationship with professional staff in their home community*
- *Providing information about services and supports in a safe, nurturing environment*

The gathering focuses on healing journeys for these women by teaching and modeling good and healthy behaviours. Stella Bone a First Nations woman and Executive Director of the West Regions Child & Family Services Inc, states: *“the Reclaiming Our voices gathering has provided participants the journey to self discovery and healing by sharing their many gifts of wisdom. Participants open their*

*hearts and minds to the traditional healing ways. It is through this process we discovered our self esteem, self confidence and self healing (pg 2)”.*

I want to include some quotes from other women involved with ROV to highlight and share their experience and passion: Linda – *“It is important for us to bring the young ones and start passing on the teachings, letting them fly too and us older ones that have been around for a long time to just back up and so I want to share; FASD for me is not about going in and looking at the brain; for us we look at it a different way; what are these children’s gifts and talents; that’s how we were brought to this world and that’s how you can find those gifts and talents of that child”, (2010).*

Gina – *“I haven’t been with the agency that long but I’ve been working with youth, so I’ve always wanted to [go to the gathering] but it’s geared towards a specific clientele; it’s not all can go – one of the most surprising things I found in the first one, I couldn’t understand what was going on, what’s happening – like all these women are crying and Linda just told me and I just watched, as soon as a woman was crying, there was someone [there], like it was amazing to see; and all these women didn’t want to go home - because they were safe where they were; an then they had to go back to their home life” (2010).* The ROV mentors support the women all throughout the year, not just at the gathering.

Karen – *“I wasn’t on the committee but I was asked by Stella to bring some paperwork to her when she was over there, when I got there they were in this big conference room and could hear all these women crying, and hold on, ah.. [I thought] what they were crying for and I didn’t know what the conference was about, so I stuck around, I stayed for [the goodbyes] and they all held hands and they started singing and I started crying too and I don’t know why but I thought oh my goodness, I want to be here, I wanted to help; I wanna help with whatever I can do aye, so that was my experience with the [ROV] conference.... I never knew what FAS/FAE and all that kind of stuff was and I learned a lot from there [the gathering] because I know my family are victims my siblings are victims of that; um and we talked about it but I learned what it is” (2010).*

Sarah – *“I’ve been with the conference right from the start and for me, it’s given me – I don’t know – it’s something different; something special; that keeps pulling me back there every year; seeing the satisfaction with the women that come back over and over. I chair the Traditional piece for the Traditional Team. I’m the Chair for that piece, but I couldn’t have done it without all of these women here – organising the workshops and identifying where each team member would help. Bringing back the traditional piece for the gathering was an important piece because a lot of our women are lost; so finding their identify, helping them find their identity of who they are - Anishinabe piece in them – being*

*an Aneshanabe woman” (2010).* It was explained to me that “Anishinabe” is the people (First Nations/Aboriginal) – I believe to be similar to Noongar, Koori, Murri etc.

Before the meeting drew to a close, I expressed my heartfelt thanks for the very warm welcome and said that I would take back to share with my communities; the valuable information I learned about their sincerity and passion in helping their women make positive lifestyle changes and I congratulated them on their hard work and ROV successes. It was at this point that Linda looked directly at me and in a humble voice – extended an invitation to me on behalf of the ROV Committee:

***“We want you to come to our ROV gathering (2011 or 2012) and we want you to bring 4 other women with you; we want to meet and share with Aboriginal women from Australia”.***

What an absolute honour to receive this invitation, given the gathering is strictly for west regions First Nations women only. I felt an overwhelming sense of emotion then and now I feel we have an Aboriginal cultural obligation to fulfill.

## ***5.20 FASD in Western Australia***

It is pleasing to see there are some great projects happening in Western Australia (WA) although more is needed to be done to address FASD and the needs of these families. Below is a brief description of some of the FASD projects and resources of which I am aware.

### **5.20.1 FASD Network WA**

In 2006, as a participant of the National Indigenous Women’s Leadership Program, I had arranged for Lorian Hayes (Epidemiologist and FASD Educator from Queensland) to visit Perth to run two FASD workshops; one for parents and the other for service providers. An outcome of the service provider workshop was the establishment of the FASD Network group that is still current. The aim of the network is to look at what is happening in WA in relation to FASD and to establish what still needed to be done to raise the awareness in communities. Membership included representatives from government departments and non government agencies that were interested in learning more about FASD, raising the awareness within their workplaces and in promoting the important messages in their communities about the risks of drinking in pregnancy etc. The Network meets face to face on a 6

weekly basis to discuss what training has been done in Perth and around the state; what new information or research is available; receive updates on FASD projects in WA; set tasks for the next meeting and to listen to guest speakers that attend the meetings. Relevant guest speakers are invited to address the meeting eg: IBERA – audio visual aid; an Aboriginal specific teaching tool – its an Animation Software on functions of the human body that show illnesses and diseases eg: Diabetes, smoking, FAS etc.<sup>35</sup>

Some of the key objectives for the Network are to raise awareness and increase people's knowledge about FASD. One of the best ways we envisaged this could be achieved is through holding a conference or gathering - an idea the entire Network felt strongly about, considering the fields in which we worked. A non-government agency applied for funding on the Network's behalf (as the Network is not an incorporated group), to hold a state-wide FASD conference in Perth with objectives to: raise awareness; help promote the importance of prevention and intervention; to create a forum for many of the parents, relative carers, foster carers and adoptive parents of children with FAS or suspected FASD who are searching for answers and support; to potentially establish a parent/carer support network and to allow families to tell their stories in a warm and friendly environment. However, at the time we were seeking the support, FASD was not well known and we were not successful in obtaining the funding hence the conference did not go ahead. FASD has since had more publicity through the media and various projects and people are now more aware; there is still the genuine need for the conference to meet the needs of the parents, adoptive parent, foster carers, families and communities. Canada and the United States hold annual FASD conferences and a Bi-annual International FASD conference where grass roots people including people living with FASD, biological parents, foster parents, adoptive parents, community workers, service providers and FASD experts come together to address the needs of their communities; these conferences are supported by the government departments such as Health Canada, Child & Family Services, Native Indian Health etc. We must endeavour to seek and find; to do the same.

Additional information - the 4<sup>th</sup> International Conference on FASD titled: "*The Power of Knowledge: Integrating Research, Policy, and Promising Practice Around the World*" is being held on the 2 – 5<sup>th</sup> March 2011 in Vancouver, Canada. The conference goal is to highlight international research and practice on FASD and for participants to learn about the implication and apply practice of leading research from around the world; establish and nurture linkages among researchers, networks, governments, communities, service providers and families; foster clinical and community based research and from the lived experiences of people living with or affected by FASD. As mentioned

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<sup>35</sup> IBERA website: [www.ibera.com.au](http://www.ibera.com.au)

earlier I had the privilege of attending one of these conference and I have no hesitation in recommending this to anyone interested in learning about FASD and more importantly, for parents, carers or family members to attend as many of the participants are people living with FASD and they play an active and vital role throughout the entire conference – an absolutely amazing experience. One of the highlights was the closing ceremony which was solely facilitated by them (people of all ages, living with FASD); we (the audience) were not allowed to move, clap, talk, ask questions or interrupt in any way because it would have been too over stimulating for them; ever tried sitting for an hour in silence when you hear a mix of heart wrenching and compassionate stories told by those living the experience – it was extremely hard, especially not to clap when you hear of their highlights and achievements. Information about the upcoming conference can be downloaded from the University of British Columbia website: <http://www.interprofessional.ubc.ca/FASD.htm>.

### **5.20.2 Marulu - The Liliwan Project, Fitzroy Valley, Kimberley, WA**

The Liliwan project is a community driven initiative to address FASD and Early Life Trauma (ELT) in the Fitzroy Valley. It derived from the community strategy *“Overcoming Fetal Alcohol Spectrum Disorder and Early Life Trauma in the Fitzroy Valley”* that builds on their strengths following the community initiated alcohol restrictions and bans. Leaders in the Fitzroy community invited professionals from the George Institute for International Health to the Fitzroy Valley to talk with the community about FASD; to raise awareness and ascertain the need to undertake a feasibility study on the prevalence of FASD. As a result of that consultation the George Institute for International Health has been engaged along with the University of Sydney and Nindilingarri Cultural Health Services in partnership with the Fitzroy Valley communities to implement the strategy. A Project Team has been established to oversee and implement the Marulu - The Liliwan project which aims to engage and assess around 200 children throughout the two stage process:

- **Stage 1** - data collection, FASD education and consultation regarding potential participants for stage two
- **Stage 2** - screening to assess health, behaviour and developmental stages of children aged between 5 and 8 years (with consent, from stage 1), treatment of health issues and referral.

### **5.20.3 FASD Prevention Project - Drug & Alcohol Office (DAO), WA**

The WA Drug and Alcohol Office (DAO) was successful in receiving funding through the Council of Australian Governments (COAG) Indigenous Early Childhood Development National Partnerships Agreement for a statewide FASD Prevention project.<sup>36</sup> The project is funded over a 4 year period to develop resources that are culturally sensitive; establish workforce development initiatives and develop community awareness campaigns. The project principles includes: being culturally secure; having community dialogue; being strengths based, non judgemental and holistic; using woman centered approach; being evidence based and innovative; having collaborative and a coordinated approach within DAO and having strong links with external expertise, complimentary projects and relevant referral pathways. A Key Aboriginal Advisory Group has been established to provide cultural knowledge and wisdom, content expertise and community linkages. A project Management Team has also been established to coordinate the project and manage the administration of the project eg: reports, budgets etc.

### **5.20.4 FASD - Development of a Screening and Diagnostic Instrument, WA**

This new FASD project "*FASD Development of a Screening and Diagnostic Instrument for Australia (FASD Project)*"<sup>37</sup> from what I understand, is lead by the Telethon Institute of Child Health Research (TICHR) with collaboration from other leading FASD experts and agencies such as National Organisation for Fetal Alcohol Syndrome And Related Disorders (NOFASARD), Russell Family Fetal Alcohol Disorders Association (RFFASA), various Australian universities etc. This project is funded by the Australian Government through the Department of Health and Ageing and aims to improve capacity to identify adverse outcomes for children prenatally exposed to alcohol. An evidence based screening and diagnostic tool will be developed by using the Delphi Technique<sup>38</sup> with participants to find out the best way to screen and diagnose FASD. Participants will include: Health professionals, Social Workers, Policy and Research experts, Parents and Carers of children with FASD, Consumers and Community representatives. The project will be implemented by a team of experts from across Australia; rich in FASD wisdom, knowledge and experience. More information on this project can be obtained from the TICHR website <http://www.ichr.uwa.edu.au/fasdproject/about>.

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<sup>36</sup> Information was provided to me via email dated 11 October, 2010; for further information contact the WA Drug & Alcohol Office. [DAO@health.wa.gov.au](mailto:DAO@health.wa.gov.au)

<sup>37</sup> Information received via email dated 23<sup>rd</sup> November 2010 from NOFASARD.

<sup>38</sup> A way of obtaining the opinion of experts without bring them together etc, see [http://en.wikipedia.org/wiki/Delphi\\_method](http://en.wikipedia.org/wiki/Delphi_method)

### **5.20.5 FASD Model of Care - Department of Health, WA**

The Department of Health WA, Child and Youth Health Network as the lead agency; developed the Fetal Alcohol Spectrum Disorder Model of Care (FASD MOC). A working group with representatives from government and research organisations was established to contribute to the model and help guide the process. The FASD MOC contains information on Epidemiology, Prevention, Screening, Diagnosis, Advocacy, Workforce and Professional Development and a series of recommendations that will guide agencies across government and the non-government sectors to prevent, diagnose and treat FASD. The FASD MOC was released in 2010. Further information can be obtained from the Department of Health WA, website. [http://www.healthnetworks.health.wa.gov.au/modelsofcare/fetal\\_alcohol\\_spectrum\\_disorder.cfm](http://www.healthnetworks.health.wa.gov.au/modelsofcare/fetal_alcohol_spectrum_disorder.cfm) (see Reference number 2 in the Bibliography)

### **5.20.6 Department for Communities (DFC) – Parenting Resource**

The Department for Communities produced a FASD booklet for parents and cares to help raise their awareness on the impact of alcohol on the fetus. This booklet can be found on their website: <http://www.communities.wa.gov.au/childrenandfamilies/parentingwa/parentingresources/Pages/FoetalAlcoholSpectrumDisorder.aspx> <sup>39</sup>

### **5.20.7 Churchill Fellowship Report (2008) by Kym Crawford**

Kym Crawford (2007 Churchill Fellow) traveled to Canada to look at Education of students with FASD; her report provides good information that helps with strategies for children with FASD, in the school setting. Kym's report is available on The Winston Churchill Memorial Trust website: <http://www.churchilltrust.com.au>.

## **5.21 Australia - National FASD Support Networks**

National networks available to provide information include:

- National Organisation for Fetal Alcohol Syndrome And Related Disorders (NOFASARD), (Sue Miers, South Australia) [www.nofasard.org.au](http://www.nofasard.org.au)
- Russell Family Fetal Alcohol Disorders Association (RFFADA), (Elizabeth Russell, Queensland) [www.rffada.org.au](http://www.rffada.org.au).

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<sup>39</sup> Relates to footnote Number 27.

- National Indigenous Australian Fetal Alcohol Syndrome Education Network (NIAFASEN) (Lorian Hayes, Queensland) [www.niafasen.org.au](http://www.niafasen.org.au)
- Drug Education Network (DEN) – (Vicki Russell, Tasmania) [www.den.org.au](http://www.den.org.au)

## 5.22 National FASD Training Modules

RFFADA<sup>40</sup> in partnership with Registered Training Organisation, Training Connections Australia (TCA); developed a FASD training package for multi tiered audiences. The training consists of 9 modules that cover a variety of topics to suit the different audiences; these Modules are:

1. Pre-requisite for all other modules which takes about 3 – 4 hours
2. Designed for frontline workers eg: mental health, alcohol & drugs, social, health and welfare workers, nurses, Centrelink and employment assessors. It is based on the TICHR Alcohol & Pregnancy project material.
3. For parents, carers, foster parents, welfare, social and frontline workers; this module has been endorsed by the NOFASARD.
4. Strategies for Educators, teachers endorsed by FASD experts and experts from other specialist fields such as disabilities.
5. For employment and vocational type services and is endorsed by Elizabeth Russell author of the book “Strategies for Employment Services Specialists – with particular emphasis on FASD”.
6. Criminal Justice, correctional, probation and parole officers, lawyers and other legal staff. This module is supported by two well known professionals in the legal field; Heather Douglas (p/t) Commissioner with Queensland Law Reform Commission and David Boulding Lawyer and FASD expert in Canada.
7. Alcohol & Pregnancy for students and young people
8. FASD & Homelessness
9. FASD for Indigenous Australians (Still in consultation stage).

For further information regarding this training can be obtained from website: <http://rffada.org/training>

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<sup>40</sup> Relates to 5.21- Russell Family Fetal Alcohol Disorders Association.

## 6 Conclusion

My Churchill Fellowship Journey was a great success! I achieved most of what I had aimed to do - and more. It was the most amazing experience; one which I will cherish for the rest of my life. On this journey, I wanted to face new challenges that would build on my knowledge and enhance my learning. The opportunity arose for me to visit the hardcore area of eastside downtown Vancouver. I accepted and by doing this; completely stepped outside my comfort zone. Not only did I learn about the breadth and depth of peoples struggles, but being in the midst of it took my thinking and learning too a whole new level.

In this report I have covered a lot of information about FASD that some of you will hear or have read for the first time. FASD can be confronting especially for women who drink and already have children; are of child bearing age or know they drank during their pregnancy [more so for working women who least expect it's an issue for them – and relate it more to their client base rather than their personal] lives. I covered information about some of the most fantastic FASD programs and projects that showcase and promote their successes; experienced people sharing their personal stories and culture; observed assessments and a day in the life of mothers living with FASD. As I alluded to throughout this report we need to work together in order to achieve good outcomes that make a difference in their lives [people who are affected].

FASD is a complex issue that will not go away, so we as a people need to work out the best ways to take it on. In doing this we can take what we learned from countries such as Canada and the United States of America who have been hard at it (dealing with and addressing FASD) since about the 1970's. As was my experience, everyone from both these countries with whom I came in contact was willing and open to sharing their wisdom, knowledge and experiences and was extremely accommodating including people from across all sectors eg: community, private, professional, and government. Let's embrace this and build a stronger support base for our FASD community.

## 7. Recommendations

1. **Training** – That a FASD training program is developed (or adopted from other FASD agencies for WA) and is made readily available for use by government departments and other services in order to train staff, volunteers, parents and carers on FASD – for them to gain understanding and provide more effective support services to Individuals and families with or suspected of having FASD. It is essential that FASD training is incorporated into Induction and/or Professional development training within organisations and that it is made compulsory for workers with direct client contact. Professionals (eg: Doctors, Specialists, Social Workers etc) with no (or limited) knowledge and understanding of FASD must also be formally trained in the same circumstances if they are working directly with people at risk of FASD. The FASD training modules developed and delivered by the RFFADA and the Training Connections Australia be used to train people in WA and that it be negotiated for those trained to deliver the FASD training as an ongoing initiative in WA.
2. **Family & Children – Support** – In light of what was learned from this fellowship, it is essential that women with drug and alcohol problems are strongly supported to overcome their addictions to improve their lifestyle; gain positive skills and establish safer homes, which leads to better outcomes for their children. This can be done by strengthening programs (already in existence – if there are any); if not, then establishing a suitable program (eg: similar to PCAP) with support and collaboration from all relevant stakeholders. It is also critical that the relevant agencies working with pregnant women and have knowledge of their alcohol consumption; raise their awareness of the risks to the unborn child, in a sensitive manner; and in high risk cases, take necessary steps to work with the mother throughout the pregnancy to help minimize the risks and prevent FASD. Children with or suspected of having FASD be supported through school based programs and child care settings.
3. **FASD Partnerships and Collaboration** – A coordinated approach is required to better address the needs of people living with (or suspected of having) FASD. It is essential that government and other relevant services with a responsibility to people with diagnosis or symptoms of this disability; work collaboratively to achieve the best possible outcomes. There is a number of ways this can be addressed: (1) identify a lead agency and establish a FASD team of support workers; to build a program for families to gain access, information and support, with strong and relevant referral pathways; (2) establish partnerships between Government, non-government and the private sector to develop relevant strategies to address

FASD. (3) the FASD assessment, resource and workforce development and diagnostic projects be supported and where necessary be expanded to benefit the broader WA community. (4) establish a funded state FASD Coordinator position to liaise with agencies; coordinate training and community education needs (for agencies and families) search, maintain and distribute updated research on FASD.

4. **Traditional Ways of Parenting** – a strong and obvious finding from my Churchill study is that Indigenous cultural ie: language & teachings; remain an effective way of raising our children. The Cradle Board, the Coolaman and the baskets had essential uses and provided safe environments and enhanced child development and parent/child bonding. Aboriginal teachings on parenting needs to be further explored to find out if it fits with the current research, if so Aboriginal people be encouraged and supported to continue that practice.
  
5. **State FASD Conference** – There is a few things happening at the moment in WA in regards to FASD, which is fantastic however, it is fragmented and the FASD knowledge remains within a small group of mainly service providers, professionals and researchers. There is a need for the broader community and services to have access to this information which will allow them to be aware of the dangers of alcohol use in pregnancy and understand ways to prevent and provide intervention to those families in need. The best way to do this is by holding a state conference for individuals, families, service providers and professionals to gain this knowledge and support. Australian FASD experts are to be engaged to deliver workshops at the conference; FASD projects to be invited to showcase their projects; families and community can use this gathering to tell their stories and use it as a vehicle to build supports; and for government and relevant agencies to use this as a platform for learning and building strong partnerships to address FASD and to work out the best way forward for FASD in WA.
  
6. **Reclaiming Our Voices Program** – A child welfare sponsored and run initiative that focuses on helping families to heal and reunite or remain united (mothers to children and children to mothers). A safe environment and place where women with addictions and child welfare workers together can build strong relationships, trust and rapport; while sharing in cultural richness and healing. It was not stipulated whether the Australian women who attend; be community based women or child welfare workers or both – it would be good for a mix of both. To avoid causing these First Nations women disappointment and to fulfill what I feel is a great cross cultural learning opportunity and Indigenous obligation; it is imperative that the invitation from the First Nations women in Manitoba be honoured and that full support from the Department for Child Protection and or other relevant agencies; is provided for this to happen.

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## 9. APPENDIX

### 9.1 Travel Plan

#### CHURCHILL FELLOWSHIP - CANADA 12 AUGUST – 11 OCTOBER 2010

The dates of my travel for the Churchill Fellowship are as follows:

#### USA

12 – 31 August 2010 – Seattle, Washington State, USA

1 – 12 September 2010 - Hawaii - Healing Our Spirit Worldwide Conference  
(6<sup>th</sup> International Indigenous Gathering)

11 – 31 October 2010 – Personal Holiday (Own Expense)

#### CANADA

13 – 21 September 2010 - Vancouver, BC

22 September – 2 October 2010 - Vancouver Island – Nanaimo; Victoria, BC

3 – 11 October 2010 - Winnipeg, Manitoba

Seattle, Washington State  
12 – 31 August

#### Carolyn Hartness (USA - key contact)

Fetal Alcohol Spectrum Disorders Educator/Consultant

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Indianola, WA 98342

360-297-0411

[chartness@centurytel.net](mailto:chartness@centurytel.net)

[www.Seventh-Generation.com](http://www.Seventh-Generation.com)

***Carolyn is arranging (and accompanying me to) all appointments with her FASD colleagues and associates as outlined in this bracket below:***

**16/8 CDR - King County, Ronit Gourarie (Coordinator)** [ronit.gourarie@kingcounty.gov](mailto:ronit.gourarie@kingcounty.gov) or  
phone 206-263-8387

**17/8 Fetal Alcohol Drug Unit**  
Dr Streithguth  
Kay Kelly – Legal Issues

**18/8 Parent & Child Assistance Program**

Dr Terese Grant

**20/8 University of Washington - FASD Diagnostic Clinic**

Dr Susan Astley (Clinic Director); Dr Stirling Clarren and wife Sandy; Dr Truman Coggins; Tracey Jirikowic; Julie Gelo

**23/8 Families Moving Forward Program**

Dr Heather Carmichael Olsen

**24/8 Radiological & Neuro-imaging Psychologist**

Elizabeth Aylward (Professor)

**25/8 Judge Wartnik (Justice) and the Judge from the Suquamish Tribe**

**26/8 Head Start Program**

*Carolyn is linking me with the local Head Start Program on her reservation in Indianola.*

**30/8 Portland Northwest Area Indian Health Board FASD Tribal Project**

Carolyn Hartness and Susie Kuerschner – Mount Hood

**HEALING OUR SPIRIT WORLDWIDE CONFERENCE - Honolulu, Hawaii  
1 – 12 September 2010**

**Healing Our Spirit Worldwide Conference (3 -10 Sept 10)**

**Wed 1/9** Travel to Hawaii – use the spare time to do write up of USA visit and have a few days to site see before or after the conference. *Registration for the conference is still to be lodged.*

Contact Details: Papa Ola Lokahi  
894 Queen Street, Honolulu HI, 96813/808-597-6550  
[www.hosw2010@papaolalokahi.org](http://www.hosw2010@papaolalokahi.org)

**Vancouver, BC  
13 – 21 September 2010**

**Mon 13/9 Rest & travel day from HOSW Conference (Hawaii)**

**Tue 14/9 Centre of Excellence for Women's Health, Parents with addictions programs -**

Nancy Poole (Researcher – Addictions Research Program)  
[npoole@cw.bc.ca](mailto:npoole@cw.bc.ca) [wavelength@telus.net](mailto:wavelength@telus.net)

**Wed 15/9 Health Canada - Aboriginal Mentoring Programs**

Rachel Douglas [Rachel\\_Douglas@hc-sc.gc.ca](mailto:Rachel_Douglas@hc-sc.gc.ca)

**Thur 16/9 Sally Page - FASD Program Manager**

Joanne Nelson, A/Epidemiology & Research Officer,  
[Joanne\\_nelson@hc-sc.gc.ca](mailto:Joanne_nelson@hc-sc.gc.ca)

**Fri 17/9 Parent Child Assistance Program**

**Mon 20/9 Aboriginal Head Start – Association of BC (Still to be organised)**  
Leona Antoine, Eagles Nest – East Vancouver [eagles.nest@telus.net](mailto:eagles.nest@telus.net)  
Maria Spano, Singing Frog - East Vancouver Ph: 604-253-5388  
[www.ahsabc.com](http://www.ahsabc.com)

**Tue 21/9 Write up Time (Motel)**

**Wed 22/9 Travel to Vancouver Island - Nanaimo & Victoria**

**Vancouver Island, BC  
22 September – 1 October 2010**

**23/9 Rest Day – Nanaimo, Vancouver Island, BC**

**24/9 Mentoring Program for mothers with FASD - Nanaimo**  
Hanna Scrivens (Inter Tribal Health Authorities) [hanna@intertribalhealth.ca](mailto:hanna@intertribalhealth.ca)

**27/9 White Crow Village – FASD Society - Nanaimo**  
Kee Warner (Executive Director, Founder) [kee@whitecrowvillage.org](mailto:kee@whitecrowvillage.org)

**28/9 Travel to Victoria**

**29/9 Moms Mentoring Program, Victoria, BC**  
Janet Christie [Jan.christie@shaw.ca](mailto:Jan.christie@shaw.ca)  
Liza Miles [artsintherapy@shaw.ca](mailto:artsintherapy@shaw.ca)

**30/9 Write Up time (Motel)**

**1/10 Rest Time – Sight Seeing**

**2/10 Travel to Winnipeg**

**Winnipeg, Manitoba  
2 – 11 October 2010**

**3/10 Rest Day – Winnipeg (3<sup>rd</sup> & 4<sup>th</sup> Oct)**

**5/10 Rolling River First Nations – Reclaiming Our Voices**  
Linda Dano-Chartrand - [lindac@wrcfs.mb.ca](mailto:lindac@wrcfs.mb.ca) and Kathy Jones [kathleen.jones@gov.mb.ca](mailto:kathleen.jones@gov.mb.ca);  
Sue Mozdzen - 204.783.9190

**6/10 Deborah Kacki - Program Coordinator**  
Interagency FASD Program  
Unit 10 - 254 Stella Walk, Winnipeg, Manitoba; R2W 2T3;  
Phone: (204) 582-8658

[Interagency\\_fas@shaw.ca](mailto:Interagency_fas@shaw.ca) and [Deborah.Kacki@newdirections.mb.ca](mailto:Deborah.Kacki@newdirections.mb.ca)

**7/10 Health Canada –**

Lora Montebruno-Myco - contact for Aboriginal programs

[Lora\\_montebruno-myco@hc-sc.gc.ca](mailto:Lora_montebruno-myco@hc-sc.gc.ca)

**8/10 Research Network – study of Mentoring programs (Still to be confirmed)**

Dr Linda Burnside [Linda.burnside@gov.mb.ca](mailto:Linda.burnside@gov.mb.ca)

**11/10 Leave to travel back to USA – arriving at Los Angeles**

**PERSONAL LEAVE - USA  
12 – 31 OCTOBER 2010**

**12/10 USA - Holiday at Own Expense**

My husband will be travelling with me throughout the whole journey. We will pay for his expenses ourselves including his travel insurance.

**1/11 Leave to travel back to Australia from Los Angeles. Arrive in Sydney and on to Perth 3<sup>rd</sup> November 2010**