



NINDILINGARRI By: ATSIA B
CULTURAL HEALTH SERVICES

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The Hon Bob Debus
Chair,
Standing Committee on ATSI Affairs

1 February 2010

Dear Mr Debus,

Inquiry into Indigenous Incarceration

Thank you for the opportunity to make a late submission to the Inquiry.

I write as the Chair of the Leadership Team of the ***Strategy to overcome Fetal Alcohol Spectrum Disorders (FASD) and Early Life Trauma (ELT) in the Fitzroy Valley***, as well as the Chief Executive of Nindilingarri Cultural Health Services (servicing the Fitzroy Valley), and a lifelong resident of the Kimberley area.

Nindilingarri supports the points raised in the submission from the Kimberley law and Culture Council (KALACC) around the need for more resources for preventive and diversionary programs, and the importance that such programs are owned and managed by the local community, as is the very successful Yiriman program in the Fitzroy Valley.

The Leadership Team for the Fitzroy Valley FASD/ELT Strategy wishes to bring to your attention the strong links between involvement in the justice system including incarceration, and the prevalence of brain damage caused by maternal intake of alcohol, known as ***Fetal Alcohol Spectrum Disorders (FASD)***. The Kimberley, and other like areas, has high rates of FASD, and high rates of incarceration of young people, and this is no coincidence. The link has implications for policy and programs aiming to reduce the rates of incarceration, and to provide more effective support and diversion programs to avoid recidivism.

There has been no high-quality study of FASD prevalence in Australia, but rates are thought to be significantly higher in Indigenous communities, due to the increased frequency of binge drinking and unplanned pregnancy. Long term outcomes for children with FASD are poor. Overseas research suggests

that 90% will have mental health problems, 80% will remain unemployed, 60% will be in trouble with the law and less than 10% will be able to live or work independently at the age of 21. An American study found that 23.3% of consecutive cases sent for juvenile forensic mental health assessment clinic had FASD, and concluded that the prevalence is probably comparable to serious mental illness and yet largely silent.

The Fitzroy Valley FASD/ELT Strategy was initiated by the local community in response to the perceived high rates of children and families affected, and the resulting problems with learning and behaviour, including high rates of suicide and incarceration. The Strategy includes action plans for prevention, diagnosis/ screening and support, as well as dialogue at the district, regional, state, national and international levels, capacity building and resourcing.

We are partnering with the George Institute for International Health and Sydney University to undertake a FASD prevalence study in the Kimberley, a first in Australia, which we hope will provide a basis for a more effective response from the health, education and justice systems among others, to prevent FASD and support those whose lives are already affected. We are still seeking funding for Stage 2 of this study, and for resources to provide follow-up top people diagnosed with FASD and other developmental disorders during the study.

I have attached some background information on FASD and the justice system, also the local FASD/ELT Strategy, but invite you to meet with us to discuss our work and its implications for your inquiry in more detail.

Yours sincerely,

(PATRICIA MUIR, DIRECTOR OF SERVICES,) ON BEHALF OF

Maureen Carter
CEO Nindilingarri Cultural Health Services
Chair, Fitzroy Valley FASD/ELT Strategy

OVERCOMING FOETAL ALCOHOL SPECTRUM DISORDERS (FASD) AND EARLY LIFE TRAUMA (ELT) IN THE FITZROY VALLEY: A COMMUNITY INITIATIVE (V4 Updated September 2009)

Purpose

This document aims to:

- Present a strategy for overcoming FASD & ELT in the Fitzroy Valley
- Identify key stakeholders in this process
- Identify a multi-pronged strategy that is achievable
- Allocate responsibility for achieving agreed tasks
- Track the process / journey taken by the community and stakeholders
- Develop as ideas are fed into it.

Founding principles of this strategy:

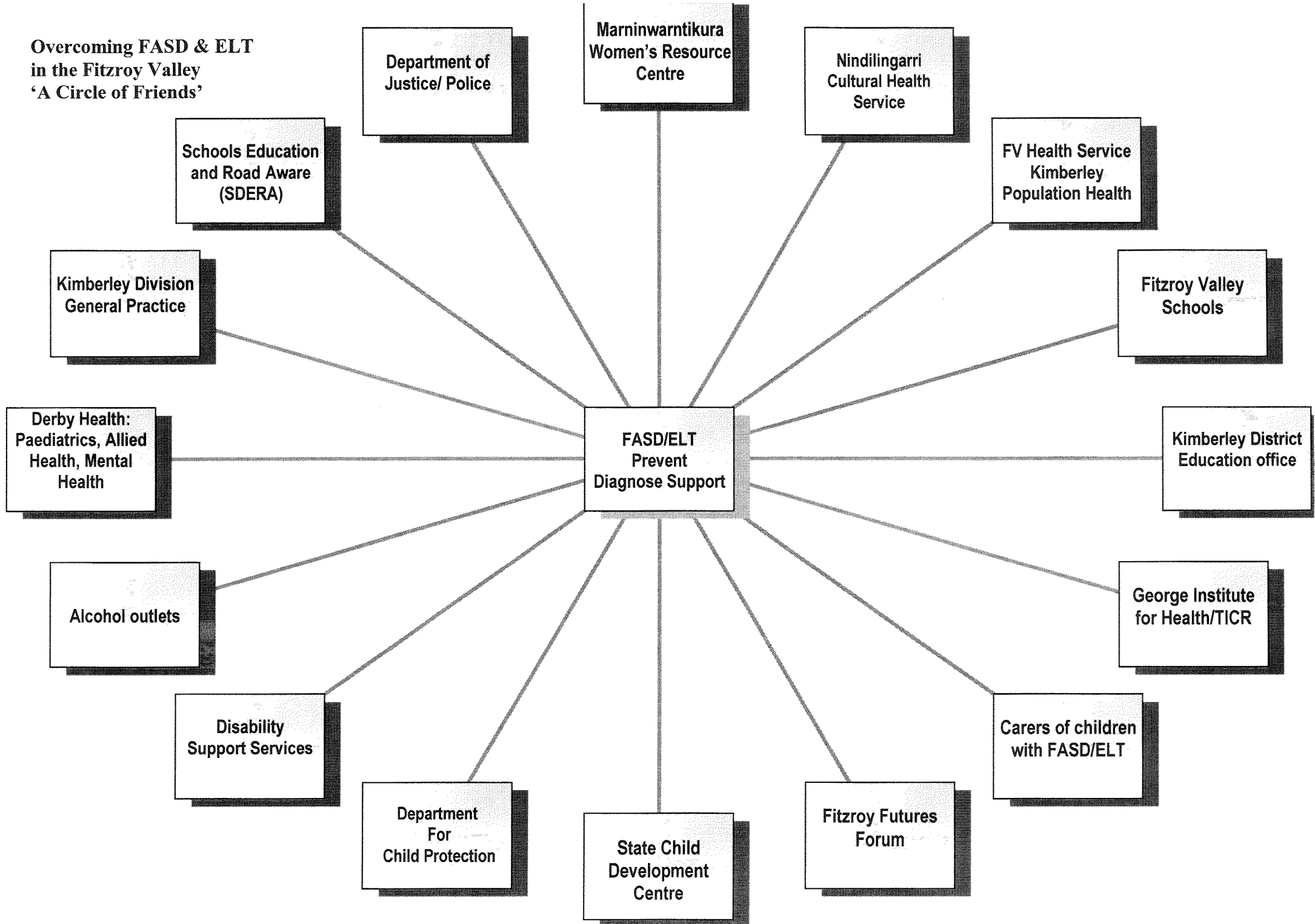
- FASD and ELT are 100% preventable
- The Fitzroy Valley community is building on the hard – won achievement of alcohol restrictions to prevent FASD
- Education and support for affected families will precede the formal diagnostic process, in order to reduce the potential for stigmatisation, and to ensure that a diagnosis is coupled with the best possible assistance and support
- FASD is often compounded by ELT, resulting in additional barriers to normal child development, behaviour and learning
- Children living with FASD are special, unique individuals, often with exceptional talents. No shame or stigma is associated with a diagnosis
- FASD is a whole – of – life issue. Education and support must follow the individual across the lifespan
- Control and leadership in developing and implementing the strategy must remain in the local community.

The FASD/ELT Strategy Leadership Team

The Strategy Leadership Team has broad representation including; Nindilingarri Cultural Health Service, Marninwarntikura Women's Resource Centre, Derby District Health, Fitzroy Valley Community Health, Fitzroy Valley Hospital, Kimberley Population Health – Healthy for Life, Kimberley Mental Health and Drugs Service, Fitzroy Valley District High School, Kimberley District Education Office, Paediatrician/Researcher, Department of Child Protection, Police.

Nindilingarri Cultural Health Service is the overall lead agency, as the major focus of the strategy is health promotion. Each sub-strategy has a nominated lead agency, with multidisciplinary teams to develop and implement action plans

**Overcoming FASD & ELT
in the Fitzroy Valley
'A Circle of Friends'**



LOCAL LEVEL ACTIVITY

OBJECTIVE

Prevent FASD/ ELT in the Fitzroy Valley, identify and support those living with FASD to achieve maximum development and enjoyment of life

SUB-STRATEGIES

PREVENTION			DIAGNOSIS			SUPPORT		
Prevention 1	Prevention 2	Prevention 3	Diagnosis 1	Diagnosis 2	Diagnosis 3	Support 1	Support 2	
Consult with community members regarding their awareness of and commitment to the FASD/ELT strategy.	Educate community members, alcohol vendors and service providers about the harmful effects of alcohol during pregnancy and early life traumas	Work with pregnant women and their families through formal support services and community-based mentoring to prevent alcohol use	Develop an evidence-based and culturally appropriate diagnostic process	Develop a screening process with communities, health services, and schools	Screen children within the Fitzroy Valley with priority to those aged 0-3.	Map the formal support services for the Fitzroy Valley. Form a multi-disciplinary management model based on international best practice and relevant to the local context	Form a network of local carers who can share stories with each other and carers across the country and internationally	
Responsibility: <i>Lead agency (lead person)</i> and other key agencies.								
<u><i>Nindilingarri (Maureen)</i></u> Marninwarntikura KALAC	<u><i>Nindilingarri (AOD HP) (Emily/Josh)</i></u> Health Education	<u><i>Kimberley Population Health</i></u> (Melissa) Nindilingarri Fitzroy Valley Health Service	<u><i>Kimberley Population Health (Rosey)</i></u> Nindilingarri Education TICHR FASD Model of Care Ref Group Children's Development Services			<u><i>Mental Health (Jo)</i></u> DCP Education Dept for Comm Dev (Strong Families) Police	<u><i>Marninwarntikura (June)</i></u> DCP Disability Services Frontier Services Respite Care KIFSA	

HIGHER LEVEL ACTIVITY

OBJECTIVE

To raise awareness of the FASD/ ELT crisis in the Fitzroy Valley, and to empower and resource Fitzroy Valley Communities to overcome it

SUB-STRATEGIES

Engage in high level dialogue on FASD			Build local capacity		Focus resources		
Dialogue 1	Dialogue 2	Dialogue 3	Capacity building 1	Capacity building 2	Resource 1	Resource 2	Resource 3
Strategic use of the media to overcome stumbling blocks, or when specific results are required	Contribute to the scientific discussion around FASD by engaging research partner/s in the FV process	Raise profile of FASD through strategic partnerships with government and corporate sectors	Participate in relevant National and International conferences and workshops	Capture the process of this Strategy	Identify and leverage existing resources within various agencies (health, education, community organisations)	Approach government, philanthropic and private sector to secure targeted funding for the FASD strategy	Engage local community resources in FASD / ELT prevention, diagnosis, and support
Responsibility: <u>Lead agency</u> and other key agencies							
<u>Marninwarntikura</u>	<u>Nindilingarri</u>	<u>Marninwarntikura</u>		<u>Nindilingarri</u>	<u>All agencies</u>	<u>Marninwarntikura</u>	<u>Marninwarntikura</u>
Nindilingarri (Patrick Davies)	Pop Health District Health TICHR George Institute	Fitzroy Futures Helen Browne CRANA Health AMA/GP Div		Health Marninwarntikura		Nindilingarri	Nindilingarri KALAC

Overcoming FASD & ELT in the Fitzroy Valley: 'The Journey'

September 2007

Fitzroy Crossing community action achieves alcohol restrictions

October 2008

FV community members meet to discuss FASD as a major problem requiring community action

November 2008

Community and interagency consultation begins – a 'Circle of Friends' is developed

December 2008

Draft Strategy to overcome FASD is developed

March 2009

Delegate attends International FASD conference in Canada. Delegates attend United Nations meeting in New York to present on the successful alcohol restrictions

March 2009

Circle of Friends meets to ratify Strategy, and allocate lead agencies for sub-strategies

April 2009

Sydney launch of Yajilarra - DVD about Fitzroy Crossing alcohol restrictions. Connections made with supporters in the private, government and not for profit sectors

May 2009

Leadership Team formed, comprising members of key stakeholder groups

May 2009 (cont'd)

Strategy coordinator appointed through ICV. Lead agencies start work on sub-strategy action plans and calendar of events

July 2009

FASD is discussed at the Women's Bush Meeting, attended by Carolyn Hartness (an Eastern Band Cherokee FASD educator. Over 100 women from all major language groups restated their support for the alcohol restrictions, and endorsed the FASD/ELT Strategy

July 2009

A partnership formed with the George Institute to make a DVD raising awareness of FASD/ELT. Discussions commence about a prevalence study, using validated diagnostic tools to identify children affected by FASD

August 2009

Sub-Strategy Working groups continue to develop action plans around prevention, diagnosis and support, including identifying the resources required for implementation

August 2009

CEOs of Nindilingarri and Maminwarntikura present Yajilarra to Australian politicians, and discuss the FASD/ELT Strategy.

August 2009

Meeting with WA Police Commissioner.

September 2009

Forum with FX Service Providers to inform and identify opportunities for co-operation and support.

September 2009

FASD discussed at Fitzroy Futures Forum

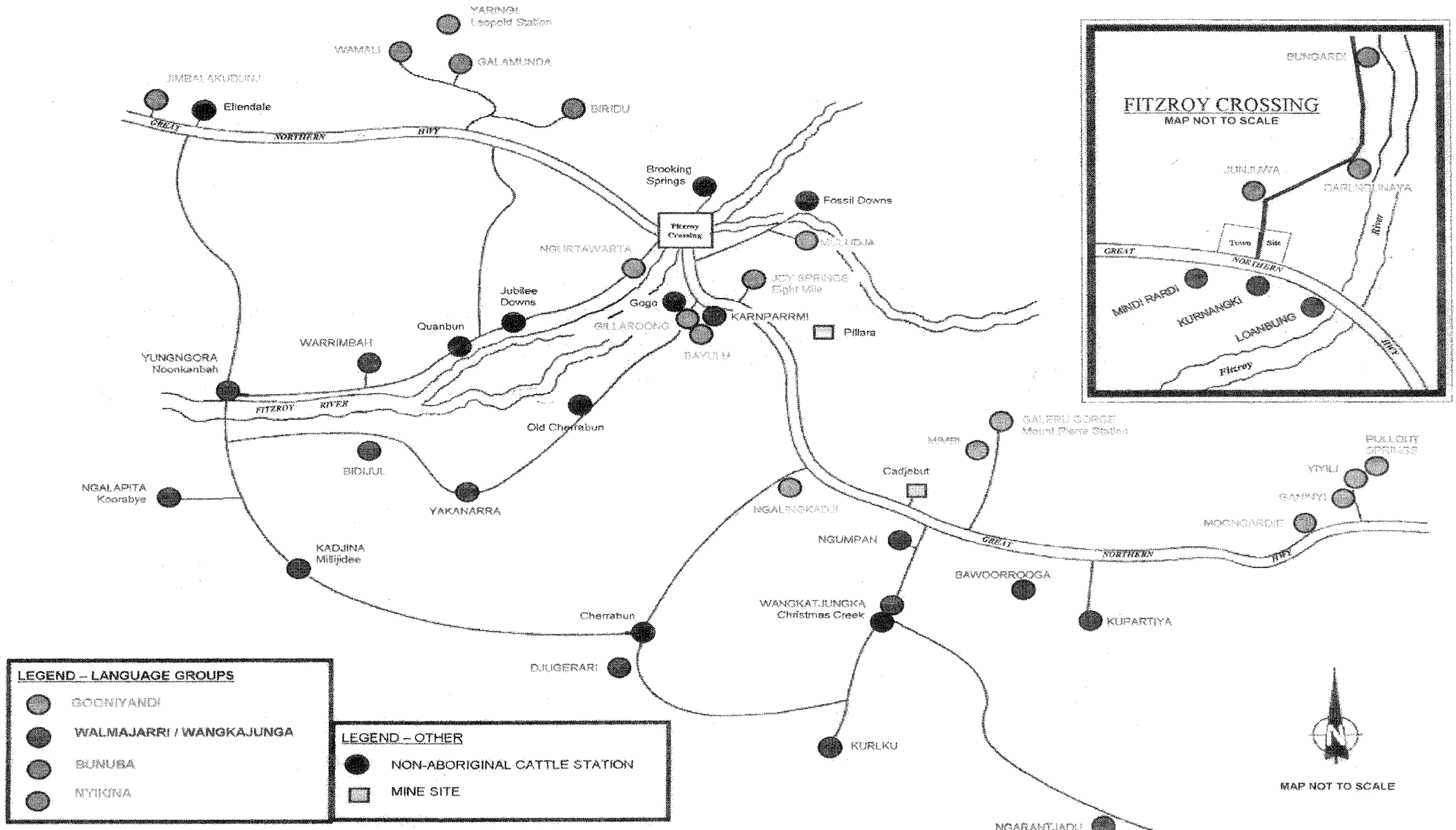
October 2009

Visit to Fitzroy Valley from Prof Elizabeth Elliot (FASD expert) and A/Prof Jane Latimer to discuss feasibility of a FASD prevalence study.

October 2009

What's next....?

FITZROY VALLEY COMMUNITIES



The Fitzroy Valley has a population of around 4,000 people. Around 1,600 people live in the town of Fitzroy Crossing. There are 44 smaller Aboriginal communities across the Fitzroy Valley, within approx. 150km radius from Fitzroy Crossing. The Fitzroy Valley covers the traditional lands of four main language groups, Bunuba, Gooniyandi, Walmajarri/Wangkatjunga and Nyikina.

A LAWYER'S BRIEF ON FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

DAVID BOULDING, LAWYER dmboulding@shaw.ca

Alcohol in the womb is a solvent and acts on the baby's developing brain like paint stripper acts on layers of old paint on furniture: it dissolves brain cells, bubbles them away. Thus, brain functions are missing.

1. FASD IS A PERMANENT BRAIN-BASED BIRTH DEFECT

Distinguish between non-compliance and non-competence. **There is a difference, and it is brain-based.**

2. FASD IS A MULTI-SECTOR PROBLEM

- It is a school, police, social, legal, medical, family, community, and national problem.
- It is a delusion to think one agency can solve this problem.

3. DO NOT RE-INVENT THE WHEEL

- Find the new research online. Start at these two websites: www.asantecentre.org and www.fasdconnections.ca
- Early assessments are critical. Seek informed help now.

4. GO PAST JUDGMENT AND UNDERSTAND THE REASONS WHY PREGNANT WOMEN DRINK ALCOHOL

- This is difficult and requires a heartfelt, clear-minded knowledge of family violence, the history of close relationships, poverty, lack of education, addiction, and an understanding of how people cope with daily difficulty.
- FASD is not restricted to poor marginalized people. Rich stockbrokers have wives who binge-drink while pregnant. Young, educated professional women binge-drink almost as a rite of passage, often not knowing they are pregnant.

5. THERE IS GOOD NEWS: IT'S CALLED THE "EXTERNAL BRAIN"

- The "External Brain" as intended by Dr. Sterling Clarren means appropriate supervision 24/7. Design appropriate structures to create opportunities for the FASD person to be successful. All the available drugs and therapy, all the jail time, all the best intentions found in court orders, will not generate new brain cells. These offenders will be the same every time they come into the courtroom. They are not going to change. It is our responsibility to create success for persons with FASD. They need help from a walking, talking committee of knowledgeable helpers.
- The "External Brain", as a legal concept, is our duty of care. It is our duty to accommodate FASD persons because we are all to be equal before the law.
 - Diane Malbin provides four practical suggestions:
 1. Match the brain before you to the task you set.
 2. Identify your assumptions.
 3. Adjust your expectations and stretch your definition of success.
 4. Change their environment.

- These suggestions are easy to say aloud but difficult to implement for four reasons:
 - Each of us has a little voice inside that says: they should not get away with this unacceptable behaviour.
 - Each of us shares a social sense that an individual could do better if the individual would just try harder.
 - If we really knew how the brain worked, we would punish differently. We would design our “teaching and corrections industries” differently. Our knowledge of the human brain is in its infancy. There is much we do not know. Many of our brain-based assumptions in the criminal system are clearly wrong. The McNaughten Rules (1853) work for you and me, not FASD persons.
 - Change is not easily accepted or even wanted, especially in rigid systems like the legal or educational systems.

Most importantly: caregivers and others charged with dealing with persons with FASD will experience near total exhaustion very quickly—this includes police, teachers, lawyers, social workers, and judges. Guard against dying inside yourself, the same way a long-distance runner guards against fading too soon. There are training tips and they involve physical, mental, emotional, and spiritual fitness—take care of yourself. Like the monotonous warnings on airlines, put on your air mask before helping others. You are useless if dead, or unable to do your appointed task.

RESOURCES:

- Fetal Alcohol Spectrum Disorder: Trying Differently Rather Than Harder, Diane Malbin.
- Fetal Alcohol Syndrome and the Criminal Justice System: Understanding the Offender with FAS (DVD and VHS), Dr. Julianne Conry. www.asantecentre.org
- The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities, Ann Streissguth and Jonathan Kanter (eds.)
- Fetal Alcohol Syndrome: A Guide for Families and Communities, Ann Streissguth
- Beautiful Smiles, Gentle Spirits. Fetal Alcohol Spectrum Disorder: A Misunderstood Problem, Margaret Michaud and Sacha Michaud (eds.)

- Many **FASD** affected persons who find themselves in the criminal justice system have not yet had their disability diagnosed. If you believe that a person you are dealing with, whether that person is an accused, victim or witness, has FASD, you should raise your concerns as early as possible in the legal proceedings so that the system can respond appropriately.
- FASD brain damage may compromise a person's ability to understand or control their behaviour, to understand the court process, or to instruct counsel. If you believe that you are dealing with a person affected by FASD you should consider issues relating to fitness to stand trial, criminal responsibility and witness suggestibility.
- FASD affected persons' **Secondary Behaviours** tend to bring them into conflict with the law more frequently than unaffected persons.
- The vast majority of adult offenders with FASD will have one or more **co-occurring** mental illnesses. The presence of multiple psychiatric diagnoses for one individual may be suggestive of FASD.
- FASD is frequently a multigenerational problem, so others in the FASD affected person's family may have similar issues which may have ramifications for interfamilial charges, evidence collection, etc.

Other sources:

Scenarios

With a warrant out for his arrest, A. turned himself in to the police. He called his lawyer, who of course advised him to say nothing until the lawyer arrived. By the time the lawyer got there, A. had provided a video statement. *(A. wanted to be helpful and had no sense of the need to listen to and follow his lawyer's advice.)*

B. came to his court date for an assault charge and suddenly decided to plead guilty. His lawyer explained that he had a good chance of being found not guilty at trial, and advised him, strongly, against pleading. B insisted. When asked by the judge if he had anything to say before sentencing, B gave a long, rambling explanation of why he was innocent. *(He couldn't handle the suspense of waiting any longer and didn't understand the court process.)*

C. was a defense witness. On the stand, the defense lawyer gently tried to ask her questions that would help C. present helpful facts. Although the questions were basic, C. found them difficult and reacted with hostility to the lawyer. *(She knew the lawyer was defending her friend, but did not understand his role, or his questions.)* C. also asked the judge to stop people in the court from speaking to each other. *(The people were her family members, there to help. However, she had difficulty concentrating on the questions because of all of the ambient noise).*

D., a young adult, was arrested for shoplifting a CD. He was given a document to appear in court but put it aside and forgot. He did not remember to tell his parents, with whom he resides. Now there is a bench warrant for his arrest and he has a much bigger problem. *(D. has very poor memory, no system of recording dates and times, and had no understanding of how important it was to come to court. He is a large, normal-looking man who functions like a child.)*

E., a youth, was arrested after some property was mysteriously damaged. He was granted bail, but his conditions required him to live at home and follow a curfew. His parents were very worried when he did not come home one day ... or the next. He appeared on the third day, surprised that his parents were in a state of anxiety and had pulled his bail. His friend had invited him on an impromptu trip, so he went. *(His memory and understanding are limited, so he had forgotten his bail conditions and it had not occurred to him to contact his parents.)*