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Report by – PRUE WALKER – 2008 Churchill Fellow

To study models of care for children with Foetal Alcohol Syndrome.

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Signed

Dated

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## Acknowledgements

I would like to acknowledge my colleagues in Central Australia who share an interest in learning more about Foetal Alcohol Spectrum Disorder and reducing its impact. I have been overwhelmed with people's interest in the outcomes of this project and their commitment to changing the status quo.

I would like to thank all the people who shared their skills, expertise, knowledge and vision with me, particularly:

Therese Grant, Susan Astley, Nancy Whitney, Larry Burd, Dr Kwadwo Asante, Margaret Vrolyk, Hazel Mitchell, Donna DeBolt, Alexandra Edwards and Morgan Fawcett. Audrey Salahub and Audrey McFarlane were particularly generous with their time and hospitality, and I would like to recognise Ric Iannolino who made extraordinary efforts to give me an insight into FASD in the community of Juneau.

Thanks to my daughter Ruby who patiently sat through meetings, conferences and workshops. Sorry about the nanny experience. Thanks to Linda and Mark in Juneau, Audrey S, Pat and Shirley, and Audrey M and family for making her trip so great.

I would also like to thank my employer the Department of Health and Families, NT Families and Children for supporting this project.

## Introduction

As a social worker in Alice Springs in 2006, I was not alone in observing the impact of prenatal alcohol exposure on children in care. Colleagues in child protection, disability services, maternal and child health, paediatricians, midwives and non-government agencies were all dealing with children with a diagnosis of Foetal Alcohol Syndrome on a regular basis.

When children are under state guardianship, there is a responsibility to provide the best standard of care possible. Children with FAS who had been placed in care due to neglect or abuse (often alcohol related) proved to be more difficult to reunify with family members, as their low weight, behavioural issues and learning disabilities meant they might not thrive in home environments assessed by social workers as providing “good enough care” for most children.

A sweep of the internet identified a range of resources – mostly from the US and Canada – documenting the needs of alcohol affected children for structured, stable environments with routine and predictability, and carers who are educated about FAS and its impact on the brain. It was also clear that children with a FAS diagnosis represent the tip of the iceberg of affected children on the FASD spectrum.

In the unique environments which comprise Central Australia, what does FAS mean for case planning? What is best practice in providing Out of Home Care? How do we manage the competing needs of affected children for stability and routine, with the importance of cultural connection, identity and belonging within families of origin?

## **Project Description**

I planned to visit agencies working in providing care services to children and families affected by FASD. My hope was to find models of service delivery which could be adapted in the Central Australian environment to improve our care for children with FASD. I was particularly interested in culturally appropriate service delivery to indigenous children in care. My key research questions included:

I developed several key research questions:

- How do Canada and the USA assess and screen children with FASD?
- What program models exist in Canada and USA for children with FASD in relation to treatment, support and care options?
- How do the child protection/care systems work with FASD in indigenous communities, especially in remote areas?
- What are the characteristics of support programs which provide positive outcomes for children and families, especially indigenous families?
- What are the lessons for service delivery in Central Australia?

I quickly realised that FASD services operate on a continuum, from early identification, screening and diagnosis; through services for affected infants, children, adults and their carers; to health provider training, community education and widespread prevention; development of local area networks; and targeted prevention for at-risk parents.

I learned that diagnosis leads to better care planning, as well as education for families, schools and carers, which itself has a preventative impact as awareness of FASD is raised in schools and at risk families. For this reason I struggled to divide this report into sections: prevention, education, training, caring. The overlap between each of these activities is significant, and some of the most impressive services I visited were engaged in all these roles.

In the end I took an exploratory approach, visiting diagnostic clinics, researchers, trainers and educators, advocates, parents and affected families, child protection agencies and care providers, indigenous social services and child welfare agencies, regional networks, funding agencies and government policy makers. Visiting so many agencies and committed individuals was a journey along the FASD service spectrum, which reinforced the interconnectedness and multidisciplinary approach which characterises FASD service provision.

## **Executive Summary**

### **Project Description**

- To investigate models of care for children with Fetal Alcohol Spectrum Disorder (FASD)
- To explore best practice in guardianship of children with FASD
- To identify opportunities to improve service delivery to children and families affected by FASD in Central Australia

### **Highlights**

- Attending the International Conference on FASD in Victoria, BC
- Meeting so many dedicated people who are passionate about FASD prevention and treatment
- Travelling through Alberta and experiencing the connections between agencies and the commitment to a shared knowledge and learning base
- Visiting Juneau and seeing a remote community provide innovative programs with limited resources but enormous good will and commitment

### **Conclusions**

- Diagnosis is the first step - without screening and diagnosis we are working in the dark
- An enormous amount of work has been done in relation to diagnosis, early assessment and screening in the US and Canada – we don't need to reinvent the wheel
- FASD can be de-stigmatised through sensitive delivery of prevention, community education, diagnosis and intervention
- Best practice models in Child Protection require a concerted approach including reduced case loads and many hours of FASD training for both carers and workers
- Agencies working with vulnerable families need to have enough training and accurate information to be able to at least ask the question – could this person have a brain injury due to FASD?
- Traditional service models need to be adapted to better accommodate the needs of children and adults with FASD
- There are models which have been proven to be effective in targeted prevention, which could be readily adapted in Australia

### **Implementation and Dissemination**

The learnings from this Churchill Fellowship will be implemented and disseminated in the following ways:

- As Manager of Out of Home Care and Youth Services talking about FASD with the staff group and raising this issue in supervision
- Improving planning for children in care with FAS and asking the question “could this child (or parent) have FASD?”
- Developing powerpoint presentations for Department of Health and Families staff including child protection, disability services, drug and alcohol workers
- Providing presentations to community agencies such as Central Australian Aboriginal Congress and NPY Women's Council
- Establishing and working with a local working group to commemorate International FASD Awareness Day

- Development of education forums on FASD for community members, professionals and carers
- Raising the issue of FASD at a policy level.

## Program

4 March 2009	Dr Therese Grant Dr Ann Streissguth	Fetal Alcohol Drug Unit, University of Washington	Seattle, Washington
5 March	Dr Susan Astley	Director of the Washington State Fetal Alcohol Syndrome Prevention and Diagnostic Network	
10 March	April Macri	FASD Key Worker, Victoria Native Friendship Centre	Victoria BC
11-14 March		International FASD conference	Victoria BC
13 March	Corrina Sparrow Yasmin Prince Desiree Sparrow Lisa George Peter Morin Sabrina Williams	Surrounded By Cedar Child and Family Services	Victoria BC
15-18 March	Dr Kwadwo Asante Audrey Salahub Dr Julianne Conry Krystal Bodaly	Asante Centre	Maple Ridge BC
21 March	Donna Debolt	FASD Consultant	Edmonton Alberta
21 March	Denise Milne Gerry Wright Marina Santos	Office of Children's Services, Cross Ministry FASD Committee	Edmonton Alberta
24-26 March	Audrey McFarlane Donna Fries Tracey Knowlton and team	Lakeland Centre for FASD	Cold Lake, Alberta
31 March – 4 April	Jerry Gurr	Community Justice Program Lethbridge Police Service	Lethbridge, Alberta
	Judy	First Steps Program	Lethbridge, Alberta
	Laura Elliott	McMan Youth and Family Services	Lethbridge, Alberta
	Kimber Sulin Davies	Lethbridge Community College	Lethbridge, Alberta
	Mark Weninger	Sifton Youth Services and FASD Cross Ministry Committee	Lethbridge Alberta
	Paul Henderson	PEAK Vocational and Support Services	Lethbridge Alberta

	Hazel Mitchell	FASD Regional Network Coordinator	Lethbridge Alberta
6 April 2009	Dr Larry Burd	Fetal Alcohol Syndrome Centre, University of North Dakota	Grand Forks, North Dakota USA
13-22 April 2009	Ric Iannolino	Juneau FASD Diagnostic Clinic Coordinator, Central Council of the Tlingit and Haida Indian Tribes of Alaska (CCTHITA)	Juneau, Alaska
	Dr Susan Hunter-Joernes Belinda Burns Judith Hayden Richard Egan Sherri Pipkin Sandy Fiscus John Kesselring Richard Eaton Dr Mark Stauffer	Juneau FASD Diagnostic Clinic	Juneau, Alaska
		CCTHITA Head Start	Juneau, Alaska
	Jordan	Juneau Youth Services	Juneau, Alaska
	Vanda Patterson	HOPE Alaska	Juneau, Alaska
		Hoonah Head Start	Juneau, Alaska
	KJ Metcalfe	Northern Light United Church	Juneau, Alaska
	Genevieve Casey	Alaska Office of FASD	Juneau, Alaska
	Dolores Cadiente Cathy Wellwood	SEARHC Behavioral Health	Juneau, Alaska
	Izabel Bowers	Office of Children's Services (OCS)	Juneau, Alaska
22 April	Sarah Dewane Alexandra Edwards	Arctic FASD Regional Training Centre	Anchorage, Alaska USA
23 April	Cheri Scott	Stone Soup Group	Anchorage, Alaska
27 April	Shane Welch	Yukon-Kuskokwim FASD Diagnostic Team	Bethel, Alaska USA
27 April	Ed Pironte	Office of Childrens Services	Bethel, Alaska
28 April	Ardyce Turner,	FASD educator and child protection worker	Bethel, Alaska
28 April	Monica Leinberger	FASD and Behaviour Specialist	Bethel, Alaska

## FAS and FASD

Fetal Alcohol Syndrome (FAS) refers to a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy.

A diagnosis of FAS requires 4 components:

- growth deficiency
- three facial characteristics – small eye openings, a thin top lip and a smooth philtrum
- evidence of central nervous system damage
- confirmed pre-natal alcohol exposure

The distinctive facial features are the only criteria unique to FAS. The term FAS is widely used in Australia and is generally diagnosed by paediatricians.

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term encompassing the range of effects of prenatal exposure to alcohol. It is not a diagnostic term although a person may be described as having FASD if they have been diagnosed with one of the conditions on the spectrum. Diagnostic terms vary between and within the US and Canada and include:

Partial FAS (pFAS):

- 1 or 2 of the three facial features
- evidence of central nervous system damage
- confirmed pre-natal alcohol exposure

Alcohol Related Neurological Disorder (ARND) (also referred to as static encephalopathy)

- evidence of central nervous system damage in 3 or more domains of functioning
- confirmed pre-natal alcohol exposure

Neurobehavioural Disorder

- evidence of central nervous system damage in 2 domains of functioning
- confirmed prenatal alcohol exposure.

Central nervous system damage can be reflected through cognitive impairments, learning difficulties, behavioural problems, poor motor skills, poor impulse control, problems in memory, concentration and attention, and poor judgement. These reflect the specific areas of the brain prenatally damaged through alcohol exposure. Individuals with FASD may have difficulty understanding cause and effect, managing time and money, generalising experiences and learning and retaining information.

Additionally, Alcohol Related Birth Defects (ARBD) can include congenital abnormalities of the muscular, skeletal, renal, auditory or visual systems – however there are no diagnostic criteria, and a causal link with alcohol exposure cannot be proven. ARBD is not usually included on the FASD spectrum.

## FAS/FASD in Central Australia

It is estimated in the US that between 0.5-2:1000 children will be born with FAS<sup>1</sup> and Canadian estimates of FAS are 3:1000. The Department Health Canada estimates that the rate of FASD is 9:1000 births and US research estimates a combination of FASD with ARND is at 9.1/1000 births<sup>2</sup>.

There is very limited data relating to FAS in Australia and specifically the NT.

### FAS

- NT Rate of FAS
  - **1.87-4.7 per 1000** live births- Aboriginal population
  - **0.68 per 1000** live births- Top-End Rate (Harris et al, 2003)
- Non Aboriginal WA State Rate:
  - **0.02 per 1000** live births
- Aboriginal WA State Rate:
  - **2.76 per 1000** live births (Bower et al, 2000)

### FASD Rate: 6-7 times the rate of FAS

- Larry Burd (2003) estimates **1 in 100** adults in correctional system in Canada have FASD

*Leanne Crough, Katherine West Health Board*

A review of children diagnosed with FAS between 2001-2004 in Australia identified that:

Paediatricians identified 92 children with FAS. Of these:

- 36% were premature
- 65% had low birth weight
- 53% had microcephaly (a small head)
- 24% had additional birth defects
- Despite these conditions, only 6.5% were diagnosed at birth.

In addition:

- 51% had a sibling with FAS
- 60% were in care
- 65% were indigenous.<sup>3</sup>

Alcohol use in Australia is highest in the NT, and greater numbers of people drink to risky levels than in other states and territories<sup>4</sup>. Even within the Territory, drinking at risky levels is

1 May PA, Gossage JP. *Estimating the prevalence of fetal alcohol syndrome: a summary*. Alcohol Res Health. 2001;25 :159 –167

<sup>2</sup> Alberta Alcohol and Drug Abuse Commission, Women and Substance Abuse information Series , *Estimating the rate of FASD and FAS in Canada*, 2004.

<sup>3</sup> Elliott, E., Payne, J. et al *Fetal alcohol syndrome: a prospective national surveillance study*, Archives of Diseases in Childhood, 2007; 93:732-737.

<sup>4</sup> Australian Institute of Health and Welfare 2008. *2007 National Drug Strategy Household Survey: State and territory supplement*. Drug statistics series no. 21. Cat. no. PHE 102. Canberra: AIHW.

higher in remote and very remote locations<sup>5</sup> with alcohol consumption in Alice Springs at four times the global average. Binge drinking among young women in particular is increasing disproportionately, and raises particular concerns given the connection between risky alcohol use and unplanned pregnancy.

Children with FASD are over-represented among children in care – the University of Washington study found a FAS rate of 1:100 among this population, ten times the national average<sup>6</sup>. A Manitoba study found that 11% of all children in care had a FASD diagnosis which represented one third of children in care with disabilities<sup>7</sup> and an Australian study found 60% of diagnosed children were in care<sup>8</sup>. The over-representation of children with FAS in care in Australia data is concerning.

Children with FASD are more likely to enter the care system due to:

- concerns about their level of care due to the impact of parental alcohol use;
- safety risks due to alcohol-related factors such as domestic violence;
- risks to growth and development, particularly failure to thrive.

In Child Protection service provision in Alice Springs, case management of children in care involves collaboration with doctors, midwives, maternal health providers, nutritionists, drug and alcohol workers among others, all of whom were aware of what appeared to be high numbers of children in care in Central Australia diagnosed with FAS. If children with FAS are over-represented in care, what about those who have *some* of the effects of alcohol exposure? We know that there is a population of children likely to have FASD, but at present there is no formal way to screen or identify these children. In Alice Springs we work with children with significant behavioural issues, often against a background which includes abuse and neglect, trauma, multiple placements (sometimes due to behavioural issues) and a culture clash between indigenous family life and urban foster care. In some cases alcohol abuse is documented as a reason for the child entering care, in others this issue may be somewhere in the background. Without screening or diagnosis of FASD, we could only speculate about a connection between behavioural and learning difficulties and FASD.

Additionally a proportion of children in care are assessed with birth defects such as club foot or cleft palate, and some have more complex disabilities. While these birth defects and disabilities have many possible causes, when it is known that an affected child was exposed to significant levels of alcohol in utero, the connection must be raised. We currently don't have the ability to link disabilities with alcohol exposure although scientific research has indicated a correlation in some areas.

## Questions for Child Protection Practice in Central Australia

In reflecting on the numbers of children affected by FAS who are in care in Central Australia, I was interested in the question – what does good practice look like? What should we be doing if we know a baby in foster care has FAS? How do we support the carers? What does it mean for

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<sup>5</sup> Australian Institute of Health and Welfare: 2005. *2004 National Drug Strategy Household Survey: Detailed Findings*. AIHW cat. no. PHE 66. Canberra: AIHW (Drug Statistics Series No.16).

<sup>6</sup> Astley SJ, Stachowiak J, Clarren SK, Clausen C. (2002) *Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population*. *Journal of Pediatrics*, 141(5):712-7.

<sup>7</sup> Fuchs, D., Burnside, L., Marchenski, S. and Mudry, A. (2005). *Children with disabilities receiving services from child welfare agencies in Manitoba*. Winnipeg, MB: Centre of Excellence for Child Welfare.

<sup>8</sup> Elliott et al 2007.

family reunification? I knew from the literature that children with FAS require structure, routine, stability, and don't manage change well. What does this mean if we hope to reunite children with their families, when those families don't necessarily live in structured environments with an emphasis on routine? When those families move between communities and towns? When a child may be at school one week but at a bush sorry camp the next? If children with FAS are already facing so many challenges, how do we balance their developmental needs with their needs for family, culture and identity? Should we be focussing on meeting developmental goals – through physiotherapy, occupational therapy, speech and language therapy, playgroups and kinder and school attendance – and if this is so, what will be the impact on our decisions to reunite children and family, in environments where these services may be extremely limited?

There may be risks in documenting a model of best practice for children with FAS if this will reduce the chance that a child in care could return home, whether to parents or to extended family, particularly in the NT where 69% of children in care are indigenous<sup>9</sup>. While I encountered an enormous volume of literature and research on the needs of children with FAS, the needs of their carers and families, and Native American and Canadian literature about supporting children and families affected by FASD, we need to better understand the lived experience of children with FAS in indigenous communities and families in Central Australia in order to make a meaningful comparison. How do traditional Aboriginal child rearing practices address or adapt to the needs of children with FAS?

As children enter either foster care or kinship care, I observed that their parents frequently go on to have subsequent pregnancies and births – equally likely to be alcohol affected, unless some intervention has taken place. Yet in the interval between a child entering care, and a mother giving birth to a subsequent child, there may be no intervention to prevent a further alcohol affected pregnancy unless the parents actively seek help.

Child Protection services are well positioned to have a role in preventing further alcohol-exposed pregnancies among families with children in care. Dr Sterling Clarren, international FASD expert, has identified the importance of identifying at-risk mothers as a FASD preventative strategy. His follow up study of mothers of children diagnosed with FAS found very poor long term outcomes reflecting their high risk lifestyles and health issues. A quarter of affected children were born *after* an older sibling had been diagnosed with FAS. This data indicates the high prevalence of FAS among siblings, which is particularly relevant to child protection service delivery. We are missing a significant opportunity to intervene with families of children with FAS in the care system in relation to future pregnancies.

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<sup>9</sup> Australian Institute of Health and Welfare 2009. Child protection Australia 2007–08. Child welfare series no.45 Cat. no. CWS 33. Canberra: AIHW.

Dr Stirling Clarren's follow up research with birth mothers identified:

- Only about 10% of birth mothers were still caring for their children. In seeking out birth mothers his data indicated:
- While many birth mothers sought services while pregnant, after their babies were removed the services withdrew until they fell pregnant again.
- 25% of children of these birth mothers were born after an earlier child had been diagnosed with FAS
- 3 years after diagnosis, 25% of birth mothers had died.
- He recommended "look for the mother".

*Keynote Address to the Yukon 2002 Prairie Northern Conference on Fetal Alcohol Syndrome*

I hoped to find services targeted to indigenous communities in Canada and Alaska which might provide insights into some of these dilemmas. However it seemed these communities had the benefit of a well-developed service system to support FASD diagnosis, education and training of providers, program development and community education. In Central Australia while individuals have championed the recognition of the impact of alcohol in pregnancy, we don't yet have a service system in which identification of and responses to FASD are embedded.

## Diagnosis

Diagnosis is critical to the identification of individuals with FASD, as a detailed understanding of the condition is important to designing services and supports which address their needs. Dr Ann Streissguth's long term research emphasises the importance of early diagnosis in prevention of poor long term outcomes in adulthood, and identifies that children with FASD suffer more negative outcomes in the long term than those with FAS, who are more likely to be identified in childhood.<sup>10</sup>

Diagnosis is the best prevention.

*Ric Iannolino, Juneau FASD Clinic Coordinator*

In Central Australia, FAS is generally diagnosed by a paediatrician – either through Alice Springs Hospital or by Remote Health paediatricians - on the basis of their assessment of the child's facial features, growth and a confirmed history of maternal alcohol use during pregnancy. The key facial features of FAS are diagnosed "intuitively" by observation of the child's face - known as a 'gestalt' approach to diagnosis. There are no tools or models routinely used to classify the facial features.

A 2005 Australian study of health professionals' attitudes, knowledge and practices relating to FAS found that only 12% of those surveyed could identify the four diagnostic criteria of FAS. 45% of providers routinely ask about alcohol use in pregnancy and 25% routinely provide information about the impact of alcohol use in pregnancy. Only 12% were providing advice consistent with NHRMC guidelines.<sup>11</sup>

If only some of the signs of FAS are present, a paediatric assessment may report "features of FAS" or "possible FAS" but no diagnosis will be made. Other children may be described as having "inter-uterine growth retardation" but the diagnosis does not specifically link this to

<sup>10</sup> Streissguth, Ann. *Fetal Alcohol Syndrome: A Guide for Families and Communities* 1997

<sup>11</sup> Payne, J., Elliott, E. et al. *Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy*. Aust N Z J Public Health. 2005 Dec;29(6):558-64.

maternal alcohol use. Birth defects may be noted, but not labelled as Alcohol Related Birth Defects. There are no Australian guidelines for the diagnosis of FASD.

Various diagnostic criteria for FASD disorders have been developed in North America. The US Institute of Medicine developed the first diagnostic tool, followed by the influential FASD 4-Digit Diagnostic Code developed in 1997 by Drs Sterling Clarren and Susan Astley at the University of Washington's Fetal Alcohol Syndrome Prevention and Diagnostic Network. The FASD 4-Digit Code is widely used although adapted in Canada in relation to the Canadian diagnostic criteria which incorporate elements of the IOM guidelines.

The FASD 4-Digit Code is designed to be administered by a multidisciplinary team, including a paediatrician, neurologist or neuropsychologist, cognitive or behavioural psychologists, speech and language pathologists, occupational therapists and physiotherapists, and social workers. I visited Dr Astley at the University of Washington, and also observed diagnostic clinics over several days at the Asante Centre in British Columbia, and in Juneau, Alaska. I also met clinic coordinators in Grand Forks, North Dakota; Cold Lake, Alberta; and Bethel, Alaska, the second and third providing a visiting service to remote communities. This model impressed me for its ability to be replicated at a local level, supported by the training and diagnostic materials provided by the University of Washington, and its ability to be used in regional settings with limited resourcing by drawing on in-kind support from professionals.

A particularly important feature of this process is the diagnostic report, which provides a high quality overview of the child's functioning in many areas, which assists in forward planning for the child and family, aiming to improve quality of life and prevent the development of secondary disabilities. The best outcomes are achieved if emotional and practical support is provided to the individual and family post-diagnosis, to implement the recommendations of the report. Clinics such as Lakeland Centre for FASD provide extensive post diagnosis support, such as advocacy with the school to understand and implement the recommendations.

Since 1999, the University of Washington clinic has conducted screening of all children entering long term care in Seattle. Standardised photographs are analysed and children presenting with all three facial features attend a diagnostic clinic. 2000 children have been screened (98% of the eligible population) and the prevalence of FAS within this population is 10/1000, ten times the national average.<sup>12</sup> Dr Susan Astley has published data indicating a reduction in the rate of FAS among the population of children in care, attributed to the range of FAS prevention and intervention programs in the state.<sup>13</sup>

The disadvantages of this diagnostic model is that the process is time consuming and relatively costly. The Bethel and Juneau teams are limited to diagnosing between 12-24 children each year. This can lead to long waiting lists and frustration among providers who are waiting for a diagnosis. I spoke to child protection workers in both locations who raised this issue as a disadvantage. Improved resourcing would enable more frequent diagnostic sessions.

Screening tools have been developed to identify individuals who may be affected by FASD and who may require diagnosis. Dr Larry Burd, Director of the Fetal Alcohol Syndrome Center at the University of North Dakota, has developed a range of tools which can be administered by a trained professional to a population – such as kindergarten students – to identify children who may benefit from further assessment or diagnosis. The advantage of these tools is that

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<sup>12</sup> [depts.washington.edu/fasdpn/htmls/foster-screen.htm](http://depts.washington.edu/fasdpn/htmls/foster-screen.htm)

<sup>13</sup> Astley SJ. (2004) Fetal alcohol syndrome prevention in Washington State: Evidence of success. *Paediatric and Perinatal Epidemiology*, 18:344-351.

they are simple to administer. Dr Burd reported that where children are routinely screened in early childhood, their schools and kindergartens develop strategies for behaviour management which can be applied to all children. Children may then be referred for diagnosis, but are not waiting for the support they need.<sup>14</sup>

Arguments have been raised that diagnosis of an alcohol-related condition is stigmatising and will have a negative impact on the family. Professionals I met in North America indicated the contrary – that identification and diagnosis could be liberating and bring a sense of relief to families, who were almost always aware that there were significant issues affecting their child but without information and resources, struggled to understand and respond effectively. Diagnosis is the first step in identifying the child's needs, at home, in the community, in school and in the transition to adulthood. The key message I learned was that education and training of those around the affected individual was the key to providing a good fit between that person and their environment.

*“...secondary disabilities should not be viewed as unavoidable; they have arisen out of the responses of the environment to those innate brain dysfunctions with which people with alcohol-related birth defects are born”.*

*Ann Streissguth (1997)*

I spent a great deal of time hearing about the impact of FASD on adults. Ric Iannolino and Margaret Vrolyk in Juneau, Audrey Salahub of the Asante Centre, Audrey McFarlane in Cold Lake and Donna Debolt and Hazel Edwards in Alberta among others, provided valuable insights into the long term impact for adults with FASD who don't have a diagnosis.

An adult with undiagnosed FASD is likely to go through life not knowing why they struggle with the tasks of daily living, why they are repeatedly in trouble with the law, why they can't manage money and why their impulsivity has such negative effects on their quality of life. Small events such as failing to understand a letter from Centrelink may have significant consequences such as loss of income and subsequently loss of housing. The people surrounding that individual are likely to treat them as an independent adult, not recognising that underlying brain damage means that the adult is likely to require ongoing support just to manage with the independent functioning that most of us take for granted. Without a diagnosis the adult is likely, from their early school days, to have continued experiences of failure and is highly likely to develop mental health conditions in response to the stressors of daily life.

The work of Dorothy Debolt and Mary Berube in Alberta highlights the need for diagnosis of adults involved in the child protection system, as a differential approach needs to be taken to adults with a brain injury who are parenting children at risk. Many of the expectations placed on parents by the child protection system are unrealistic if that adult has an undiagnosed brain injury. A typical child protection intervention with a parent might include requirements for substance abuse or mental health treatment, requirements that parents attend access visits at certain times and places, and parents are effectively penalised when they don't meet these expectations. An adult with FASD will struggle to meet these requirements. In particular, a substance abuse problem may be masking a brain injury, and the assumption that reducing substance abuse will automatically improve parenting capacity may be false. Diagnosis of adults is increasingly prioritised by clinics including the Lakeland Centre for FASD which has expanded adult diagnostic services. FASD service provision across Alberta also has a strong

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<sup>14</sup> Poitra et al A school-based screening program for fetal alcohol syndrome, *Neurotoxicology and Teratology*, Volume 25, Issue 6, November-December 2003, Pages 681-688

focus on addressing the impact of FASD across the lifespan, not just in childhood or adolescence.

I was fortunate to meet Morgan Fawcett, a 17 year old native Alaskan flute player who reflected on the positives of a diagnosis. Morgan has used his understanding of his condition to become a FASD educator. His knowledge of FASD has enabled him to work to his strengths, recognise his limitations and accept support in the areas of life he needs it. He discussed his recent MRI scans with interest, and was able to reflect on his diagnosis with considerable insight:

*“FASD affects my life in many ways. First and one of the more serious brain dysfunction is my memory. I have a short term memory... there’s not much that I remember, its there and then its gone. I have various tics, poor eyesight, no sense of smell, deformed ear canals and hips, poor coordination ... I fatigue easily. I have a submucous cleft palate.*

*“I’m musically inclined and my fingers were made for instruments... it affects my life, it stimulates my brain and my body, its one of the very few things I can do. It calms me down, I’m a little more sensitive to stress... it relieves when I play, it lowers my heart rate and blood pressure, it’s like a meditation. You’re totally relaxed, your brain works a little better and you can concentrate a little better. Now I get a chance to share my gift with people and teach.”<sup>15</sup>*

## **The FASD Service System**

Due to the low profile of FASD in Australia, little attention has been given to FASD among the general population, and there are few FASD-specific services. I was impressed by the range and spectrum of services in North America for families and children affected by FASD. They include:

- pre- and post-diagnosis counselling
- post diagnosis support including assistance in implementing the recommendations of a diagnostic report
- FASD key workers within an agency, providing a range of support, advocacy and education services to families parenting a child with FASD
- Targetted prevention in the form of intensive outreach support for high risk mothers with the aim of preventing future alcohol affected pregnancies
- Coaching programs for families parenting children with FASD
- Transition to adulthood programs for teenagers with FASD
- Intensive home support programs for adults with FASD who are also parents
- Children are also supported through a range of intensive intervention programs which although not targeted at children or young people with FASD, provide therapeutic responses:
  - Supports to young people and adults entering the correctional system
  - Summer camps for children with FASD

Many of these FASD programs have been developed within large agencies, in a context in which FASD has been recognised and diagnosed for many years, where data regarding prevalence of FASD is known and where all staff have received specific FASD training.

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<sup>15</sup> Morgan Fawcett, interview, KTOO FM, Juneau Alaska 10 September 2007

I was also impressed by the numbers of adoptive and biological parents of children with FASD who had been actively involved in the development of the service system, including lobbying for funding and for recognition of the needs of children with FASD. I felt, in the case of adoptive parents, that this had been contributed to by some of the policies regarding children in care – that permanency planning for children in care is adoption. Permanency planning for adoption must take place in the USA after a child has been in care for between 15-22 months. Adoption is final, the child is issued with a new birth certificate and parental rights are terminated. There is a cohort of adoptive families who adopted children 20+ years ago, prior to FASD diagnostic services being widely available. These children were subsequently diagnosed with FASD, sometimes as adults in their 20s, and their adoptive parents found themselves as advocates for their child. Many of these adoptive parents had seen their children struggle into adulthood, with addiction issues and periods of incarceration, and all were concerned about the future of their 30+ year old child and were planning for their adult child's financial future.

## Child Protection Responses to FASD

Children in care with FASD represent a vulnerable population and require multiple supports from a cross-disciplinary perspective. Children removed from the care of their parents were identified as having needs beyond standard care provided within Children's Services in Alberta.

Dorothy Badry, *Fetal Alcohol Spectrum Disorder Standards: Supporting Children in the Care of Children's Services*, 2009

I visited child protection agencies in Juneau, Bethel, and Edmonton and spoke with a range of individuals from agencies providing services to families including those involved with child protection services. I was impressed that staff seemed to have knowledge about FASD, access to training, avenues for diagnosis (even if sometimes difficult to access) and awareness of at least some of the issues affecting service provision to this group of children. Staffing, resource allocation and increasing demand for services were familiar themes.

It was particularly interesting visiting agencies in both Alberta, Canada and in Alaska to note that many years of education, awareness raising, training, collaborations between agencies and program development had contributed to a high level of awareness among workers and a visibility of the issues around FASD. The existence of specific programs addressing FASD within larger welfare agencies means that FASD issues are entrenched within the agency at an organisational and policy level.

For child protection workers, training is critical – without knowledge of FASD, case workers don't see it, don't suspect it and don't know what to do about it. Once workers have knowledge of the issues, they need training in responding and developing strategies and in appropriate case management models.

I found the most clearly articulated approach to FASD in child protection in Alberta. Donna Debolt and Mary Berube, both having worked as FASD consultants within the child protection sector, coauthored a paper entitled "Guidelines to Intervention in Families," (2002, revised 2003) which outlines how social workers can meet the needs of families and children affected by FASD.

They outline the importance of child protection workers asking the question: Is this family affected by prenatal alcohol exposure? Which individuals are affected? A differential approach needs to be taken to address the specific needs of children, carers and parents.

<b>Individual</b>	<b>Presenting issues</b>	<b>Needs</b>
Child affected by FASD	Difficulty learning Behavioural problems	An early diagnosis of FASD, followed by assessment of strengths and limitations; Protected environments, increased supervision and structure. A supportive family that understands their disabilities; Advocates for home and school A management team, including paediatric care, speech/language, education, skill-building, and behaviour management focussed on prevention of behaviours.
Carer unaffected by FASD	Frustrated In crisis Feels nothing works May want child removed from their care	Ongoing FASD education Support before and after child's diagnosis Grief and loss counselling A case manager Planned respite Connections with other carers
Carer affected by FASD	Likely to have many children they can't care for May deny there are problems or blame others Disorganised May be homeless or transient Difficulty managing time and money May have addictions Likely to have been a victim of sexual assault Struggle to meet own needs	Diagnosis Functional assessment to identify strengths and weaknesses Access to disability services if eligible A structured environment A mentor to act as a "Do For"* Support, guidance and advocacy Prevention of homelessness Prevention of additional pregnancies Ongoing assessment to determine whether a child in their care is at risk, whether the child's needs exceed the parenting capacities of the child.
Non-affected child of affected parent	Parentified Anxious Concerned about the problems in the home Able to demonstrate strengths Will make gains when in improved environment	Safety Basic needs to be met Resilience strengthening Traditional interventions such as therapy A relationship with the biological parent
Affected child of affected parent	As for affected child above, but Unlikely to complain Won't realise anything is wrong in the home	As for affected child above An increased level of supervision to ensure safety as child will not ask for help May need to be in care or have in home supports as needs may exceed parenting capacity.

From Mary Berube and Donna Debolt, 2003

*\*Debolt and Berube refer to a “Do-for” as “an individual who provides respectful remedies for the affected individual, including structure and supervision on an ongoing basis, and without the expectation that client compliance ensures the continuation of the service.” I found this term was used by many workers across Alberta.*

This research has evolved into *Communities of Practice*, a program of best practice in child protection, which was implemented in 2005 in Lethbridge, Alberta. On the basis of the success of the program it has been expanded in 2009 to cover 120 children in three localities and a control group. The primary aim of the project is to increase placement stability for children with FASD. Key elements of the model include:

- Reduced case loads in order to provide a higher ratio of case work hours per child
- A set of standards for assessment and screening, case work, case planning, home visitation, family contact and foster care support
- FASD training for case workers and foster carers
- Limitations on the number of children in each placement
- Different strategies depending on whether the parent also has FASD.

The program was evaluated by Dorothy Badry, who identified areas of improvement for children in the pilot, including:

- Improved placement stability
- Reduced risk behaviours
- Reduced school absences
- Training was valued and carers were invested in the program

Others issues which emerged included:

- Family visitation was a source of conflict and perceived as the major source of disruption in children’s lives by foster carers
- A diagnosis of FASD may impact on the child’s wellbeing and a protocol for disclosure to the children and families needs to be developed
- A limit of two children with FASD in the home was a source of conflict with carers.

The initial challenge of this research was that no prior published research literature existed regarding the care of children with FASD who were in the care of the state.

Dorothy Badry 2009.

## **Care Options for Children with FASD**

The majority of children in care reside in foster care, with residential care generally a last resort for children with behavioural or other issues which prevent them being placed in a family setting. I visited a number of agencies providing accommodation to children and young people including those affected by FASD.

### **Surrounded by Cedar**

Surrounded by Cedar in Vancouver is an innovative service providing foster care and guardianship to indigenous children and young people. Under new legislation, the agency has taken over Guardianship for children in care from the Office for Children,

## Sifton Family and Youth Services

Sifton Family and Youth Services operates a 10 bed youth residential treatment service run by the Office for Children's Services in Lethbridge, Alberta, for young people aged 12-17 with severe behavioural issues. Many of the residents have drug and alcohol issues, and many come from families where parents have addictions. Residents may have been assessed with ADHD or Conduct Disorder, and have histories of struggling to engage in school or other settings. 30-40% of young people are indigenous. Program Director Mark Weninger estimates that half the children in the service at any time have diagnosed or suspected FASD.

Sifton provides a secure care option for two children at any time, who are court-ordered to the service for a 30-day period because their behaviours pose a high risk to themselves or others. The young people in secure placements are unable to leave the facility, while others can engage in community activities. In order to integrate the young people in secure beds with the other residents, the entire facility is locked. Mark indicated that when the agency began taking secure clients, locks were fitted to doors and non-breakable glass was installed. Otherwise there have been no significant modifications to the building. As there are no divisions between young people in secure beds and other residents, the agency can take a higher number of secure placements if needed. At the time I visited, none of the 10 beds were being used for secure placements.

Sifton is a therapeutic service and much of the therapy is conducted 'on the run'. Clients require significant work on developing social skills and day to day functioning. The program is resourced by a part-time psychologist who works with individuals and runs groups. The psychologist also conducts supervision with all case workers. Counselling with young people is very basic, as verbal processing speed is often very slow. A girls group works on issues of self esteem, and anger management is also addressed. Some of the therapies are hands-on. Twice a week residents attend the Humane Society and work with animals which have been abused.

The centre is well resourced with a staffing complement of around 23, including supervisors, case workers, teachers, and a cook. A youth programming coordinator arranges outside activities, and a family support worker arranges family contact for residents and prepares for their return home.

Staff in the agency can see remarkable changes among the most challenging young people, although not all young people are able to maintain these changes when they leave. Mark estimated that the program has a 40% success rate with young people being able to maintain a positive direction for 12 months after leaving the program. He emphasised the role of neuropsychological assessments identifying a young person's strengths as well as deficits in order to help young people become successful. He reported that working with indigenous children poses one of the biggest challenges and an area in which the service has fewer successes. The program is working with the University of Calgary in relation to data collection and analysis.

## 3M - Wraparound Model

Between 1998 – 2004, Alaska became dependent on Residential Psychiatric Treatment Centers (RPTC) for treatment of severely emotionally disturbed young people. During this time, placement of children out of the state grew by 800%. It was estimated that 56% of children placed out of state had been prenatally exposed to alcohol.

Widespread concerns existed about the displacement of young people from their communities and families, and loss of cultural connections. The cost was high, and Alaska was not building local service capacity. In response to these issues, the Alaskan government developed an initiative called *Bring the Kids Home*, a partnership between government, families, tribes and community agencies. The Office of Children's Services is a key player in implementation of the initiative which aims to:

- Significantly reduce the numbers of children and youth in out-of-state care and ensure that the future use of out-of-state facilities is kept to a minimum.
- Build the capacity within Alaska to serve children with all intensities of need.
- Develop an integrated, seamless system that will serve children in the most culturally competent, least restrictive setting, and as close to home as possible.<sup>16</sup>

Funds are being directed towards community based accommodation and support services. These include short term models, aiming to address crisis and assist children to return home, and group homes based on behavioural treatment models.

The Federal Government has provided \$15.4 million over 5 years to the Alaska Department of Health and Social Services to establish home and community based alternatives to residential care for young people aged 14-21 who have been diagnosed with Severe Emotional Disturbance or FASD. It has been recognised that traditional treatment programs have had very limited success with this target group, and new models of service provision are needed. Outcomes of the demonstration project will be used to inform development of a national treatment model.

The program commenced in 2007 and is known as the 3M model – which stands for Modelling, to learn desired behaviours, Mentoring, to reinforce consistency in desired behaviours, and Monitoring, to continue collect and evaluate data. Also known as the Wraparound model, the model is home and community based, uses a strengths approach and draws on natural and inclusive supports and cultural appropriate interventions. The first stage of the program focussed on young people currently living in residential therapeutic care to develop alternative home and community based options for their care.<sup>17</sup>

## **Centres for FASD**

I visited Centres for FASD in British Columbia and Alberta, Canada. FASD Centres bring together a range of services including diagnosis and support together with education and research.

## **The Asante Centre for Fetal Alcohol Syndrome**

The Asante Centre for Fetal Alcohol Syndrome in Maple Ridge, British Columbia, is a registered charity and has been operating for eight years. Services provided include

- Diagnostic services for children, young people and adults by a multidisciplinary team
- Outreach service providing diagnosis to remote communities
- Coordinated care plans for the future care of children or adults affected by FASD
- Support services before, during and after diagnosis

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<sup>16</sup> [www.hss.state.ak.us/commissioner/btkh/default.htm](http://www.hss.state.ak.us/commissioner/btkh/default.htm)

<sup>17</sup> [www.hss.state.ak.us/commissioner/fasd-rptc-whatish.htm](http://www.hss.state.ak.us/commissioner/fasd-rptc-whatish.htm)

- Counselling and family centred intervention services such as behaviour consultations, caregiver therapy sessions and play groups
- A youth justice program providing assessment and support for young people before the courts
- Professional consultation services
- Speech and language services
- Onsite experiential learning and Multidisciplinary Diagnostic Team training
- Education and training
- Networking
- Maintaining a clinical database
- Research.

Over two and a half days I was fortunate to observe a FASD diagnostic clinic at the Asante Centre in Maple Ridge. The centre sees a combination of clients referred through the public health system, and private clients such as families seeking pre-adoption assessments. I learnt that this was a process required in the child protection system, as the likely costs of long term care are calculated prior to an adoption arrangement – and a diagnosis of FASD can result in considerable long term costs.

The clinic is led by Dr Kwodwo Asante, a paediatrician who has been interested in FASD since working in the Yukon and Northern Territories of Canada where he observed children with alcohol related birth defects. Audrey Salahub is the Executive Officer and has worked in the area of FAS for many years. The diagnostic team includes Dr Julianne Conry, child neuropsychologist, who participated in the development of the Canadian Guidelines for Diagnosis of FASD, and Krystal Bodaly, a speech and language pathologist.

It was particularly interesting to see the importance of functional assessment. The Asante Centre uses particular tools, in particular the Vineland Adaptive Behaviour Scale which assesses communication, daily living and socialisation. A child with FASD might score in normal ranges for IQ or literacy, but is likely to be assessed with functional impairments. Such an assessment also identifies the child's strengths and provides guidance for future intervention and planning.

Audrey Salahub coordinates post-diagnosis support to families, and emphasises the importance of not leaving a family unsupported during what can be a difficult time. As a parent of a child with FAS, Audrey is a passionate and skilled advocate and was fundamental in the establishment of the Asante Centre.

## The Lakeland Centre for FASD

The Lakeland Centre for FASD in Cold Lake, Alberta, grew out of a regional committee which formed in 1994 in order to host an FAS conference. The committee engaged in prevention campaigns, developed resources and training, and hosted other conferences. In 2000 the committee sent members to Seattle to investigate the University of Washington diagnosis model and implemented this model in Cold Lake drawing on in-kind support from professionals. The Centre provides a range of services including:

- Children's diagnostic team
- Adult diagnostic team
- Pre and post diagnosis support services
- Mothers to Be Mentorship Program
- Training and education

- Resource development

Cold Lake is a town of 11,000 people in the north of Alberta. The town has an Aboriginal population of 8.7%. The Lakeland Centre services the north-east region of the province, which includes four smaller towns, seven First Nations Communities and four Metis settlements, including surrounding communities. I spent several days with Audrey McFarlane, Executive Director of the Lakeland Centre for FASD and met with staff from each of the program areas.

The Lakeland Centre operates one of 11 diagnostic teams across Alberta, more than in any other province of Canada. Diagnosis is based on the FASD 4-Digit Code, and assessments can be conducted in the community. The Children's team meets twice a month, and the adult team meets monthly. The Centre employs a Diagnostic Service Manager, Donna Fries, who coordinates the process and a Referral Coordinator who provides pre-diagnostic coordination for 15+ age group.

The diagnostic process is as follows:

- the child is seen by a psychologist before the clinic
- facial measurements are taken by a paediatrician
- speech and OT tests are conducted
- the child is interviewed depending on age
- parents or carers are interviewed to gather information about family issues
- confirmation of maternal alcohol use is sought by the Coordinator prior to the clinic
- the clinic uses the 4-Digit Diagnostic code
- On the day of clinic, a diagnosis is made and a report containing recommendations for the child developed by the team
- The diagnosis includes the 4-Digit Code diagnosis, any other conditions or disabilities, an assessment of the child's strengths and weaknesses with a focus on positives, and a list of recommendations (Between 6-12)
- Every child and adult diagnosed gets a copy of a book "Calming the Storm" produced by the Centre.

Adult diagnosis is similar, although in some cases family or carers may not be involved in the process.

Since the Centre began diagnosing children nine years ago, the profile of the agency has increased and greater awareness is leading to improved referrals. Significant work has been done with schools in the area, and schools now frequently contact the Centre for advice and make referrals for diagnosis. The primary referral source is from Elementary schools (kindergarten to grade 4).

Audrey indicated that 40% of children seen by the Centre are living with their birth family and this proportion is gradually rising. In the first years of the Centre, the majority of referrals came from Children's Services. Gradually referrals started to come for children living with biological parents, as schools and family members increasingly made referrals. The Centre now serves entire multigenerational families, and is considered a safe place to come for help and support.

Receiving a diagnosis on the FASD spectrum is challenging and staff need to emphasise the positives and strengths of the child and family in the process. Recommendations coming from the diagnosis are critical, as these provide direction for how the child's needs could best be met in the home, school and community. Recommendations can be quite specific because members

of the diagnostic team know what services are available in the community. Sometimes services can be provided by family members.

I asked about shame and blame in diagnosis, particularly in a rural community. Audrey identified that sometimes in families in conflict, if the mother is still using alcohol or drugs, and there is ongoing family conflict, a diagnosis may lead to family members blaming the mother. Some communities are very open about FASD and want information and to raise awareness. Other communities are more closed and don't want to talk about the issues. These differing community perceptions will influence how the individual family will manage the diagnosis. On occasion Children's Services may request that the report is not distributed to family if the matter is sensitive.

Although it can be difficult for a young person receive a diagnosis, it can also be helpful for them to gain an understanding of why they function the way they do. The emphasis on the strengths and positives of the young person can also make the message easier to receive. However an alcohol related diagnosis can be very emotionally challenging.

Post-diagnosis information for schools identifies the child's learning rate and strengths, helping the schools build programs and problem-solve around the student. This may mean adaptations such as shorter school days or reducing the stimulation in the classroom. The Centre helps the school to acknowledge the parents' knowledge about the child, and by working with schools to create positive environments, reassures parents that school is a safe place for their child to be.

In relation to the adult team, recommendations may focus on areas such as employment, disability services, or corrections. While some adults may be linked into disability services, these services don't always fit the FASD population. Services may work on the basis of the individual's 'choice' to receive a service – but this model doesn't work with FASD. There is increasing evidence that new approaches to young people and adults with FASD are needed

The Centre employs two staff as FASD Coordinators who work to support children and their families in the six months post diagnosis, and one Adult FASD Coordinator. The Coordinators resource and support the individual and their support network to implement the recommendations in the report. The role includes connecting with families after the clinic and helping them share the information with others including extended family and schools. The Coordinators model how to talk about a diagnosis and model advocating for the child with the school. Coordinators support the family to become a good advocate for the child. They also prepare the school to receive the diagnosis in a non-judgemental way. Audrey indicated that the work done by the Centre with families has paid off, as schools are now very knowledgeable about FASD and are able to take over once information and recommendations have been provided.

A child's foster family may need information and support, but a birth family will need additional support. With the rise in birth families seeking diagnosis, the issues in supporting families post-diagnosis are becoming more complex as families may have higher needs.

Post-diagnosis support to adults can be more challenging as fewer services are likely to be involved. FASD is classified as a disability in Alberta, and individuals can qualify for disability employment services. A functional assessment may indicate whether the adult is able to engage in employment or training. There may be a recommendation that the adult requires income management. Individuals can seek to have their funds managed by a trustee, and this can assist in stabilising the adult. Audrey identified that as more adults are being diagnosed, the lack of supports is becoming more evident. As a result the Coordinator may have a more hands

on role in assisting the individual to become stabilised and making links to services or sourcing supports.

A new position has been created, that of Transition Worker, to provide a bridge between adult and child services for young people transitioning to adulthood. The aim of this position is to develop pathways between the two service systems.

The Centre has a strong profile in education and training in the community and has produced a number of resources for carers, family members and professionals. Mentors conduct regular presentations and education campaigns with schools about risks of alcohol in pregnancy. The Center runs a popular annual “Mocktail Night” in which high school students compete with community groups to design non-alcohol drinks. The drinks are photographed and a calendar is produced as a promotional tool.

The Centre runs a series of annual summer camps for children with FASD. This provides respite for parents and a positive experience for children in a setting and a program chosen with their needs in mind. Parents enjoy receiving positive feedback about their children, and can appreciate their child’s strengths and attributes.

In 2008 the Lakeland Centre became one of Alberta’s Regional FASD Service Networks, with an increased focus on diagnosis and interventions across the lifespan and targeted prevention services. Priorities for the Centre include the development of accommodation options for young people with FASD.

## **Preventing Future Alcohol Affected Pregnancies**

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

The Parent-Child Assistance Program (PCAP) has been developed and managed by Dr Therese Grant from the University of Washington since its inception in 1991. The model evolved from Dr Grant’s work in the Fetal Alcohol and Drug Unit, with the aim of establishing whether an intensive, paraprofessional support program targeting high risk mothers would prevent prenatal exposure to drugs or alcohol in future pregnancies.

PCAP is a three year, relationship-based, intensive home visitation program for women who are at high risk of giving birth to a child affected by FASD. Women are identified either because they are using substances in pregnancy, or because they have already given birth to a child with FASD. Intervention is focussed on preventing further alcohol affected pregnancies.

The model has now been expanded to support more than 500 families in Washington and has been replicated in many locations in the US and Canada. Para-professional mentors conduct home visits to a small case load of women over three years. The program design recognises the transience and pattern of service disengagement common among individuals leading high-risk lifestyles, and delivers services accordingly. Mentors aim to work with women to either engage in substance abuse treatment, reliable birth control or both. By identifying and prioritising small goals which will make a positive difference to each woman (using the “Difference Game” developed by Dr Grant<sup>18</sup>), mentors are able to build relationships and through this process, work on longer term goals. The program emphasises practical support and assistance

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<sup>18</sup> [http://depts.washington.edu/fadu/Difference\\_Game\\_Article.pdf](http://depts.washington.edu/fadu/Difference_Game_Article.pdf)

with tasks such as shopping or transport, which can pose significant difficulties to women who lack resources or who are in poor health. Women are never asked to leave the program.

*The lives of mothers enrolled in PCAP are characterized by poverty, upbringing by substance-abusing parents, childhood abuse, abusive adult relationships, trouble with the law, and chaotic and unstable living conditions. As products of this background they are often distrustful of community service agencies. PCAP paraprofessional advocates have themselves overcome many difficult life circumstances prior to achieving successes in school, jobs, and parenting. Because of this, the advocates are able to inspire trust and hope, and act as realistic role models and guides toward meaningful change.*

### *PCAP Program Information*

PCAP is a research program, and Therese reviews the assessments of participants, conducted at regular intervals to assess alcohol and drug use and quality of life, and also reviews supervision notes of mentors. She provides regular data reports to each program site, identifying the gains made in relation to the program goals of reducing the risk of alcohol affected pregnancies, and also in relation to improved quality of life of participants. These reports are seen to contribute to staff retention, as mentors receive regular, high quality feedback about their achievements and gains as well as areas for improvement.

Program data is positive and PCAP has been listed with the US Substance Abuse and Mental Health Services Administration (SAMHSA) National Registry of Evidence-based Programs and Practices, having been reviewed by independent reviewers.

The effectiveness of PCAP has been demonstrated. Among 156 PCAP mothers recently exiting the program: 88% completed alcohol/drug treatment; 47% had been abstinent from alcohol/drugs for more than 6 months at program exit, and 89% had more than 6 months abstinence from alcohol/drugs while in the program; 73% were using a contraceptive method on a regular basis, and 51% were using a more reliable method; 25% delivered a subsequent child, and of these 41% were clean and sober throughout the pregnancy, and another 37% quit using alcohol and drugs after pregnancy recognition.

A study of 45 original PCAP clients followed-up an average of 2.5 years after graduation indicated that benefits of the program were sustained. The proportion of clients abstinent from alcohol and drugs for at least 6 months at the time of interview increased significantly from 31% at graduation to 51% at follow-up. Those abstinent for at least one year increased from 38% to 48%. Subsequent births decreased from 27% during the program to 9% during the follow-up period.

<http://depts.washington.edu/fadu/>

Therese is currently working on a new paper looking at predictions for women retaining the care of their children. She has identified that the possibility of having children returned to mothers is a motivating factor to their engagement in the program.

I visited the First Steps program in Lethbridge and Mothers-To-Be-Mentors in Cold Lake, both in Alberta. With some variations these are based on the PCAP model.

First Steps in Lethbridge, Alberta, is located in a regional health services where it is linked to the Home Visitation Service which supports new parents. Mothers-To-Be-Mentors is a program of the Lakeland Centre for FASD in Cold Lake, Alberta, which also provides diagnostic services. Staff of both agencies identified similar themes:

- Staff retention was high, due in part to the feedback on client outcomes provided and support for mentors
- There was difficulty accessing residential rehabilitation services, particularly in more remote areas and where women had children in their care
- Fidelity to the model is important
- Women identified as using drugs (rather than alcohol) are accepted into the program, as women may identify drug use as their primary issue but this frequently is accompanied by alcohol use
- A focus on birth control is particularly important if women are unable to access detox services. Women's quality of life improves if they do not give birth to further children who are removed from their care
- Staff observe a pattern of women falling repeatedly pregnant until they are able to keep one of their children
- There can be conflict between the voluntary nature of the program and the child protection requirement for women to participate.

Audrey McFarlane of the Lakeland Centre for FASD also identified the young age of mothers in the program (many under 18) and reported that half the women in the program were themselves exposed to alcohol in utero, reflecting the intergenerational nature of FASD.

## **Developmental Support Services**

Children with FASD require developmental support. I visited several services with a focus on addressing the developmental needs of disadvantaged or at-risk children. Such services are ideal locations for the identification of and early intervention for FASD in children and often lead to referrals for diagnosis.

## **Childhaven**

Childhaven in Seattle provides long daycare for children who are either subject to child protection intervention, or whose parents are engaging in substance abuse treatment. These children are particularly vulnerable and are at high risk for FASD. Established as a child abuse prevention program, founder Patrick Gogerty believed that some of the most at-risk children are those aged 0-2 who are not engaged in school or pre-school and where social isolation means their welfare is not being monitored by others.

The centre has a unique approach. All children are collected and taken home each day which allows staff to monitor the home environment. Staff have training in play therapy and low staff:child ratios apply. Children are assessed on entry using the *Diagnostic Classification of Mental Health And Development Disorders Of Infancy and Early Childhood* as well as medical, vision and hearing assessments, which are repeated at intervals to identify any areas of delay. Assessments can serve as a screening process for FASD. Each child has an individual treatment plan with specific goals. Ongoing and intensive therapies are provided on-site, which means that children's development can progress independently of the parent's capacity to address these needs. Case managers ensure children receive funding for the services they require.

The therapeutic setting assists children to catch up developmentally and reduces the long term impact of abuse and neglect. Supervision to staff is provided by Dr Bruce Perry, a clinician and international authority on the effect of trauma on children's brain development. Programs run year-round, rather than being based on the school year, so children receive therapy all year. Parents are encouraged to visit, receive coaching and parenting skills training, and receive regular feedback through monthly home visits. Reports on progress are provided to the child protection agency.

While the program cannot address all issues of concern within the family, the intensive therapeutic environment ensures that children have a safe place in which to develop and grow to the best of their ability, and that all possible interventions are in place to enable children to overcome early disadvantage. Children with FASD can confidently be identified and interventions put in place. Childhaven evaluations have identified very positive outcomes for children and these outcomes had a lasting impact.<sup>19</sup>

## Head Start

Head Start is a comprehensive child development program for children aged 0-5, which focuses on health, early education, medical and dental care, nutrition, cultural heritage and the love and support of parents and family. Children enrolling in the program go through an application and screening process, which identifies any developmental or social issues which may require support. A plan is developed for each child outlining their health, development, learning and family support requirements.<sup>20</sup>

I visited several of the Head Start sites in Juneau, Alaska, auspiced by Central Council of the Tlingit and Haida Indian Tribes of Alaska (CCTHITA), and one in the remote village of Hoonah. The program runs Centre-based care for preschool aged children, while addressing the goals in each child's plan. Children and families are supported to ensure children are dressed appropriately for the weather and for play; two healthy meals are provided each day; discipline is appropriate; and children are collected and dropped off each day.

Head Start is a site for early intervention. Children requiring assessments or therapeutic interventions can receive them at the centre. Parents are supported to become involved in the centres through parent committees and risk issues can be identified through daily contact between staff and families.

Ric Iannolino, Juneau FASD Diagnostic Clinic Coordinator, identified that referrals to the FASD Diagnostic Clinic often come through Head Start centres, as the developmental assessments identify problematic behaviours or issues. Ric also conducts FASD training with the program providers, and program staff have a good awareness of FASD.

## Supports to Individuals and Families Affected by FASD

Individuals with FASD and their families need support at the time of diagnosis, which can generally be provided through a diagnostic clinic. However many families and carers require support to manage behaviours, deal with transitions such as from adolescence to adulthood, and manage participation in schools and workplaces. A range of service models exists across agencies to provide targeted responses to individuals, families and carers.

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<sup>19</sup> [www.childhaven.org](http://www.childhaven.org)

<sup>20</sup> [http://www.acf.hhs.gov/programs/region10/programs/region\\_10\\_head\\_start.html](http://www.acf.hhs.gov/programs/region10/programs/region_10_head_start.html)

## Themes in Service Provision

Services for individuals with FASD differ to generic family support services through the specific knowledge of FASD issues and themes, and through the development of services targeted to address these issues. I met with Donna Debolt, a key person in FASD service provision in Canada, with 26 years experience in the child protection sector, and now working as FASD consultant. She has been involved in the development of many of the FASD initiatives in Lethbridge and across Alberta and conducts training across the province and other parts of Canada. She coordinates the Communities of Practice project supporting children in the child protection system.

Through her training, curriculum development and participation in FASD program design, Donna has promoted some themes in FASD which were repeatedly referred to by practitioners in Alberta. I attended a training workshop Donna conducted in Lethbridge. Some of her key messages which have been incorporated in FASD-specific service design and delivery include:

### **The impact of FASD on adaptive functioning affects an adult's interaction with the service system**

- a person with FASD will say they understand what they are being told, but if asked to explain they are likely to 'get mad'
- they would rather be in trouble than look stupid
- they don't think they need help and will often say they don't need a service
- as a result they are often considered ineligible for services

### **Traditional risk assessments don't work with people with FASD**

- individuals with FASD will attempt suicide spontaneously, impulsively, without planning and in reaction to a negative event – these risks may not be identified in traditional risk assessments which focus on planning, intention and access to means.
- Risk assessments which rely on the client having an understanding of cause and effect don't work with FASD affected individuals
- Individuals with FASD can't be relied on to keep themselves safe - safety will need to be provided through a safe environment and supervision.
- Addiction can be more successfully managed through removing supply – rather than through cognitive/behavioural interventions
- Interviewing children with FASD will not provide a full picture because children often don't remember what happened yesterday and may not give an accurate account of events. Children with FASD may not complain of pain or discomfort.
- Self harming can be learned behaviour – a change of environment may be more successful than counselling which relies on cognitive behavioural interventions

### **Interventions need to acknowledge that adults with FASD have brain damage**

- Child protection interventions need to recognise that an addiction may be masking a brain injury – the parent may give up alcohol or drugs but still be unable to parent due to functional impairment.

- Agencies often expect too much of individuals with FASD and set them up to fail. This can put people at risk through lack of supervision and support. A mother who says she can make up a baby bottle correctly still needs monitoring if it is known that she has a brain injury.
- Probation conditions need to recognise that individuals with FASD will fail to keep curfews, requirements not to drink alcohol, or other restrictions – they may need supervision to maintain their own and others' safety.

### **Competence leads to Compliance leads to Engagement**

- Interventions with children or adults with FASD should create opportunities for the individual to be competent – increase the time spent by the individual doing what they are already good at.
- If an individual feels competent, they will be more open to engagement and this will build compliance
- The goal of a child attending school may not be literacy, it may be that everyone wants the child to be in the class – an experience of feeling competent and connected.

### **FASD Key Worker Program**

The FASD Key Worker Program places a support worker for children and families affected by FASD into a more generic welfare agency. I visited the Victoria Native Friendship Society in Victoria, British Columbia, which provides a range of community services including career and education services, early childhood development services and youth services.

April Macri is the FASD Key Worker and supports 18-20 families, children and individuals with FASD in Victoria. She is one of several Key Workers located in various agencies in the region. FASD Diagnosis occurs at the Queen Alexandra Children's Centre. The program is managed by the Aboriginal Early Intervention Team which also oversees the Aboriginal Infant Development Program which is an important source of referrals. However the majority of referrals are for children over the age of six or seven, as often children are not diagnosed before this age.

April estimated that about half of the children accessing the program are in foster care. The FASD Key Worker program can tailor support to the needs of each family or individual. In some cases the worker will participate in mediation with the Department of Child Protection regarding whether the child can return home to birth parents. The worker also provides post-diagnosis support, counselling, education and training, resources on FASD and can act as an advocate with the child's school. The worker can also supervise access visits. Each family receives a visit approximately fortnightly. The worker aims to develop relationships with the families in order that the families feel confident in seeking out support, when needed.

Training is provided though Whitecrow Village, a centre for FASD education and training in British Columbia, and many resources have been developed by the Government in Alberta which are accessed online.

Locating a FASD Key Worker within a support service in the Aboriginal community means that issues of FASD are embedded in the agency and can be kept on the agenda.

## FASD Community Outreach Program

McMan Youth Family and Community Services is a non-government agency which provides a range of services from several sites in Alberta, including a FASD Community Outreach Program. Coordinated by Laura Elliott, this service provides education, information, advocacy and support to parents and carers of individuals with FASD. The program works with 9-15 families using a coaching model. The program draws on Donna Debolt's model of support to carers, including regular planned respite, FASD training, coaching, and grief and loss counselling. McMan was one provided with additional funds under the Regional FASD Network with the requirement that services be delivered across the lifespan, rather than directed only at children and young people.

In 2009 McMan commenced a Life Coach program, employing two workers to support individuals with FASD, with the aim of preventing secondary disabilities. The Life Coaches take young people to appointments, drive them to work, prompt them to take medication, and work on daily living skills. The program is loosely based on the PCAP model being an intensive outreach relationship-based program.

Laura conducts FASD training including sessions in schools, teacher training, and also teaches at Lethbridge college in the FASD course. She is contributing to the writing of a new case management module under development.

## Family Support Programs

Catholic Social Services in Alberta is a not-for-profit agency servicing over 60,000 individuals a year with a range of programs including foster care, aged and disability services, corrections and substance abuse services. The agency provides a range of programs to support individuals with FASD and their families and carers across multiple sites. A First Steps program is offered, based on the PCAP model explored above. Other services are modelled on PCAP principles of long term, relationship based, outreach support.

Step by Step Program works with adults with FASD who are parenting children over a 3 year period. The McDaniel Youth Program provides similar support to young people aged 14-19 who have been diagnosed with FASD, with the aim of providing support over three years to support the transition to adulthood.

The agency also offers Coaching Families, a program supporting carers of children with FASD to improve wellbeing and stability, to enhance protective factors and to decrease the risk of secondary disabilities.

An evaluation of three programs found that needs of participants decreased over time, demonstrating the effectiveness of the programs in delivering outcomes.<sup>21</sup>

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<sup>21</sup> Rasmussen, R, Hennevald D, Badry D and Denys K. *The Effectiveness of FASD Programs on Outcomes for At-Risk Mothers, Families and Parents with FASD*, Conference paper, 3<sup>rd</sup> International Conference on FASD 2009

The program also showed the benefits of FASD-specific service provision within the framework of a large NGO agency. Staff can consult with others in the agency when an individual with FASD presents at any part of the service system about appropriate service pathways and responses. Staff awareness of FASD is also raised through co-location with a FASD-specific service.

## **Young People with FASD in the Criminal Justice System**

Involvement in the criminal justice system is common among individuals with FASD – Ann Streissguth identified that 60% of people with FASD aged 12 and over had been in trouble with the law. Young people with FASD are disadvantaged in the legal system due to the nature of their brain injury. Difficulties in memory, abstract thinking and understanding of cause and effect lead to problems such as:

- admitting involvement in crimes
- giving false confessions
- forgetting what they are in court for
- not learning from experience and repeating the same crimes over and over again.
- not understanding the implications of a guilty or not guilty plea
- not seeing prison as a deterrent
- not showing remorse in court
- not succeeding in restorative justice processes.

Lawyer David Boulding's paper "Mistakes I have made with FAS Clients"<sup>22</sup> lists errors he feels he made in dealing with people with FAS and FAE – many of which relate to assuming that the individual understood what was happening. Being asked to look at a situation from someone else's perspective may be too complex. Young people with FASD don't recognise the social cues that tell them to show empathy or remorse and don't impress judges and magistrates.

### **Community Justice Project, Lethbridge**

The Community Justice Project in Lethbridge, Alberta, provides a service to young people in the criminal justice system where FASD is diagnosed or suspected. Jerry Gurr is a Lethbridge police officer who manages the project, which aims to divert young people with FASD from the criminal justice system, to identify and advocate for high risk young people, to make court recommendations and to influence case management.

Jerry Gurr reviews the court lists each week to identify young people aged 12-17, and if it is identified that a child has FASD, Jerry will become involved in assessment and case planning. This involves gathering information about the young person, trying to understand the offences, the young person's behaviours and triggers, and opportunities for diversion, and working with carers, families and school to make environmental changes to improve the young person's capacity not to reoffend. Jerry has input to probation conditions and suggestions conditions that a young person will have capacity to comply with. He develops case plans to assist young people to avoid reoffending, and advocates for the young person with the police prosecutor and the judge.

The project aims to reduce the time spent by young people with FASD in custody, but also to prevent future offences and ensure that both the young person, their family and the community

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<sup>22</sup> [www.davidboulding.com](http://www.davidboulding.com)

is safer. Jerry advocates both that the disability of FASD is taken into account during sentencing, and that more appropriate and well informed plans are put into place to prevent future offences being committed.

Because the position is collocated with police, information is readily shared, communication channels exist and Jerry has access to prosecutors and lawyers. Many young people are found suitable for diversion programs and the effectiveness of diversion among young people in general is well known. Outcomes can be less punitive and are more likely to lead to behaviour change.

Jerry also conducts training with new police recruits – he estimates that since the project commenced, 50% of police in Lethbridge have received some FASD training. The Project has seen a decrease in reoffending by young people, and has proven that it can identify high risk young people and divert them from the justice system. The project has contributed to better education for family members and schools to assist young people to avoid the criminal system.

The Project literature indicates that the project has evolved from reacting to young people becoming involved in the criminal system, to being proactive in the community to increase awareness of FASD and identifying young people at risk, in an attempt to divert these young people before they become involved with the courts.

## **Regional Responses to FASD**

I spent time in both Alberta, Canada, and Juneau, Alaska, meeting a range of service providers and policy makers involved in the issue of FASD. Regional coordination of service delivery, regional networks, and state responses to FASD all impact on delivery of services within a region. Training packages on FASD which are delivered across a region can promote consistency of knowledge about FASD among service providers.

### **Responses to FASD in Alberta, Canada**

Alberta has been a leader in the field of FASD and child protection practice. Interest in this issue can be traced back to a training conference held in Lethbridge in 1992 by Children's Services. It was identified that training for workers about the unique needs of children with FASD was required. Practice standards were developed and in the early 1990s Children's Services developed two FASD Specialist positions, and appointed Mary Berube and Donna Debolt. These workers consulted and trained child protection workers and foster carers across Alberta – Donna Debolt estimates that 10,000 people received FASD training between 1998-2003. The FASD programs First Steps (modelled on PCAP) commenced in Lethbridge in 1997 and the Lethbridge Community Justice Project in 1999.<sup>23</sup>

Government investment in FASD has been coordinated through the Alberta FASD Cross Ministry Committee. The Alberta Partnership on FAS was established in 1998 to improve coordination between government around FAS, and evolved in 2002 into the Alberta FASD Cross Ministry Committee. The aim of this Committee is to develop a coordinated framework for addressing FASD in the province of Alberta. The Committee is led by Alberta Children and Youth Services and includes 10 Ministries and five statutory bodies, including those responsible for health, Aboriginal relations, education, seniors, employment, justice and alcohol regulation.

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<sup>23</sup> Badry, D, Pelech W and Norman D. 2005 Fetal Alcohol Spectrum Disorder Practice Standards Evaluation Project, Final Report, Centre for Social Work Research and Development, October 2005

In 2005 \$1.84 million was allocated to a series of demonstration projects which had been identified in an evaluation as “emerging best practices’ in FASD. Alberta now has a FASD 10 Year Strategic Plan which provides funding to enable service provision to be expanded across the Province with a focus on addressing the impact of FASD across the lifespan. Regional FASD service networks are funded to provide diagnosis and assessment, prevention and support services. The Networks are responsible for developing priorities for funding and are responsible for allocation in their region.<sup>24</sup>

Alberta is a member of the Canada Northwest Fetal Alcohol Spectrum Disorder Partnership (CNFASDP), which uses a cross-jurisdictional approach and a common approach to prevention and support.

The Alberta FASD 10 Year Strategic Plan identifies key areas for action:

1. Awareness and Prevention
2. Assessment and Diagnosis
3. Support for Individuals and Caregivers
4. Training and education
5. Strategic Planning
6. Research and Evaluation
7. Stakeholder engagement

Vision: That Alberta has a comprehensive and coordinated provincial response to Fetal Alcohol Spectrum Disorder across the lifespan and a continuum of services that is respectful of individual, family, culture and community diversity.

*(FASD 10 Year Strategic Plan 2007-2017)*

## Lethbridge, Alberta

Lethbridge is the largest city in Southern Alberta and a hub for service delivery in the region. I met with Hazel Mitchell, the Network Coordinator for South Alberta. The Network includes a Leadership Team which includes all the agencies receiving FASD funding, as well as other key stakeholders. Collaboration between agencies ensures that a consistent approach is taken to FASD across agencies. Leadership meetings also ensure that agencies have good service networks to improve client service pathways, and identify training needs and issues within the region. The South Alberta network also plays a role in raising awareness of FASD, currently working with the disability sector to ensure that adult disability services are responsive to individuals with FASD. Hazel identified challenges such as the focus within disability services on increasing client independence, when this message may be counter productive with FASD-affected adults who may need to accept that they need help and support in their daily lives.

I met with Paul Henderson, CEO of PEAK Vocational and Support Services, a program which provides support to adults with intellectual disabilities, head injuries, mental health issues and FASD to enter into employment. Paul identified that a specific focus on the needs of adults with FASD ensured that appropriate programs were developed. For example, a work-based program recognises that adults with FASD have poor sleep patterns and sensory issues, so each day the program starts with a group walk in order to get participants moving, active and ready to participate. The program also promotes the practice of individuals spending time doing

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<sup>24</sup> [http://www.fasd-cmc.alberta.ca/home/documents/FASD\\_10yr\\_plan\\_FINAL.pdf](http://www.fasd-cmc.alberta.ca/home/documents/FASD_10yr_plan_FINAL.pdf)

things they are good at, rather than learning new skills – a theme raised by Donna Debolt in her training workshops.

PEAK is now involved in the development of an Adult Justice Program based on the Community Justice Program in Lethbridge for young people. This project commenced in February 2009 and assists adults with FASD to navigate the legal system and provides front line support.

To address another local service gap, the South Alberta FASD Network is working on establishing a diagnostic clinic in Lethbridge which will include adult diagnosis, similar to the model provided in Cold Lake. The implementation of the Communities of Practice model is also a focus within the region.

The Network regularly draws on the skills of Donna Debolt, a well respected FASD consultant who has had a key role in Lethbridge and across Alberta (and other provinces of Canada) in developing the skills and knowledge of the FASD sector. Donna is based in Edmonton and runs regular training across Alberta. Donna provides general FASD education, case management, and service development for individuals with FASD.

Lethbridge College conducts a one-year *Fetal Alcohol Spectrum Disorder Education Certificate* which is conducted online and includes units on intervention strategies for FASD, brain and behaviour, applied behaviour analysis and positive behaviour support, case management and prevention of FASD. Two practicums are incorporated. The course allows graduates to transfer into the second year of a Disability and Community Rehabilitation program. The core units are considered mandatory training among service providers – Introduction to FASD, and Intervention Strategies for FASD.

Kimber Norbury Sulin from Lethbridge College indicated that while FASD issues are included within general developmental disability education, the needs of individuals with FASD can be better met through provision of more focussed training. Models of service delivery that encourage individuals to become independent of support often fail for individuals with FASD, and these people cycle back through services. She identified that the standard approach to disability services is often unsuccessful with this group, and that the College is working to provide specific training on case management and service planning for FASD affected individuals. Donna Debolt is participating in the development of curriculum.

Donna also consulted with the Toronto FASD Training, Consultation and Mentoring Leadership Team, which aimed to enhance FASD related services by nominating staff from member agencies to be skilled up as FASD trainers and mentors. Through the provision of intensive training, these individuals gained skills in FASD education and training, and in providing specific consultation services to children and families. These trainer/mentors now resource other agencies in Toronto, having provided FASD consultation sessions for 150 children and training to 890 staff and carers.

This project is a model of building community capacity designed to respond to FASD without relying on funding to establish a new agency or program. Agencies volunteered their staff to become FASD consultants and these individuals now provide an in-kind service to other agencies. There are now a panel of FASD mentors who can be requested to provide a FASD consultation or training session. In addition to the services provided, the project has raised awareness of FASD among a service network.

## Responses to FASD in Alaska

The State of Alaska established the Office of FAS within the Department of Health and Social Services in 1998 to address what was perceived as a devastating problem of prenatal exposure to alcohol. Alaska reported the fourth highest rate of alcohol consumption in the United States, and high rates of binge drinking.

In 2000, Alaska received 5-year funding of \$US 29 million to build a statewide integrated approach to FAS prevention. The multidisciplinary model of diagnosis for children, using the 4-Digit FASD Diagnostic Code, was implemented. It was intended that programs would become self funding through Medicaid rebates, and funding was incrementally reduced each year.

An evaluation of data from the Alaska Birth Defects registry in 2006 indicated that:

- 951 children have been assessed for FASD since 1999
- Of these, 9% of children were diagnosed with FAS,
- 50% were diagnosed with Static Encephalopathy
- 34% were diagnosed with Neurobehavioural Disorder

Of the children referred for diagnosis:

- 50.3% of children referred for diagnosis were Alaskan Native
- 26.6% were living with one or both natural parents
- 59.3% were in adoptive or foster care
- 19.5% of children had older siblings with an FASD diagnosis
- 15.3% had a younger sibling with a diagnosis

Summary Report of the Alaska Multidisciplinary FASD Diagnostic Team Data, Behavioral Health Research and Services, University of Alaska Anchorage, 2006.

Alaska currently funds FASD programs at an annual cost of \$1.4m US. There are three components to the programs:

- Community based diagnostic services – 8 teams are currently operating
- Training on FASD for service providers
- Community based strategies to prevent and intervene in FASD related issues.

Community based programs include an annual family FASD camp; school based education for secondary students on the risks of alcohol in pregnancy; and early substance-use screening in pregnancy.

FASD training for service providers is provided through two courses developed by the Office of FAS and the University of Alaska:

FASD 101—Disabilities of Discovery: Insights into Brain-Based Disorders

FASD 201—Developing Successful Interventions and Supports

There are 42 active FAS trainers in Alaska and over 3200 individuals have participated in training, with a 31% increase in FASD knowledge across the state.<sup>25</sup>

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<sup>25</sup> Alaska State Budget, Department of Health and Social Services, AK Fetal Alcohol Syndrome Program financial year 2008.

The University of Alaska (Anchorage) Behavioural Health Research and Services (BHRS) has recently won a significant grant to become a Fetal Alcohol Spectrum Disorder Regional Training Center (FASD RTC). The role of the RTC is to enable doctors, nurses, psychologists, social workers and other health professionals and students to engage in primary and secondary prevention of FASD. The Centre will conduct training and prevention activities across Alaska including online training, and will target students in academic programs at the University of Alaska.

The Center will draw on the core competencies in FASD education developed through the US Center for Disease Control, and will identify the specific needs of Alaskan health and welfare providers. BHRS has previously conducted large scale surveys of provider knowledge, attitudes and behaviour in relation to FASD and has also conducted the data evaluation for the FASD Diagnostic teams in Alaska.

Center for Disease Control key competencies for working with FASD include:

- Foundation
- Screening and Brief Interventions
- Models of Addiction
- Biological Effects of Alcohol on the Fetus
- Screening, Diagnosis, and Assessment of FAS
- Treatment Across the Lifespan for Persons with FASDs
- Ethical, Legal, and Policy Issues

[www.cdc.gov/ncbddd/fas/curriculum/index.htm](http://www.cdc.gov/ncbddd/fas/curriculum/index.htm)

Also within the University of Alaska Anchorage, the Center for Human Development provides training about developmental disabilities to clinicians, service providers, carers, families and foster parents. In 2010 the Centre is hosting a conference on Identifying and Treating FASD Issues Intertwined with Behavioral Health problems, in particular training participants on the use of the 3M model outlined above.

Other supports to carers are provided through the Stone Soup Group, an Anchorage agency which supports families with children with special needs. I visited Cheri Scott, FASD Support Project Manager and a founding member of the agency. As an adoptive mother of a young adult with FASD, Cheri has personal awareness of the needs of carers for support, diagnosis and training. The agency provides regular workshops in FASD 101 and 201 for carers and runs the Alaska FASD Family Support Website which provides information and resources to families parenting children with FASD.

Recent data indicates that the preventative efforts in the state are paying off. Alaska has reported a 32% drop in the rate of FAS between 1996-2002. The rate of FAS among native children dropped from 17 times higher than the non-native rate to 5 times higher than the non-native rate.<sup>26</sup>

## Juneau, Alaska

Ric Iannolino is the Juneau FASD Diagnostic Clinic Coordinator, a position he has held since 2003. The position is auspiced by the Central Council of the Tlingit and Haida Indian Tribes of Alaska (CCTHITA) and receives limited funding. His role incorporates training, advocacy and

<sup>26</sup> [http://hss.state.ak.us/press/2010/FAS\\_pr\\_021810.pdf](http://hss.state.ak.us/press/2010/FAS_pr_021810.pdf)

community education in Juneau and surrounding villages, many of which are remote.

Ric coordinates the clinic, which meets monthly. Two children can be assessed each month, a total of 24 each year. Ric liaises with the panel members, provides training to new members, and ensures that assessments are completed prior to the clinic date so that all the information required to assess a child is available on or before the day.

The Juneau clinic includes a neurologist, speech and language pathologist, psychologist, school psychologist, paediatrician, parent navigator and administrator. So much work goes into the preparation that the team cannot afford to postpone a clinic due to illness, so a backup person is identified for each of the team members.

The parent navigator works with the family through the clinic process, assisting them to complete the application and supporting them after the diagnosis. Margaret Vrolyk is one of two volunteers, and as an adoptive parent of a son with FASD, understands the concerns of families and the long term impact of a FASD diagnosis. She spends several sessions with the family completing referral information, and will spend a couple of hours each week with them after the diagnosis.

I visited the Office of Children's Services (OCS) and met with staff from policy, resources and the local Juneau office. FASD is a particular issue for children in care due to national policy requiring the adoption of children in long term care. In assessing adoptive parents, a subsidy is determined and any special needs must be identified at this time. Once a child is adopted, their file is closed and any information regarding pre-natal exposure to alcohol will not be made available. There can be significant pressure on carers to seek a diagnosis prior to adoption, as otherwise supports may not be costed into the carer subsidy. However the Juneau office of OCS staff reported that mothers may be more willing to divulge information such as substance use in pregnancy once parental rights have been terminated.

Carers receive training through the Alaska Center for Resource Families which provides foster and adoptive families with online training resources, including a compulsory core curriculum addressing topics including foster care regulations. Foster carers earn credits for units completed, which includes FASD training.

The Juneau OCS office reported that around 30 children had been referred for FASD diagnosis in the past seven years. Rates of children with FAS are low but FASD is significant. Ric Iannolino provides training and education to staff, but more education is needed to enable workers to prepare better case plans and know how to support families affected by FASD. Like most child protection offices, there are sometimes inadequate supports and resources available and the recommendations of diagnostic reports cannot always be implemented.

With Ric, I attended a meeting organised by KJ Metcalfe of the Northern Light United Church with church and community members, solicitors and judges to discuss the recognition of FASD in court and legal processes. KJ is the adoptive parent of several young adults with FASD. I was impressed at the level of commitment in the legal community to improve responses to this group.

Ric also took me to visit Juneau Youth Services<sup>27</sup>, providing therapeutic care to young people, Hope Community Resources Inc, providing accommodation to adults with disabilities, and to a number of Head Start programs (discussed above). The position of FASD clinic coordinator

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<sup>27</sup> <http://www.jys.org/residential.php>

has contributed to service networks being aware of FASD and particularly, aware of where to seek training and advice.

SEARHC is the South East Alaska Regional Health Consortium representing 18 Native communities, and provides a range of health services in the region. I met with mental health therapist Cathy Wellwood and Tribal Judge Dolores Cadiente from SEARHC Behavioural Health, an integration of mental health and substance abuse services. The agency provides mental health and substance abuse residential treatment and outpatient services, among others.

The issue of FASD is well recognised within the agency and Dolores noted the high rates of suicide which occur under the influence of alcohol. She identified the increased risk to individuals with FASD due to their impulsive behaviours, and successful approaches rely on removing the person from the environment and surrounding them with care and supervision – often relying on family resources. The Wraparound model of service delivery was identified as particularly helpful to Native Alaskans as it does not require people to leave their community to receive treatment.

## Bethel, Alaska

I visited the community of Bethel, a remote town on the Yukon-Kuskokwim Delta (YKD) which is a hub for many remote indigenous villages. Bethel has some similarities to the Central Australian context including the challenges of service delivery to remote communities. The region has a high rate of FAS and until recently was the last “damp” community in Alaska, meaning that alcohol could be brought into the community but not purchased locally. Residents recently voted to lift alcohol restrictions, but have also voted against the granting of liquor licences, with the issue currently being further debated.

In some families and villages in the region, generations of people have been prenatally exposed to alcohol. Monica Leinberger, a FASD/behavioural specialist for the schools district in Bethel estimates that 1:10 children are either prenatally exposed to alcohol or live in homes where alcohol is an issue. Monica supports around 90 students with FASD, and of these 8 have FAS. Alaska has four times the rate of FAS compared to other states in the US.

Ardyce Turner, a local Yupik woman who has a rich history working in the area of FASD in Bethel gave me a historical perspective. Ardyce has worked with the YKD Health Corporation, as a FASD coordinator and case manager, and is now with the Office of Children’s Services. She described how in the 1980s a public health nurse at the hospital noticed a lot of children with distinctive facial features and learned that their mothers had used alcohol in pregnancy. Her observations prompted a local interest in FAS. In 1986 a FAS taskforce was established and a community education campaign emerged, encompassing radio talk shows, newsletters, health fairs in villages and substance abuse education in schools. Ardyce attributes the high rates of awareness of FASD to the influence of long term community education campaigns. Although it took years, community members persisted in educating GPs, training, and development of resources. Ardyce used to attend community parties and feasts where people would identify her as someone who talked about FAS. She found that people wanted more information about what they could do to prevent FAS.

In 1997 the state of Alaska began to take notice of the concerns about FAS and in 1999 Bethel was successful in setting up one of the first diagnostic teams. Ric Iannolino (now Juneau clinic coordinator) provided training for alcohol education counsellors. Ardyce saw the impact of support programs to mothers, providing education about the effects of alcohol use and attempting to de-stigmatise the issues. Traditional teachings about how women used to take

care of themselves and their babies were revisited. The region has, however, experienced funding cuts since 2006 as much of the funding provided to FASD-related services has been diverted to other conditions such as autism which are seen as a national priority.

Shane Welch coordinates the FASD Diagnostic team which is based at the hospital in the Behavioural Health department. The team has diagnosed 200 individuals in the YKD region and has been generally successful. It can be difficult to get clinical psychologists to participate and a diagnosis can take up to 12 months to complete. Ardyce identified the need for improved psychometric testing to better reflect cultural norms, as some of the traditional testing misses some of the strengths of Yupik children.

Ed Pironte from the Office of Children's Services estimated that almost every child in care in the region has been exposed to alcohol and a disproportionate number of children have the facial feature of FAS. He indicated that the diagnostic process is time consuming and doesn't always lead to improved pathways as the services needed are not locally available. Often diagnoses do not happen early enough and there are insufficient resources to prevent secondary disabilities. Children then end up in the correctional system. By the time OCS see the children they are often at risk of harming themselves or others, or may be admitted to the psychiatric ward in Anchorage which removes them from their family and support networks.

After a diagnosis, there is little support available particularly in the villages. Most of the post diagnosis support is provided by Monica Leinberger who also participates in the YKD Diagnostic team as a parent navigator, helping families through the process.

Within the school system, Monica identifies children who have a diagnosis of FASD or are in the process of being diagnosed. Once they have a diagnosis, she works with the school and family to ensure that they understand the evaluation results, identifies the level of support required within the school, observes the child in school and participates in the development of a plan for the child at school.

Monica covers 27 sites in YK Schools District including five locations in Bethel. The rest are in villages. Monica is aware of at least one individual with FASD at every site. She estimates that 9% of children diagnosed live with their birth parents and less than half of the remainder live with extended family. Monica reports increasing numbers of referrals for diagnosis from birth parents, which she attributes to a reduction in the stigma of FASD due to 10 years of community education. Ardyce also identified that people are becoming more confident in raising FASD as a possible concern.

FASD Training is available online, through Ardyce, and through workshops in Anchorage. Many staff complete the FASD101 unit online and most have at least a general understanding of FASD.

Vicki Koehler is director of social services with the Orutsararmiut Native Council (ONC) which employs Indian Child Welfare (ICW) workers. These staff members engage with the Office of Children's Services to work with indigenous families. The ONC also runs an in-home family preservation program based on traditional Yupik parenting. Vicki identified the importance of family members caring for children with FASD being able to access support and education, and being linked into support models based on traditional culture which allow families to return to traditional models of child rearing.

Some of the themes reported were familiar to service delivery in Central Australia – high turnover and staff burnout in child protection; difficulty accessing addiction services; lack of

placement options for children; lack of services to assist post-diagnosis, and a significant impact of alcohol across the community. However the strengths of the region are evident in the commitment of long term service providers to the issue of FASD prevention, the willingness of community members to learn about FASD and work towards solutions, and the strong focus on identifying and addressing FASD within the education system. While the region is still grappling with the role alcohol plays in the community, culturally appropriate service provision was a strong theme, along with the rediscovery of traditional child rearing practices.

## Conclusions

FAS is under-recognised in Australia, and FASD is an invisible condition – both for the individual and within the service delivery system. The rates of FASD in the US and Canada suggest that Australia is likely to be similarly affected and that rates are likely to be higher in Central Australia given alcohol consumption data. We must do more to identify and diagnose these conditions, in order to provide treatment pathways and develop service responses.

Recommendations for Central Australia include:

- Development of screening and diagnosis for FASD is vital. Screening can provide a cost-effective method of identifying at-risk individuals and may be sufficient to direct individuals to appropriate services
- FAS is over-represented among children in care, and FASD is likely to affect the majority of children in care.
- Care responses need to be developed – the principles of the Communities of Practice model could be implemented in Central Australia
- Mothers of children with FAS and are likely to have further affected children without intervention and are likely to have poor long term outcomes.
- Prevention is vital – particularly for high risk mothers who are in contact with the child protection service. Specific responses need to be developed for this group who will not engage well with mainstream services. The relationship-based PCAP model has been proven to be effective in reducing the risk of further alcohol affected pregnancies with this target group.
- Professionals' knowledge of FASD is limited in Australia. FASD training needs to be widely available to professionals and support services in order that they can identify the condition and develop service responses within their agencies. Training should address case planning. There are many modules which could be locally adapted.
- Families and carers need specific FASD training and support to assist them to manage the care of affected individuals.
- Individuals with FASD need services that can maximise their quality of life and minimise secondary disabilities. Generic service models are often a poor fit for individuals with a brain injury. Services can be adapted to be inclusive of individuals with FASD through evaluation and planning – but agencies need thorough knowledge of the needs of individuals with FASD.
- Incorporation of FASD within service networks can raise awareness of the issues and inform service systems to be more responsive to this population.

Further work is needed to explore culturally appropriate models of service provision to indigenous families in Central Australia who are caring for FASD affected children.