

SB

127

<TARGET><BILL>SB 127</BILL><SUBJECT>SB
127</SUBJECT><COMM>HHSS27</COMM></TARGET>

Alaska State Legislature




Interim:
716 West 4th Ave.
Anchorage, Alaska 99501
(907) 269-0199

Session:
State Capitol Building
Juneau, Alaska 99801-1182
(907) 465-4945

Senator Kevin Meyer Senate District O

TO: Representative Wes Keller, Chair
House Health & Social Services Committee

FROM: Senator Kevin Meyer 

DATE: February 23, 2012

RE: House H&SS Request for Hearing SB 127

This is a request for a House Health and Social Services Committee hearing for SB 127, which would establish September 9 each year as Fetal Alcohol Spectrum Disorders Awareness Day.

The following documents are attached and will be sent electronically:

- Sponsor Statement
- Latest version of the bill: 27-LS0810\A
- Fiscal Note
- Support Documents
- Support Letters
- Staff member assigned to the bill: Christine R. Marasigan, 465-6876
- Invited Testimony: Kate Burkhart, Executive Director of the Alaska Mental Health Board Advisory Board on Alcoholism and Drug Abuse

Please contact Christine if you have any questions regarding this legislation.

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Senate District O

SPONSOR STATEMENT FOR SB 127

"An Act establishing September 9th each year as Fetal Alcohol Spectrum Disorders Awareness Day."

SB 127 would proclaim September 9th each year as Fetal Alcohol Spectrum Disorders Awareness Day (FASD).

Alaska has the highest known incidence of FASD in the United States. This is a condition caused by prenatal exposure to alcohol, which can result in permanent brain damage, birth defects, learning disabilities, behavioral problems and most tragically, the loss of individual potential.

While FASD affects all racial and socioeconomic groups, it is a 100% preventable condition. FASD Awareness Day is observed internationally on September 9th. This serves as a reminder on the ninth day of the ninth month of the year that during the nine months of pregnancy a woman should abstain from alcohol.

SB 127 would observe FASD Awareness Day by promoting the awareness of the effects of prenatal exposure to alcohol.

FISCAL NOTE

STATE OF ALASKA
2012 LEGISLATIVE SESSION

Bill Version SB127
 Fiscal Note Number _____
 () Publish Date _____

Identifier (file name) SB127-DOA-FAC-2-10-12 Dept. Affected Administration
 Title Fetal Alcohol Spectrum Disorders Awareness Day Appropriation General Services
 Allocation Facilities
 Sponsor Senator Meyer
 Requester Senate Health & Social Services OMB Component Number 2429

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	FY13 Appropriation Requested	Included in Governor's FY13 Request	Out-Year Cost Estimates				
			FY14	FY15	FY16	FY17	FY18
OPERATING EXPENDITURES	FY13	FY13	FY14	FY15	FY16	FY17	FY18
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants, Benefits							
Miscellaneous							
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0	0.0

FUND SOURCE (Thousands of Dollars)

1002	Federal Receipts							
1003	GF Match							
1004	GF							
1005	GF/Prgm (DGF)							
1037	GF/MH (UGF)							
1178	temp code (UGF)							
TOTAL		0.0	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS

Full-time							
Part-time							
Temporary							

CHANGE IN REVENUES

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Estimated **SUPPLEMENTAL (FY12) operating costs** _____ (separate supplemental appropriation required)
 (discuss reasons and fund source(s) in analysis section)

Estimated **CAPITAL (FY13) costs** _____ (separate capital appropriation required)
 (discuss reasons and fund source(s) in analysis section)

Why this fiscal note differs from previous version (if initial version, please note as such)

Not applicable, initial version

Prepared by Vern Jones
 Division Division of General Services
 Approved by John Cramer, Deputy Commissioner
Department of Administration

Phone 465-5684
 Date/Time 2/10/12 6:45 PM
 Date 2/10/2012

FISCAL NOTE

STATE OF ALASKA
2012 LEGISLATIVE SESSION

BILL NO. SB127

Analysis

This bill establishes September 9th as Fetal Alcohol Spectrum Disorders Awareness Day. It is anticipated that there will be no fiscal impact.

TEN THINGS YOU SHOULD KNOW ABOUT FAS

1. Drinking during pregnancy can cause permanent damage to a developing fetus.
2. FAS is one of the most common causes of mental retardation, and is the only cause that is entirely preventable.
3. According to recent State of Alaska DHSS surveillance data, more than 126 children are born at risk for FASD each year in Alaska.
4. Prenatal exposure to alcohol can cause brain damage and other permanent birth defects.
5. Obtaining an FAS diagnosis can improve an individual's ability to function in the world, and may reduce secondary disabilities like depression and school failure.
6. FASD is found in all races and all socio-economic groups – wherever women drink alcohol FASD exists.
7. There is no safe level of alcohol consumption during pregnancy.
8. Women should stop drinking prior to trying to conceive – alcohol can cause damage to a developing fetus even before a woman knows she is pregnant.
9. FASD is 100 percent preventable.
10. With the right diagnosis, support and understanding, many individuals with FASD are living happy and full lives.

**Advisory Board on Alcoholism
and Drug Abuse**



Alaska Mental Health Board

ALASKA MENTAL HEALTH BOARD
ADVISORY BOARD ON ALCOHOLISM AND DRUG ABUSE
431 NORTH FRANKLIN STREET, SUITE 200
JUNEAU, ALASKA 99801
(907) 465-8920

February 13, 2012

Senator Kevin Meyer
Alaska State Capitol Room 103
Juneau, Alaska 99801

Re: SB 127 — Fetal Alcohol Spectrum Disorders Awareness Day

Dear Senator Meyer,

The Advisory Board on Alcoholism and Drug Abuse and the Alaska Mental Health Board express their appreciation and support for SB 127 permanently establishing September 9 as Fetal Alcohol Spectrum Disorders Awareness Day each year. As you know, fetal alcohol spectrum disorders are 100% preventable. Raising awareness and recognition of this fact will help prevent more Alaskan children from being born affected by prenatal alcohol exposure.

Even more importantly, an annual day of FASD awareness and prevention will increase understanding of the special, and often very individual, needs of individuals diagnosed with fetal spectrum disorders. Too often the services and supports they need to thrive – at home, at school, and in their communities – are not available. By designating a day to focus on the unique issues of fetal alcohol spectrum disorders and their impact on Alaska, we can not only support Alaskans with FASD but also prevent future Alaskans from experiencing FASD.

Thank you for your continued work on this important issue.

Sincerely,

J. Kate Burkhart
Executive Director

cc: Robert Coghill, Jr., Chairman ABADA
Dan Meddleton, Chairman AMHB



**Arctic Fetal Alcohol Spectrum Disorders
Regional Training Center**
Center for Behavioral Health Research and Services
University of Alaska Anchorage
P.O. Box 241626
Anchorage, AK 99524
Tel. (907) 786-6381
arcticfasdtrc@uaa.alaska.edu
www.uaa.alaska.edu/arcticfasdtrc

Senator Kevin Meyer
Alaska State Capitol Room 103
Juneau, AK 99801

February 16, 2012

Dear Senator Meyer:

The *Arctic Fetal Alcohol Spectrum Disorders Regional Training Center* (Arctic FASD RTC), based at the University of Alaska Anchorage, submits this letter in support of SB 127 "An Act establishing September 9 each year as Fetal Alcohol Spectrum Disorders Awareness Day".

The mission of the *Arctic FASD RTC* is to train a broad range of healthcare professionals and students in the prevention, referral, identification, and treatment of FASDs. Since our inception in late 2008, we have strived to reach Alaska health and allied healthcare providers and students in programs leading to health and allied healthcare professions about strategies for the prevention of alcohol exposed pregnancies, diagnosis and assessment of FASDs, and effective treatment and interventions across the lifespan for individuals who experience an FASD and their families.

Every day, we see first-hand the challenging outcomes for mothers and children associated with prenatal alcohol exposure. All FASDs are completely preventable if a woman does not drink alcohol during pregnancy. Public education and awareness on this issue is vital in the nation-wide effort to reduce the prevalence of this preventable spectrum of disorders.

While Alaska has the highest prevalence rate of FASDs in the country, we also lead the nation in efforts to reduce this prevalence rate through education and awareness efforts around the state. Receiving permanent recognition for the annual FASD Awareness Day by the state legislature would continue to advance these efforts in a very meaningful way.

Sincerely,

A handwritten signature in black ink, appearing to read "Christiane Brems".

Christiane Brems, PhD, APBB
Director, Arctic Fetal Alcohol Spectrum Disorders Regional Training Center
Director, Center for Behavioral Health Research and Services



February 13, 2012

Senator Kevin Meyer
Alaska State Legislature
State Capitol Building
Juneau, Alaska 99801

Re: SB 127 Fetal Alcohol Spectrum Disorders Awareness Day

Dear Senator Meyer,

Thank you for sponsoring SB 127, which establishes September 9th each year as Fetal Alcohol Spectrum Disorders Awareness Day. The Governor's Council on Disabilities and Special Education strongly supports SB 127, which will bring awareness about the lives of those affected by alcohol spectrum disorders. The establishment of this Fetal Alcohol Spectrum Disorders Day highlights the completely preventable nature of fetal alcohol spectrum disorders and emphasizes the importance of abstaining from alcohol for the duration of a nine-month pregnancy. This important bill will also increase our state's awareness regarding the many Alaskans who struggle with fetal alcohol disorders.

The Governor's Council strongly supports Senate Bill 127 to establish an awareness day specifically highlighting fetal alcohol spectrum disorders and hopes it helps to increase the support for individuals and families already struggling with FASD as well as prevent future Alaskans from experiencing FASD.

Respectfully,

Eric Gebhart
Council Chair

Alaska FASD Partnership

Advocacy ▪
Diagnosis ▪ *Case Management* ▪
Prevention
▪ *Substance Abuse Treatment for Pregnant Women* ▪
Parent Navigation ▪
Training for Parents
▪ *Public Awareness* ▪
Education ▪ *Housing*
▪ *Employment* ▪
Alternatives to Incarceration ▪
Court Interpreters ▪
Training for Judges ▪
Supported Housing ▪
Case Workers ▪
Training for Educators ▪ *Life Skills* ▪ *Traditional Healing* ▪
Intervention ▪
Training for Medical Professionals ▪
Family Support



Alaska FASD Partnership

The Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership is a coalition of over 85 organizations and individuals committed to addressing issues related to FASD in Alaska.

The mission of the Alaska FASD Partnership is to promote awareness, prevention, and effective life-long interventions for those affected by prenatal exposure to alcohol and their families.

The Partnership was formed in early 2010 after a groundswell of stakeholder effort and public comment to the Advisory Board on Alcoholism and Drug Abuse and its partners about the need for a more organized effort to address FASD in Alaska.

Seven workgroups of the Partnership are actively addressing a variety of issues to determine gaps and barriers to serving people impacted by FASD, developing policy and funding recommendations, promoting public awareness and workforce development, promoting collaborations, research, training, and more, including:

- Diagnosis and Parent Navigation
- Family and Peer Support
- Prevention and Treatment for Pregnant Women
- FASD and the Education System
- FASD and the Legal System
- Services for Adults with FASD
- Professional Development

The Partnership is guided by a steering committee represented by individuals, organizations, and state agencies, including the Departments of Health & Social Services, Corrections, Education and Early Development, Labor and Workforce Development, and the Alaska Court System.

Visit our webpage or contact us via the information below.

Alaska FASD Partnership

Advocacy ▪
 Diagnosis ▪ Case
 Management ▪
 Prevention
 ▪ Substance Abuse
 Treatment for
 Pregnant Women ▪
 Parent Navigation ▪
 Training for Parents
 ▪ Public Awareness ▪
 Education ▪ Housing
 ▪ Employment ▪
 Alternatives to
 Incarceration ▪
 Court Interpreters ▪
 Training for Judges ▪
 Supported Housing ▪
 Case Workers ▪
 Training for
 Educators ▪ Life
 Skills ▪ Traditional
 Healing ▪
 Intervention ▪
 Training for Medical
 Professionals ▪
 Family Support



AK FASD Partnership Members

Abused Women's Aid in Crisis (AWAIC) (Anchorage)
Advisory Board on Alcoholism and Drug Abuse (Statewide)
Alaska Behavioral Health Association (Statewide)
Alaska Center for Children & Adults (Fairbanks)
Alaska Children's Services (Anchorage)
Alaska Mental Health Board (Statewide)
Alaska Mental Health Trust Authority (Statewide)
Alaska Peer Support Consortium (Statewide)
Alaska Youth and Family Network (Anchorage)
All-Alaska Pediatric Partnership (Anchorage)
Anchorage Coordinated Resources Project (Mental Health Court) (Anchorage)
Anchorage School District (Anchorage)
Arctic FASD Regional Training Center (Anchorage/Statewide)
Assets Inc. (Anchorage)
Association for the Education of Young Children-SEAK (Southeast)
Big Brothers Big Sisters of Alaska (Statewide)
Boys & Girls Home of Alaska (Fairbanks)
Camp Fire USA Alaska Council (Statewide)
Central Council of the Tlingit & Haida Indian Tribes of Alaska (Southeast)
Christian Health Associates (Anchorage)
Copper Basin Neurodevelopmental Center (Anchorage)
Deltana Community Services Partnership (Delta Junction)
Dena A Coy/Southcentral Foundation (Anchorage)
Diocese of Juneau (Juneau)
Fairbanks Community Behavioral Health Center (Fairbanks)
Family Centered Services of Alaska (Fairbanks)
Frontier Community Services (Soldotna)
Gastineau Human Services (Juneau)
Governor's Council on Disabilities and Special Education (Statewide)
Hoonah Indian Association (Hoonah)
Hope Community Resources (Kodiak)
Independent Living Center (Homer)
Kenai Peninsula FASD Program (Kenai Peninsula)
Ketchikan Indian Community (Ketchikan)
Kinetictions (Juneau)
Kobuk Valley Consulting (Kiana)
Kodiak Area Native Association (Kodiak)
Juneau Family Health and Birth Center (Juneau)
Juneau FASD Diagnostic Clinic (Juneau)
Juneau Partnerships for Families and Children (Juneau)
Lower Kuskokwim School District (Bethel)
Lynn Canal Counseling Services (Haines)
Nenana City School District (Nenana)
Nome Youth Facility (Nome)
Nondalton Tribe (Nondalton)
Regional Wellness Forum (Seward Peninsula)
Set Free Alaska, Inc. (Wasilla)
Southcentral Foundation FAS Diagnostic Team (Anchorage)
Southeast Regional Health Corporation-Behavioral Health Division (Southeast)
Southeast Regional Resource Center (SERRC) (Statewide)
Southern Kenai Peninsula (SKP) Communities Project (Kenai Peninsula)
Sprout Family Services (Homer)
Stone Soup Group (Anchorage/Statewide)
Tongass Substance Screening (Ketchikan)
UAA Department of Health Sciences (Anchorage/Statewide)
UAA Center for Human Development (Anchorage/Statewide)
Volunteers of America Alaska (Anchorage/Statewide)

....and many individuals

Alaska FASD Partnership

Advocacy ▪
Diagnosis ▪ *Case Management* ▪
Prevention
▪ *Substance Abuse Treatment for Pregnant Women* ▪
Parent Navigation ▪
Training for Parents
▪ *Public Awareness* ▪
Education ▪ *Housing*
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Alternatives to Incarceration ▪
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Training for Judges ▪
Supported Housing ▪
Case Workers ▪
Training for Educators ▪ *Life Skills* ▪ *Traditional Healing* ▪
Intervention ▪
Training for Medical Professionals ▪
Family Support



Statewide Recommendations of the Alaska FASD Partnership

Diagnosis

- Develop use of telemedicine to expand diagnosis and treatment statewide
- Expand use of screening tools/EPSTD (Early Periodic Screening, Diagnosis and Treatment)
- Expand training for primary care/behavioral health providers

Family/Peer Support

- Expand Family FASD Camps to rural areas
- Work with Alaska Peer Support Consortium (AKPSC) to develop peer specialist network
- Expand training for primary care/behavioral health providers

Prevention and Treatment for Pregnant Women

- Expand training for substance abuse treatment providers and alcohol beverage servers
- Vary "Do Not Drink When You Are Pregnant" signage in public places
- Support FASD messages on pregnancy tests
- Expand substance abuse screening and treatment for females of child-bearing age

FASD and the Education System

- Educate district superintendents and staff about successful models for addressing FASD, e.g. those models used in Lower Kuskokwim and Anchorage School Districts
- Present to State Board of Education on FASD
- Expand use of FASD 101 and FASD 201 at in-services, conferences, etc.

FASD and the Legal System

- Change mitigating factors related to FASD
- Expand screening at Department of Corrections (DOC) and Division of Juvenile Justice (DJJ)
- Expand training for DOC/DJJ staff
- Improve transition services for individuals with FASD (assistance with housing, treatment, medication, employment, training, education, case management, etc.) from Corrections

Professional Development

- Expand training opportunities for professionals (primary care and behavioral health providers, educators, probation and correctional officers, attorneys and judges, etc.)
- Distribute resources (books, pamphlets, digital information) to stakeholders statewide
- Expand FASD 101/201 and "FASD Into Action" across professions and cultures

Adult Services

- Improve transition services for adults with FASD (assistance with housing, treatment, medication, employment, training, education, case management, etc.) from foster care, education and correctional systems
- Train employers, educators, peer specialists, and substance abuse treatment providers
- Expand diagnosis for adults
- Develop FASD service system for adults

AMERICAN BAR ASSOCIATION
COMMISSION ON YOUTH AT RISK

Resolution for August 2012 Meeting of the ABA House of Delegates (3/22/12 Third Draft)

RESOLVED, that the American Bar Association urges attorneys and judges, as well as state and local bar associations and law school clinical programs, to support training that enhances understanding of the child and adult disability of Fetal Alcohol Spectrum Disorders (FASD), its impact on individuals in the child welfare, juvenile justice, and adult criminal justice systems, and the importance of collaboration with medical, mental health, and disability experts to promote:

- a) Skilled civil, juvenile, and criminal legal representation for persons with FASD;
- b) Enhanced access to FASD experts for screening and assessing persons suspected of having this disability;
- c) Appropriate responses to the over-abundance of FASD-affected persons in foster care, juvenile delinquency cases, adult criminal proceedings, and correctional facilities; and
- d) Use of FASD knowledge in court for the mitigation of sentencing, as well as in the use of alternatives to incarceration and execution, including therapy and comprehensive services, to help rehabilitate individuals and reduce recidivism.

FURTHER RESOLVED, that the American Bar Association urges that state and federal laws, and policies at all levels of government, reflect the serious effects of prenatal alcohol exposure by:

- a) Including FASD, alcohol-related neurological disorders, alcohol-related birth defects, and persons suffering from the effects of fetal alcohol abuse generally within the statutory definition of developmental disabilities and the listing of conditions that provide medical and other benefit coverage for screening, diagnosis, and treatment to help enhance the lives of those with these conditions;
- b) Allocating comprehensive resources for the early identification, diagnosis, intervention, and treatment of persons with FASD;
- c) Fully implementing provisions, including those in the federal Child Abuse Prevention and Treatment Act, for more effective screening and referral processes to help ensure that infants and toddlers affected by FASD are identified at the earliest possible age and provided assistance at the earliest opportunity;
- d) Developing programs designed to enhance the lives of and protect persons living with FASD (and to support their families), including youth transitioning from foster care and juvenile justice systems, since these impairments make those with this condition especially vulnerable to physical and sexual assault; and
- e) Increasing public awareness, especially for women of childbearing age and substance-abusing women generally, about FASD and the importance of preventing alcohol-related birth disorders.

Report

Introduction

Fetal Alcohol Spectrum Disorders (FASDs) are a group of conditions that can occur in individuals whose mother drank alcohol during pregnancy. This can result in severe physical and emotional symptoms. FASD is a serious problem in the United States that warrants greater attention. This past

Fetal Alcohol Spectrum Disorder and the Criminal Justice System



FASD: Fetal Alcohol Spectrum Disorder



FASD is an umbrella term covering a range of birth defects and brain damage resulting from prenatal exposure to alcohol. The term FASD is not used as a clinical diagnosis, but

encompasses diagnoses such as Fetal Alcohol Syndrome (FAS) and related disorders. FAS is diagnosed when a child shows retarded growth, a specific pattern of minor facial anomalies and neurological damage. Children who do not show all the features of FAS may receive a diagnosis of partial FAS, Fetal Alcohol Effects, Alcohol-Related Neurodevelopmental Disorder, or Alcohol-Related Birth Defects. All persons with a FASD have lifelong cognitive, social and behavioral disabilities.

Trouble with the law

FASD often goes unrecognized, or is misdiagnosed as ADHD or another disorder. The behavior is sometimes blamed on environment or poor upbringing, while the true underlying cause may be brain damage due to prenatal exposure to alcohol. Youth and adults with FASD get into trouble due to their cognitive disabilities:

- Poor grasp of right and wrong.
- No feeling of guilt.
- Lack of impulse control.
- Poor understanding of cause and effect.
- Do not learn from experience.
- Vulnerability to peer pressure.
- Social immaturity: think and act much younger than chronological age.

How many persons with FASD are in the criminal justice system?

It is not known how many people in the criminal justice system have a FASD. A report of the US Centers for Disease Control estimates that 60% of people with an FASD over the age of 12 have been in trouble with the law, and that 35% have been incarcerated.¹ A Canadian study found that 23% of young offenders remanded to a forensic psychiatric inpatient assessment unit had a FASD.²

Problems in dealing with the police

Youth and adults with FASD may panic during encounters with the police, or alternatively, may be very friendly and, in an effort to please, admit to crimes they did not commit. Questioning may confuse them due to their intellectual disabilities:

- Poor short- and long-term memory.
- Difficulty with concept of time (past, present, future, how long).
- Poorly developed concept of property (“It was just lying there, so it didn’t belong to anybody.”)
- Difficulty separating fact and fiction.

“ The person with FASD can be misunderstood in court, victimized in jails, and mismanaged in the transition back to the community, unless those working with the individual are aware of FASD and its implications.”

Fast & Conry (2004)

Helping offenders with FASD

Police, attorneys and judges should be aware of the limitations that accompany FASD. Offenders should be screened for FASD. Detention may be unproductive, resulting in copying deviant behavior. Lifelong structure and supervision is the best way to avoid recidivism.

Resources

FAS: Implications for Correctional Service, Canada
<http://www.csc-cc.gc.ca/text/rsrch/reports/r71/er71.pdf>

FASD Legal Issues Resource Center--U. of Wash.
Information and cases in the US justice system
<http://depts.washington.edu/fadu/legalissues/>

FASD and the Justice System--Canada
Information and cases in the Canadian justice system
<http://fasdjustice.on.ca/>

Factsheet FASD and the Criminal Justice System
http://fascenter.samhsa.gov/documents/WYNK_Criminal_Justice5.pdf

References

1. Streissguth, AP *et al.* Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Final Report to the Centers for Disease Control and Prevention (CDC). 1996. Seattle, University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06.
2. Fast, DK *et al.* Identifying fetal alcohol syndrome among youth in the criminal justice system. *J. Dev. Behav. Pediatr.* 20, 370-372 (1999).
3. Fast, D.K. & Conry, J. The challenge of fetal alcohol syndrome in the criminal legal system. *Addict. Biol.* 9, 161-166 (2004).

David Michael Boulding - Lawyer

Fetal Alcohol and the law

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About David
Contact Info

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

DAVID BOULDING, LAWYER
 PORT COQUITLAM, BRITISH COLUMBIA
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

- Jan Lutke advises: 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 Canadians. 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:

- o Each of us has a little voice inside that says: they should not get away with this unacceptable behaviour.
- o Each of us shares a social sense that an individual could do better if the individual would just try harder.
- o 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 I, not FASD persons.
- o Change is not easily accepted or even wanted, especially in rigid systems like the legal or educational systems.

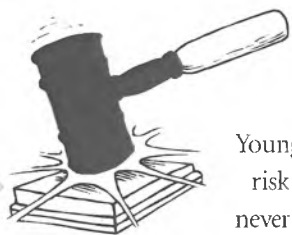
Most importantly: caregivers and others charged with dealing with persons with FASD will experience near total exhaustion very quickly—this includes police, teachers, lawyers, social workers, and judges. Guard against dying inside yourself, the same way a long-distance runner guards against fading too 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.)
- Web Resources by Dr. Kathy Sulik, Ph.D., University of North Carolina (Embryologist).

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FETAL ALCOHOL SPECTRUM DISORDERS AND JUVENILE JUSTICE: HOW PROFESSIONALS CAN MAKE A DIFFERENCE



[T]here is hope. We can change how lawyers, clients, police, judges, probation officers, prison guards, and family members work with FAS clients.¹

—David Boulding, attorney for clients with fetal alcohol spectrum disorders

Young people who are affected by fetal alcohol spectrum disorders (FASD) are at increased risk for involvement with the juvenile justice system.^{2,3} Most youth who have an FASD have never received a diagnosis or services, and they reach the system after a long fall through the cracks.

HOW IS FASD LINKED TO PROBLEMS WITH THE JUVENILE JUSTICE SYSTEM?

Youth with an FASD were born with brain damage that can make it difficult for them to stay out of trouble with the law. They do not know how to deal with police, attorneys, judges, social workers, psychiatrists, corrections and probation officers, and others they may encounter.

Professionals who work with the court system can reach out to young people who may have an FASD to ensure that they receive needed help. Education and training can help professionals identify young people who may have an FASD. This can help them get fair treatment and appropriate services.

WHAT IS FASD?

“FASD” is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

The term FASD is not used as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year in the United States.⁴

WHAT ARE THE CHALLENGES FOR YOUTH WITH AN FASD?

FASD’s effects on the brain can result in cognitive or behavioral deficits. These deficits may include mental retardation, learning disabilities, hyperactivity, attention deficits, and poor social skills. These and other problems associated with FASD may increase the chance that a person will break the law.

Individuals with an FASD typically are impulsive and have trouble foreseeing the consequences of their actions. They

may have a poor sense of personal boundaries. Many are very susceptible to peer pressure and can be easily led. Their judgment is often poor.²

FASD also presents challenges throughout the judicial process, from questioning through arrest, hearings, sentencing, and detention. Many youth who have an FASD have poor communication skills, while others may “talk” much better than they can function. They may become confused under pressure. They often cannot understand their rights and may confess or otherwise implicate themselves and others, even if they are not guilty. Youth who have an FASD may believe that if they confess, they will be allowed to go home. They also want people to like them and may provide a false confession in an effort to please the police.

Youth who have an FASD typically have memory problems, which can contribute to forgotten court dates or meetings with probation officers, judges, and attorneys. Their risk for victimization in detention is high, as they may fall prey to other inmates.

It can be difficult for persons with an FASD to learn from their mistakes. Because the judicial process can be lengthy, they may not draw a connection between their actions and the later consequences. Once released from detention, youth who have an FASD may commit similar offenses and cycle through the system again and again.

HOW CAN THE SYSTEM HELP YOUTH WITH AN FASD?

Youth should be screened for FASD at all entry points into the juvenile justice system. Those who work in the system, especially attorneys and social workers, should look for a history of behavior that suggests an FASD. They also should ask questions about prenatal exposure to alcohol. When they suspect that an FASD is present, they should request a complete



evaluation by clinicians qualified to diagnose an FASD. The evaluation should include assessments of possible co-occurring psychiatric disorders and adaptive behavior.⁵

Attorneys should be aware of FASD and use their knowledge to advocate effectively for their clients, particularly in proceedings related to:

- **Competency**—Youth with an FASD may be unable to understand the charges against them and participate in their own defense.
- **Diminished capacity**—Young people with an FASD may find it difficult to distinguish right from wrong, form intent to commit an offense, and understand consequences.
- **Decisions to decline/remand/waive**—Youth with an FASD are likely to be safer in a juvenile facility than in an adult prison due to potential victimization.
- **Sentencing**—In some cases, attorneys may be successful in presenting FASD as a mitigating or exculpatory factor. They also should explore alternative sentencing options.
- **Treatment**—Court-ordered treatment is sometimes the only way for youth with an FASD to receive appropriate interventions.

Information from evaluations, medical records, family history, and school and employment records should be included in presentencing investigations. The outcome may influence whether or not the youth will be detained, where, for how long, and what support he or she will receive. Appropriate services are essential, including medication or substance abuse treatment (if necessary), vocational training, life skills training, mentoring, and advocacy.

Detention of youth with an FASD may be unproductive. It can increase the risk of recidivism because they may copy the deviant behavior of other juveniles. For probation or aftercare, a highly supervised, structured living arrangement is critical for success. People with an FASD often have difficulty managing their money or tending to household chores. Attorneys should ensure that clients who were receiving developmental disabilities support do not lose their benefits while they are in the system.^{6,7}

Throughout the judicial process, communication with young people who have an FASD should be concrete, simple, and repetitive. Youth with an FASD have trouble following multistep instructions and understanding figures of speech. Using frequent reminders, visual cues, and open-ended questions can help them follow rules and understand what is happening.

FASD is not an excuse for breaking the law. However, all youth, including those with an FASD, deserve to be treated fairly by the juvenile justice system. Increased awareness and action at all levels of the system can offer a lifeline to young people with an FASD. In addition, the potential benefits to society, through decreased crime and costs, are tremendous.

ADDITIONAL RESOURCES

SAMHSA FASD Center for Excellence. 2005. **What You Need To Know: Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis.** Rockville, MD: fasdcenter.samhsa.gov

Minnesota Organization on Fetal Alcohol Syndrome. **Tools for Success: Working With Youth With Fetal Alcohol Syndrome and Effects in the Juvenile Justice System Resource Guide.** www.mofas.org

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Stop and think. If you're pregnant, don't drink.

For more information, visit fasdcenter.samhsa.gov or call 866-STOPFAS.

www.stopalcoholabuse.gov



SAMHSA
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FETAL ALCOHOL SPECTRUM DISORDERS AND THE CRIMINAL JUSTICE SYSTEM

There was a part of me that was angry, but I also knew that the police department and the justice system were uninformed about how vulnerable and easily swayed people [with an FASD] are.

—Mother whose son with an FASD was wrongly convicted of a crime

FETAL ALCOHOL SPECTRUM DISORDERS



FASD is an umbrella term describing the range of effects that can occur in an individual prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. FASD is not a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

REASONS PEOPLE WITH AN FASD GET IN TROUBLE WITH THE LAW

Studies show that people with an FASD have specific types of brain damage that may cause them to get involved in criminal activity. These individuals show:

- Lack of impulse control and trouble thinking of future consequences of current behavior
- Difficulty planning, connecting cause and effect, empathizing, taking responsibility, delaying gratification, or making good judgments
- Tendency toward explosive episodes
- Vulnerability to peer pressure (e.g., may commit a crime to please their friends).

Persons with an FASD may break the law without intending to do so. For example, they may touch people when it is unwanted and think they are just being friendly. They may take things that do not belong to them because they like them.

People can take advantage of individuals with an FASD. They may talk them into committing crimes. Females with an FASD may be involved with destructive men for food, shelter, attention, or drugs.³ These relationships put them at risk for arrest.

NUMBER OF PEOPLE IN THE CRIMINAL JUSTICE SYSTEM WITH AN FASD

It is difficult to know how many people in the criminal justice system have an FASD. Data are limited, and populations vary by State. In addition, few systems screen for FASD or conduct a full diagnostic assessment. Researchers

at the University of Washington estimate that 35 percent of individuals with an FASD have been in jail or prison at some point. They also estimate that more than half the people with an FASD have been in trouble with the law.¹

The number of people with an FASD in the criminal justice system is assumed to be high. In the United States, approximately 3 million people are in jail or prison. Based on estimates of FASD in the general population, as many as 28,036 inmates could have an FASD.²

ISSUES RELATED TO FASD IN THE CRIMINAL JUSTICE SYSTEM

Laws vary by State and case law is binding only in the State or circuit where the case was decided. Only Supreme Court cases are binding nationally. However, several general issues can arise for attorneys and judges dealing with persons with an FASD:

- **Competency to stand trial**, which is the ability to understand the charges, participate in a trial, and assist in one's own defense. Persons with an FASD may not understand the charges against them. They may find criminal proceedings confusing. They may have problems with time management and come to court late or not at all. Several cases address competency and FASD.⁴⁻⁶
- **Validity of expert testimony regarding diagnosis.** Questions arise about the types of exams that are sufficient to determine a diagnosis of an FASD. For example, what if maternal alcohol use during pregnancy is unknown?^{7,8}
- **Diminished capacity.** Capacity refers to the ability to understand right and wrong and to understand the

WHAT YOU NEED TO KNOW



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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likely outcome at the time of the act. Some crimes require evidence of intent for the person to be found guilty. Defense lawyers may argue that persons with an FASD cannot form the intent to commit crimes because they cannot foresee the likely outcome.⁹

- **Effect of FASD on sentencing.** Lawyers have appealed the death penalty by arguing that FASD was not introduced as evidence to support a lesser sentence.¹⁰⁻¹²
- **Ability to testify.** Persons with an FASD are highly suggestible and may not be able to give accurate testimony. They are prone to making false confessions.¹³
- **Recidivism.** Offenses do not appear to get worse, such as from auto theft to robbery. However, persons with an FASD tend to repeat crimes of opportunity, such as shoplifting. Their thought process seems to be, "I want. I take."¹⁴

WAYS THE CRIMINAL JUSTICE SYSTEM CAN ADDRESS THE NEEDS OF PERSONS WITH AN FASD

Because of their disabilities, persons with an FASD may repeat the same mistakes many times. Thus, support to improve functioning might be more appropriate than rehabilitation. This approach focuses on education, job training, and family support, rather than punishment. Medication may also help. In some cases, adults with an FASD who had multiple jail stints for petty, impulsive acts avoided jail when given appropriate medical treatment.³

Understanding how persons with an FASD respond to certain situations can help. Due to sensory issues, they can become overwhelmed by bright lights, causing them to panic and run from the police or resist arrest. Because they are eager to please,

many unknowingly waive their rights by signing forms that they do not understand. In addition, they may consent to being searched or take responsibility for the crimes of others to win favor.

Sentencing is also an issue. Some persons with an FASD respond well to the intense structure and rules of prison. Others are vulnerable to attack, exploitation, and manipulation by other inmates. Some do not understand prison rules and break them. Because corrections officers may not understand FASD, they may punish inmates with an FASD for failing to follow directions. It is critical to offer training on FASD to all corrections staff so they can learn strategies to respond to inmates with an FASD.

Once on probation, persons with an FASD may have trouble meeting probation requirements. They can have problems managing time, recalling appointments, and making plans. Therefore, they may need a greater level of supervision. A relative or support person may need to be assigned to follow up on probation requirements. Highly structured probation that includes supervised living, life skills education, and drug and alcohol treatment can be very effective.¹⁵ In fact, supervision can help prevent crime. Many clients with an FASD can remain crime free with intense supervision.¹⁴

Other effective alternatives to prison include halfway houses, group home treatment centers, or electronic monitoring at home. In such cases, emphasis must be placed on creating a well-structured environment with predictable rules and consequences. In these settings, persons with an FASD can continue to participate in the community but their behavior will be more closely monitored.¹⁶

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National Organization on Fetal Alcohol Syndrome

Helping children & families by fighting the leading known cause of mental retardation & birth defects

FASD: What the Justice System Should Know



Alcohol abuse and pregnancy are common among women in the criminal justice system.

- An estimated 70 to 85 percent of inmates need substance abuse treatment.
- Approximately one in four women is either pregnant or postpartum when she enters prison.

The Justice System can help to prevent Fetal Alcohol Spectrum Disorders (FASD) among the incarcerated population by offering educational workshops on FASD and addiction counseling for women inmates.

Behavioral impairments due to FASD make affected individuals more likely to get in trouble with the law

- Sixty-one percent of adolescents and 58% of adults with FASD have been in legal trouble.
- Thirty-five percent of those with FASD over the age of 12 had been incarcerated at some point in their lives.

Many individuals with FASD will never socially mature beyond the level of 6 year-old child.

Other factors that may place persons with FASD at risk for involvement with the criminal justice system include:

- Difficulties in impulse control;
- Intellectual deficits;
- Poor judgment skills; and
- A history of abuse and/or neglect.



Problems individuals with FASD may encounter when dealing with police include:

- Being persuaded by the police (even inadvertently) to admit to crimes which they did not commit;
- Taking responsibility for crimes committed by others in order to win the favor of more sophisticated companions or to please the police;
- Consenting to searches of themselves or their possessions in circumstances in which non-disabled sophisticated individuals would not;
- Panicking during encounters with the police, running away or resisting arrest;
- Saying that they understand their legal rights when in fact they do not; and
- Making potentially incriminating statements about how serious any misconduct may have been.

The Justice System can help FASD-affected individuals by:

- Educating judges, lawyers and parole officers about the characteristics and behaviors of persons with FASD;
- Establishing screening, analysis, and treatment procedures for those with FASD who enter the juvenile justice or adult criminal justice system;
- Establishing/utilizing alternative sentencing programs for persons with FASD who have committed non-violent offenses; and
- Offering referral information for the children of incarcerated women who may have been prenatally exposed to alcohol.

FASD and the Legal System

"FASD is not an excuse, it is a reason".

Fetal Alcohol Spectrum Disorder (FASD) is a range of clinical conditions including Fetal Alcohol syndrome (FAS), Partial Fetal Alcohol syndrome (pFAS), Alcohol-related Neurodevelopmental Disorder (ARND) and Alcohol Related Birth Defects (ARBD). Many of these individuals go unrecognized as they appear "normal" with above average IQ's and are often defiant or disruptive. The spectrum of neurological damage with FASD causes many different cognitive and behavioral problems.

Currently our legal system is based on fundamental principals of freewill and choice. However, the whole issue of FASD challenges these precepts.

Whether or not we are able to overcome the issues of identification and diagnosis of FAS in the court system is not the context of this discussion. Diagnosis or not, we are still left struggling to understand the issue of FASD and its relationship to offending and the law. There are a number of issues we must begin to understand and address.

1. Individuals with FASD have an increased susceptibility to involvement with the legal system.

FASD individuals are highly suggestible, often have a negative self-image and almost always get caught by the legal system because they can't plan ahead. These individuals have poor adaptive behavior, poor language ability, they acquiesce when they don't understand, confabulate because their memory is faulty, and fail to reason through issues. Julie Conry's study (Conry, 1999) reports that approx 25% of youth prison populations in British Columbia are FAS affected and 50% have other disabilities. This results in a high representation of disabled youth who are now labeled criminal. A Seattle study found 60% of FAS affected individuals were in conflict with the law (Conry, 1999)

2. Courts are designed to deal with a model of intervention that assumes a person is responsible for their future behavior.

The court system is inappropriate and unworkable for FASD affected individuals. The model of the courts is based on the notion of freewill and choice and that the accused is responsible for their future behavior. Judges need to ask that people affected with FASD have a fixed point of responsibility who monitors the specific and concrete plans for day-to-day living. A fixed point of responsibility requires someone who knows how to advocate for access to those services in the community that will best facilitate the FASD individual's needs. FASD affected are often without family supports that could act as such for them. A model that has been successful in the deinstitutionalization of the handicapped is the individual program plans (I.P.P.'s). Should we not consider the concept of Individual Sentencing Plans (I.S.P.'s) where the emphasis is on the individual's plans and there is identification of a fixed point of responsibility to ensure that those needs are met?

3. FASD affected individuals have little or no concept of cause and effect. We must ask

whether or not their actions can then be deemed to be criminal.

An FASD affected individual is not able to link cause and effect which of course limits their ability to anticipate consequences. They are unable to integrate all of the information from cause and effect situations, leading to an inability to look at the "whole picture". These are serious cognitive impairments. We must ask ourselves if it is morally or ethically acceptable to punish handicapped individuals. More humane methods of dealing with FASD in the legal system can be utilized.

4. FASD are victimized in the court system and the jail setting.

FASD display a number of characteristics, which have a negative effect in the court and in the prison system where there is a definite expectation of ability to comply with "appropriate behavior". They are often non-compliant, "stubborn", misinterpret cues, go to far, don't respond to adult approval, ignore verbal limit setting, have trouble adjusting in social situations, over or under react, may show flat affect or lack of eye contact, are spacey or lack initiative, have inappropriate responses to situations and have an apparent lack of remorse. Failure to engage in appropriate behavior leads to the desire to "teach the youth a good lesson", one which he will usually be unable to learn.

5. We don't spend enough time early in their conflict with the law, trying to understand the underlying causes for why people come into the system.

Criminal lawyer's are taught to ask the question of guilt and innocence but these are not the right questions to ask FASD affected. We need to ask "why are you here", "What should happen to you now", "Why did this happen" and "what can we do to ensure that this doesn't happen again"? The vast majority of accused do not warrant incarceration. This could be reduced by 50% if we focused on these questions. (Canada places second in the Western World for number of incarcerated citizens)

6. We can lower the risk of re-offending by establishing effective strategies for working with FASD individuals.

Incarceration is not the only form of punishment in our society. The increased use of the principles of restorative justice could assist in diverting these disabled individuals from the legal system and ensure appropriate community supports. There are no restrictions on the kinds of offenses that can be diverted so as long as the issues of public protection and the needs of the individual are addressed there is a potential here to decriminalize people with disabilities.

Viable Alternatives

Judges are asking for alternatives. They are becoming more aware of the need to deal with this disability in a more proactive way. An "aggressive, comprehensive, intervention and treatment program" is required. Information Management Systems that keep track of FASD affected people are required and Therapeutic Courts like those used in the Toronto Drug Courts should be developed.

Circle Courts are being explored in Saskatoon (Judge Turpel-LaFond, Saskatoon Provincial Courts, 2001). These team-based, mediation oriented, interagency courts create a "circle of care" support network that utilizes the inter-community expertise and family supports to create a solid support network for the FASD affected. The provision of appropriate legal services for FASD affected is not

specialized treatment. It is however differential treatment with the goal of ensuring an outcome of equality. All disabilities deserve to have an outcome of equality in our society.

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Suggestions for more user-friendly court hearings

Barrow has about 4,500 people. It's the farthest north community in the United States. The Barrow court serves an area about half the size of California, with a population of about 10,000 people. We do a lot of telephonic hearings. Most of the population is Inupiaq Eskimo, but there are a large number of other racial and cultural groups, too. These suggestions are offered in a spirit of humility, knowing that there are many different kinds of courts, different types of cases and different amounts of time available for each case. These thoughts are personal to me based on over 29 years as a judge in this community: they are not an official position of the Alaska Court System.

- Realize that a person who appears to understand everything, and even says they understand, **may not**. There may be language problems and cultural misunderstandings about the justice system. There may be mental conditions like Fetal Alcohol Spectrum Disorder in which (for example) a young adult in his or her 20's actually has the ability to understand of an elementary school student. Some "red flags" that I consider in being especially careful to accommodate the person:
 - ✓ Diagnosis of FAS/FAE/FASD or other mental challenge.
 - ✓ A very traditional type of person who may just not understand the Western justice system.
 - ✓ Judge's personal knowledge or indication in file that the person had an alcoholic mother and/or a very disrupted childhood.
 - ✓ A follower in criminal activity but is the person getting caught.
 - ✓ Keeps getting into trouble multiple times, especially in similar type of cases.

- ✓ In special education or left school early.
 - ✓ Others say the person is impulsive—does not think before doing actions.
 - ✓ Back in court for multiple, relatively minor, probation violations.
- Slow down and check in with a person during an explanation of rights or similar hearing to make sure that the person knows what is going on. Pauses are probably necessary between different major points just to make sure the concepts sink in. When questions are being asked, pauses may be necessary for the person to respond in a manner that is comfortable and that will allow sharing of information that the person wants to say. Offer a chance to consult again with the attorney after the explanation.
 - Consider using visual aids, such as writing on large sheets of paper or on a wipe on/wipe off board. Logistics in the courtroom may make this difficult.
 - A rural court like Barrow involves frequent use of telephonic hearings. Using the telephone is extremely convenient and cost-effective for everyone. But such hearings present special issues. If silences are necessary during telephonic hearings, explain what is going on so that the frustration level for the person(s) on the phone can be reduced. Sometimes, it's impossible to do a telephonic hearing with certain people involved in the justice system. The lack of personal contact may reduce their ability to understand. It may be possible simply to combine two hearings done in person at a future date instead of having one telephonic (like a change of plea) and the other (like a felony sentencing) in person. We have arranged for a preparation of a presentence report and then conducted a combined change of plea and sentencing with a remand to jail immediately following the hearing.
 - Be sensitive to your own cultural biases. Someone may not look at you directly. It may be the person is ignoring you. But, in that person's culture, it may be a sign of respect.

Some shy juveniles dealing with justice system personnel in this part of Alaska may raise their eyebrows to indicate "yes". Though not saying anything, they are responding to the question. Saying "he let me do something" might mean the other person allowed it to happen or it might mean that the other person forced it to happen.

- Do not assume that the attorneys involved have had the time to explain what is needed to their clients in a way that the client can understand. There may have been a lack of time or a lack of understanding of a client's mental conditions (such as FASD). I believe that it's the judge's responsibility to make sure the persons involved in the hearing understand what happened.
- Where possible, use plain English in what is said and what is written. Written forms should have places for a defendant or juvenile to initial so that the person focuses on each portion of the form. Concrete language is best. Having "white space" and easy to read type is helpful, even if it uses more paper! We need to avoid having the whole experience being a "blur" of words.
- When appropriate, check in with the lawyer's client about their personal schedule when setting a court hearing. The convenience of the judge and attorneys may not coincide with other factors like making sure that a child's hearing occurs after the school day.
- Once structure has been provided to a juvenile by a conduct agreement and treatment, the juvenile may do much better. Busy professionals may suggest that the interventions are no long needed. Be very cautious about removing the structure, since that portion of the environment of the juvenile may be the source of the success being experienced.
- **Bottom line: the goal of timely judicial decision making ("moving cases") must not displace having respect for all the participants' need to understand what is happening.**

GENERAL CONDITIONS OF PROBATION

**I KNOW THAT I MAY BE SENT TO JAIL IF I DON'T OBEY ALL
THESE RULES
I AM PUTTING MY INITIALS TO SHOW THAT I UNDERSTAND**

1. I will follow all the direct court orders in this sentencing order by the deadlines stated in this order.

My initials: [_____]

2. I will contact my probation officer the next work day after my sentencing (if no jail time) or the next work day after I get out of jail. **My initials:** [_____]

3. I will ask my probation officer before moving to a new place, leaving my approved region of residence or before getting a new job. **My initials:** [_____]

4. I will try to find a job, if I can. When I don't have a job, I will give my probation officer proof of my job search efforts or other activities if asked to do so by my probation officer.

My initials: [_____]

5. I will visit my probation officer before the tenth of each month, or as otherwise directed. If my probation officer says it is okay, I can call or fax a report instead.

My initials: [_____]

6. I will not carry firearms or any hidden weapon.

My initials: [_____]

7. I will let my probation officer know about any friends or family on felony supervision or have a felony conviction. I will not associate with other felons without first getting permission from my probation officer. Brief incidental contact is okay.

My initials: [_____]

8. No matter where I am, I will stay sober. I cannot drink any alcohol, including "homebrew".

My initials: [_____]

9. I will stay out of trouble and follow the laws.

My initials: [_____]

10. I will tell my probation officer if I buy or sell a car, truck, snow machine, or ATV.

My initials: [_____]

11. I will follow any special rules given by my probation officer or the judge, in order to enforce these general and special conditions of probation.

My initials: [_____]

**SPECIAL CONDITIONS OF PROBATION FOR
XXXXXX**

**I KNOW THAT I MAY BE SENT TO JAIL IF I DON'T OBEY ALL
THESE RULES**

I AM PUTTING MY INITIALS TO SHOW THAT I UNDERSTAND

1. I will stay sober. I will not drink, order, make or possess alcoholic beverages, including homebrew. I will only live in a residence where there is no alcohol (including homebrew) present.

My initials: [_____]

2. I will be "drug-free." I will not use or possess any illegal drugs, including marijuana. I will only live in a residence where there are no illegal drugs (including marijuana) present.

My initials: [_____]

3. I will promptly give samples of my breath (including a "PBT") or urine at the direction of my probation officer to test for use of alcohol or illegal drugs. I will promptly give enough of a sample so that the test(s) can be done.

My initials: [_____]

4. I will not knowingly enter or remain at a place where alcohol is the main thing being sold. This rule includes bars, liquor stores, and bootlegger's houses.

My initials: [_____]

5. My Probation Officer can search me without a warrant or the Probation Officer can tell a police officer to do the search

without a warrant. The search can include my body, my personal property, my living space, my vehicle, or any vehicle that I control. This search is for alcohol, including homebrew; illegal drugs, including marijuana, and items used for taking drugs ("drug paraphernalia").

My initials: [_____]

6. Within thirty (30) days after my probation begins, I will contact an alcohol/substance treatment program approved by the Department of Corrections and arrange to have an assessment for alcohol/substance abuse treatment. I will take the first available assessment for treatment. If treatment is recommended, I will enter, actively participate and successfully complete the treatment, which may include residential treatment of up to **thirty (30) days**.

My initials: [_____]

7. As arranged by my Probation Officer, I will get an evaluation for alternatives to violence/anger management from a program approved by the Department of Corrections. I will follow any treatment recommendations in the evaluation. I will not stop treatment without approval of my Probation Officer.

My initials: [_____]

8. I will sign the permission slips ("releases") so that the Department of Corrections can monitor my participation and attendance at any of the evaluations and treatment programs and receive copies of evaluations, progress reports and discharge summaries.

My initials: [_____]

9. I will submit to taking of a swab from inside my cheek and the taking of fingerprints for the DNA Identification System when my Probation Officer asks me to.

My initials: [_____]

10. I will have no contact with the victim in this case, XXXXX without permission from my supervising probation officer. In addition, I will not use the services of any employee of City Cab in Barrow, Alaska.

My initials: [_____]

11. I will have no contact with co-defendants XXXXXX & XXXXXX without permission from my probation officer. But incidental contact is okay.

My initials: [_____]

12. If restitution is ordered, I will make payments on a schedule approved by my probation officer. I will provide income and expense records to help set up a reasonable payment plan.

My initials: [_____]

IN THE DISTRICT/SUPERIOR COURT FOR THE STATE OF ALASKA

SECOND JUDICIAL DISTRICT AT BARROW

STATE OF ALASKA,)
)
 Plaintiff,)
)
 vs.)
)
 _____,)
)
 Defendant.)
)
 DOB: _____ DOV: _____)

BAIL ORDER

Date Judge's Initials
 This order is valid until _____

Case No. 2BA-____-____ CR

ATTORNEY:

- I will get a private attorney. My initials: [_____]
- I want an attorney and the court agrees I cannot afford one:
 - My attorney is the Public Defender. P.O. Box 429, Barrow, AK 99723. Phone: 852.2520 or 1.800.478.2521. My initials: [_____]
 - My attorney is the Office of Public Advocacy
 100 Cushman Street, Suite 100, Fairbanks, AK 99701.
 Phone: 907. My initials: [_____]
 - My attorney is _____
 Address: _____
 Phone: _____ My initials: [_____]
- I do not want to have an attorney. I know I can ask for an attorney later. My initials: [_____]

COURT DATES:

- My next court date is _____ at _____ for
 pretrial conference omnibus hearing _____
 My initials: [_____]
- Another court date is _____ at _____ for
 calendar call _____ My initials: [_____]
- Another court date is _____ at _____ for
 jury trial _____ My initials: [_____]
- I can call in for all my hearings except my jury trial. I have to be in Barrow for my jury trial. Phone: 907.852.4800 or the "866 line."
 My initials: [_____]

BAIL PROMISES: FOLLOW THESE RULES AND BE SUCCESSFUL ON BAIL!

I promise the Judge/Magistrate that I will follow the rules that the judge/magistrate has checked.

I will stay away from alcohol completely. [0.00 BrAC] My initials:
[NO alcohol]

I will be "clean" of illegal drugs and stay away from them. My initials:
[NO illegal drugs]

I will only be in places that have no alcohol and no illegal drugs. My initials:

I will take a "PBT" when an officer asks me to. I know the officer has to have a good reason for asking. My initials:

I will go to the police station with my photo id EVERY DAY and take a "PBT." In Barrow, I will go between 11:00 a.m. and 1:00 p.m. In a village, I will go during the times set by the village police officer. My initials:

While in town, I will ONLY be a passenger in a car, truck, snow machine or four-wheeler. My initials:

I will stay away from: _____
[Including NO calls, texting, sending letters or email, Facebook posts, My Space or other messages, either]. My initials:

I will always be at least 100 feet away from this place:

My initials:

I can go to this place ONCE with an officer to get my personal things. My initials:

I will be with _____ who is my "third party custodian"
 all the time _____ . My initials:

I will let the police search my living space, my clothes, or my car/truck for
 alcohol illegal drugs weapons. They don't need a warrant. My initials:

I will be inside or right beside a house from _____ p.m. to _____ a.m. OR
 at times set for me by my probation officer. My initials:

I will stay in touch with my attorney. My initials:

If I change where I live, I will tell my attorney or the court within a day. My initials:

I will get a written OK from the Court before I leave
 Alaska and Barrow _____ My initials:

I will stay out of trouble and follow all the laws. My initials:

_____ My initials:

**** YOU MAY BE ARRESTED WITHOUT A WARRANT IF YOU VIOLATE ANY OF THE BAIL PROMISES****

RELEASE OR BAIL BOND:

“Own recognizance.” I do not have to give any money to be released, But if I do not show up for court or follow the rules, I could be arrested and put in jail. My initials:

Unsecured appearance bond. I don't have to give any money right now. But the state could get the money from me later if I don't follow the rules. The bond is an “appearance bond” for \$ _____. This bond is to make sure I come to court for all my hearings. My initials:

Other bonds. I have to get everything arranged before I can get out of jail. Any money I give can be lost to the State if I do not follow the promises I have made.

The bond is a cash **“performance bond”** for \$ _____. Cash in that amount has to be given to the jail or court before I can get out of jail. This bond is to make sure I follow all the promises except the one about coming to court. My initials:

The bond is an **“appearance bond”** for \$ _____. Either cash in full amount or 10% of the amount, or a bond from a bonding company has to be given before I can get out of jail. This bond is to make sure I come to court for all my hearings. My initials:

Not bailable. The judge/magistrate has decided I have to stay in jail right now. I can ask for a bail review later on. My initials:

AGREEMENT BY DEFENDANT

I PROMISE to follow the rules the judge/magistrate checked. I know I can get in trouble if I don't. I could be put in jail and the State could take my bail money. The police could charge me with new crimes like “Violation of Conditions of Release,” “Failure to Appear,” and “Unlawful Contact.” I give permission for the Clerk of Court to accept for me any paperwork needed for the state government to get the bail money if I cannot be found.

_____ Today's date: _____
My name (sign your name)

_____ My address for mail
Phone numbers: Cell _____ Home _____ Work _____

PROMISE BY THIRD PARTY CUSTODIAN

I accept the duty of making sure the defendant follows the promises made in this court form. I will make sure the defendant comes to court or jail as ordered by the Judge/Magistrate. I understand that I can be charged with a misdemeanor crime that has up to one year in jail and up to a \$10,000 fine or up to 90 days in jail and up to a \$2,000 fine if I do not call the police right away if the defendant does not follow the bail promises in this case.

_____	_____	_____
Custodian's Signature	Date of Birth	Home Phone
_____	_____	_____
Residence Address	City State	Work Phone

COURT ORDER

Based on the above information, the Court makes the following order:

- 1. The defendant must obey all promises checked in this court form.**
- 2. Arrest without a warrant is allowed for violation of any of the bail conditions.**
- 3. If an attorney is "checked" above, that attorney is appointed to represent the defendant.**
- 4. The defendant shall be released, after any required bail has been posted or other court order such as a court-approved third party custodian has been satisfied.**
- 5. The defendant may be transported to any appropriate jail if the defendant has not posted any required bail within 48 hours.**

_____	_____
Date	Judge/Magistrate

I certify that copies distributed to: Defendant Barrow jail Village of _____ Police (fax)
 DA PD Defense Attorney _____ Adult Probation _____
 _____ on _____, _____, Clerk.

THE SUPERIOR COURT FOR THE STATE OF ALASKA
SECOND JUDICIAL DISTRICT AT BARROW

In the Matter of:)
)
)
AKA)
)
A minor under 18 years of age.)
)
Date of Birth: _____)

- CONDUCT AGREEMENT
 CONDITIONS OF PROBATION

CASE NO. 2BA- - - DL

I WILL PUT MY INITIALS IN THE [] TO SHOW I UNDERSTAND AND AGREE WITH EACH RULE.

1. I won't drink alcohol. []
2. I won't use illegal drugs like marijuana. []
3. I will take a "PBT" or "UA" test when the police or the probation officer asks me to. []
4. I won't buy or carry any weapons, unless I'm out hunting with an approved adult. []
5. The police or my probation officer can search my clothes, things I am carrying, my living space or a vehicle I'm in for alcohol, drugs, or weapons. []
6. I will come to my court hearings when I'm supposed to. []
7. I will follow the rules of my parents or guardians or the probation officer. []
8. I will go to school when it is open and follow their rules. []
9. I will stay where I am living or be with my parent or guardian or other approved adult between 10:00 p.m. and 7:00 a.m. every night. []
10. I will stay out of trouble and follow the law. []

Special Rules. These rules are part of this case. _____, Judge

11. will talk to the counselors about what kind of treatment I may need to help me stop using alcohol or illegal drugs. []

12. I will do the treatment the counselors say to do. Treatment might be in Barrow with Inupiat Teens Taking Control or off the North Slope. []

13. I will sign papers so the probation officer knows about the assessment and treatment. []

14. I will also follow these rules:

_____ []

I understand all these rules and I will follow them.

My signature

Witness: _____
Probation Officer

Promise of parents or guardians:

We also understand these rules. We will make sure the minor follows them, and we will call the police if the minor does not do so. We understand that if the minor does not follow them, the minor could be arrested and put in a locked place for juveniles. We agree to bring the minor to the court hearings.

Parent/Guardian/Custodian

Parent/Guardian/Custodian

COURT ORDER

Based on these promises, IT IS HEREBY ORDERED that the minor follow these rules. The minor can be released from any detention.

Recommended on _____
(date)

Effective Date: _____

Superior Court Master

Superior Court Judge
Michael I. Jeffery
Type or print name

I certify that on _____
a copy of this document was sent to:

- DJJ Minor Attorney Parent/Guardian
- DA GAL Placement Facility Other: _____

Clerk: _____

An Arctic judge's journey with FASD

BY HON. MICHAEL I. JEFFERY

An Arctic judge's journey with FASD

BY HON. MICHAEL I. JEFFERY

A trial court judge knowledgeable about Fetal Alcohol Spectrum Disorders struggles with adapting the operations of his court to the needs of FASD-affected individuals in the Alaskan Arctic. His background in learning about FASD through cases and training and the methods he has brought to the Barrow Superior Court to attempt to make the justice system more understandable and fair to persons affected by FASD are described. His frustration at not being able to evaluate the degree of impairment from FASD experienced by the affected persons in the courtroom and the appropriate accommodations needed for each person are also described.

KEY WORDS: FASD, Arctic, justice system.

Barrow, Alaska,¹ is the northernmost community in the United States. It is the hub community of the North Slope Borough,² an expanse of about 89,000 square miles of Arctic tundra, ponds, critical habitat for wildlife, and the home of the resilient Inupiaq Eskimo people and other ethnic groups.

AUTHORS' NOTE: *The comments in this article are personal and do not represent the Alaska Court System. For additional information about this article contact: The Honorable Michael Jeffery, e-mail: mjeffery@courts.state.ak.us.*

¹ Estimated 2003 population of 4,286, including 59.3% Inupiaq Eskimo persons. (North Slope Borough Department of Planning & Community Services 2003, BRW-3, BRW-5).

² Estimated 2003 population of 7,307, including 74.21% Inupiat Eskimo persons. (North Slope Borough Department of Planning & Community Services 2003, NSB-3, NSB-6).

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The wind blows for hundreds of miles across the Arctic plain. The small amount of air pollution in Barrow is carried by the winds from Russia and China. The sun shines nonstop in the summer, but it does not rise in the winter for about 8 weeks.

A group of Inupiaq Eskimo people ("the Inupiat") settled in Barrow in ancient times because of the food resources, including caribou, ducks, seals, and the bowhead whale. In the late 1800's the bowhead whale attracted the intrepid Yankee whaling crews for whale oil and baleen. The whalers not only drastically reduced the population of bowhead whales; they also brought alcoholic beverages with them. The Inupiat were introduced to a substance that is still part of daily life, used by many natives and nonnatives alike.

In precontact times, the Inupiat had traditional laws administered by consensus of the whaling captains and elders (Case, 1984). In the late 19th century, the traditional law was supplemented by the U.S. Revenue Cutter Bear whose captain dispensed Western justice during annual visits, until Charles Brower, a nonnative former whaler who had married into the community, became territorial magistrate. From Alaska statehood on January 3, 1959 to the early 1980s, Barrow was served by dedicated local magistrates, without formal legal training, supplemented by Superior Court judges who would visit on occasion.

After a year of work as a legal services attorney in Boston, a near-fatal car crash, and almost 5 years in India, I moved to Barrow in mid-January 1977 to open an office for the Alaska Legal Services Corporation. I traveled to all seven North Slope villages as part of this work. In 1982, I was appointed the North Slope's first resident superior court judge and have continued this service since. Alaska has a statewide court system. The Barrow Court has been staffed since 1982 by a superior court judge and magistrate, with the support of the hard-working court staff. The magistrates serving since 1984 have all had law degrees. The court serves an area of about

80,000 square miles,³ including Barrow, six of the seven Arctic villages, and the Prudhoe Bay oil complex.

My journey with FASD begins

The ancient Greek philosophers Plato and Aristotle recognized the problems caused to children by mothers drinking during pregnancy, but in 1968, French researchers first described the existence of common issues associated with children thus born (Lemoine, Horousseau, Borteyru, & Menuet, 1968). In 1973, researchers in Seattle, Washington identified a set of characteristics occurring in children with mothers who drank alcohol during pregnancy. They called these characteristics Fetal Alcohol Syndrome (FAS) (Warren, 1997).

Since 2004, the term Fetal Alcohol Spectrum Disorders (FASD) has been used to describe a variety of conditions that can occur when a child has been exposed to alcohol while in the mother's womb (CDC, 2009).⁴ Fetal Alcohol Syndrome is the most easily diagnosed and studied of the FASD conditions because of distinctive physical features, but the number of individuals affected by all of FASD conditions is 9-10 times the number affected by FAS (Briacombe et al. 2009).

I was completely unaware of all this information during my years in Barrow with Legal Services and during my early years on the bench. I don't remember when I first heard about "Fetal Alcohol Syndrome or Fetal Alcohol Effects" (the former terms used for FASD), but Clayton's⁵ case in 1990 was a crash course for me.

³ This area is about the same size as Minnesota (79,610 sq. mi., 206,189 sq. km.) (Bockenbauer & Cunha, 2004).

⁴ "Fetal Alcohol Spectrum Disorders" is not itself a diagnosis. The term includes the following diagnoses: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS) (most of the features of FAS), static encephalopathy (alcohol exposed) (an unchanging brain condition with central nervous system damage and prenatal alcohol exposure), and neurobehavioral disorder (alcohol exposed) (central nervous system impairment without structural or neurological abnormalities). The last two categories have also been described as "Alcohol-Related Neurodevelopmental disorders" (ARNND) (Fetal Alcohol Syndrome Diagnostic and Prevention Network, n.d.).

⁵ The names of all persons involved in cases have been changed.

Clayton had appeared before me as a juvenile delinquent. Shortly after his 18th birthday, he received an adult felony conviction for taking money from the cash register of a local restaurant. He was back in front of me in 1990 for his second felony, sexual assault in the second degree, for the sexual touching of a teacher in a remote classroom. His energetic defense attorney on the second felony discovered that the sober couple that raised Clayton had adopted him—his birth mother had been afflicted with severe alcoholism. The defense attorney was able to get her client diagnosed by a mental health professional who was familiar with FAS/FAE, and the conclusion was “fetal alcohol effects.” The diagnosis recognized the damage to his brain even though he did not have the short stature and facial features of Fetal Alcohol Syndrome.

Under the sentencing laws in effect in 1990, Clayton was facing a maximum sentence of 10 years and a “presumptive term” of 4-6 years on the new charge.⁶ In Alaska, the only way for a defense attorney to obtain an adjustment of a presumptive term is to convince the sentencing judge by clear and convincing evidence that it would be manifestly unjust to sentence the person according to the presumptive term (Alaska Statute 12.55.165(b)).

The defense attorney contended that it would be manifestly unjust to sentence Clayton without considering his fetal alcohol effects condition. Her solution was that there should be less than the required four years of jail time, followed by supervision of the Department of Corrections in a far less restrictive setting. I agreed with her arguments and followed the presumptive sentencing statute's requirements by referring the case to a three-judge sentencing panel of other superior court judges. If at least two members of the panel agreed

⁶ The current Alaska sentencing scheme for sexual felonies has drastically increased the jail time for these crimes. Now a person with one prior nonsexual felony convicted of sexual assault in the second degree is subject to a maximum of 99 years and a presumptive range of 10-25 years (Alaska Statute 12.55.125(i)(3)(B)).

after a sentencing hearing in front of them that the panel should accept the case, they would be able to sentence Clayton without being bound by the presumptive term. If they did not accept it, they would refer the case back to me, the sentencing judge, to impose the presumptive term (Alaska Statute 12.55.165(b)).

They did not accept the case, finding that the fetal alcohol effects issue was a mental health consideration not included in the Legislature's existing mental health mitigating factor, and that judges should not add new mental health considerations when the Legislature had already spoken. They stated that the Department of Corrections would have discretion to release the inmate to a halfway house during the jail time, and they referred the case back to me.

Since our spring judicial conference was being held in Fairbanks, Alaska, at the appropriate time for the resentencing hearing, the parties agreed that I would do the hearing there. Fairbanks is the location of the nearest long-term jail to Barrow and is located about 500 miles south. As it happened, just before the Fairbanks conference my long plane flights to and from a meeting on the East Coast provided the opportunity to read a book that opened my eyes to the challenges facing families and children affected by fetal alcohol exposure. The book was Michael Dorris' *The Broken Cord* (Dorris, 1990), a memoir about raising a child afflicted with mysterious difficulties that proved to be FAS.

As required by statute, I sentenced Clayton to the four-year presumptive term with a recommendation for classification to a halfway house. But as I looked at him, I suddenly was deeply affected by the thought of so many defendants like him that would really not understand or benefit from the longer jail sentence. I got emotional and left the bench abruptly at the end of the hearing. The defendant appealed the three-judge panel decision but the Alaska Court of Appeals affirmed (*W. R. L. v. State*, 1992).

There is some good news: The Department of Corrections followed my recommendation and did release Clayton to a halfway house during the jail term. He is now living in the Anchorage area and he has a guardian/conservator to help manage his affairs. Court records show only one misdemeanor case for Clayton since his 1990 felony case.

After my encounter with Clayton, I was appointed to the Alaska Criminal Justice Assessment Commission, which had been established to allow representatives of all three branches of government and other citizens to review the criminal justice system “and to collectively develop recommendations to alleviate the problem” of prison overcrowding (Alaska Criminal Justice Assessment Commission, 2000). I advocated for inclusion of “organic brain disorder” as a mitigating factor in felony presumptive sentences. Although the Commission adopted the proposal,⁷ this statutory amendment has not been passed by the Legislature.

My understanding increased during a 1996 Barrow conference on FAS/FAE sponsored by the North Slope Borough Health Department. The organizers arranged for many inspiring speakers including Ann Streissguth, Ph.D., from Seattle, Washington, (one of the leading researchers on FASD) and Jan Lutke from Vancouver, British Columbia (who is raising and effectively advocating for her adoptive children with FASD), as well as experts from Alaska. As I attended the sessions and continued my work at the court that week, I began to realize that the lifelong effects of exposure of a fetus to alcohol in the mother’s womb affected the justice system in countless ways. I also realized that it would be impossible to know for certain in a particular hearing who was affected and who was not, and how deeply prenatal alcohol exposure affects any given person. The frustration this understanding left with me remains with me daily.

⁷ Proposal 19: “The legislature should create a statutory mitigating factor for use at criminal sentencing, recognizing when the wrongful conduct was substantially affected by an organic brain disorder” (Alaska Criminal Justice Assessment Commission, 2000, p. 71).

Characteristics of FASD that are recognized as presenting difficulties for the justice system

It is not surprising that the justice system in Barrow is struggling to adapt to FASD. That the challenges faced by persons affected by FASD impact the justice system has been recognized in other jurisdictions as well. A recent example is the September, 2008, conference in Whitehorse, Yukon Territory on *The Path to Justice—Access to Justice for Individuals with Fetal Alcohol Spectrum Disorder*. The conference attracted 130 delegates from across Canada and the United States, and the summary conference report discusses characteristics of FASD that present severe problems for adaptation by the Canadian justice system to these conditions.

Dr. Sterling Clarren, a physician involved with FASD issues for over thirty years and now CEO and Scientific Director of the Canada Northwest FASD Research Network in Vancouver, British Columbia, described persons with FASD who have been diagnosed early in life as having “mysterious maladaptation.”

First, they don’t do well in school and social experiences; by the time they get to [be] adults they are often alienated or have exhausted their care givers, so they are out on their own, and these combined lead to social isolation, poor job performance, poverty, mental health problems, homelessness, victimization, and criminogenesis (Fraser, 2008, September, p. 6). He recognized that “there are often no apparent physical characteristics that predict FASD. Individuals with FASD may appear ‘normal’ and often have good verbal communication skills. Without specific knowledge of the common behavioral characteristics associated with FASD, it is difficult to ‘flag’ or identify someone that may have this disability” (Fraser, 2008, p. 8).

The 2008 conference identified additional reasons that the justice system has difficulty adapting to persons with FASD:

Furthermore, behaviors associated with individuals with FASD are also common among offenders that do not have FASD. For example, offenders with and without FASD are often considered to be impulsive, thrill-seeking, and lacking in judgment. Individuals from both groups who are involved with the criminal justice system may

have substance abuse and mental health problems, along with limited employment and education histories. Also, co-occurring problems such as anti-social personality disorder, conduct disorder, or attention deficit disorder may be masking an underlying condition of FASD.

Justice professionals, whether they are police, defense counsel, Crown [prosecutors], judges, victim services workers, or corrections officers, only spend limited time with a client. The short period of time spent with each client often results in the professional not knowing much about the client, including if they have a disability. It often takes more time than professionals have to clearly communicate with individuals with FASD to ensure that they fully understand what is being said to them. Also, some behavioral characteristics associated with FASD are sometimes seen by justice professionals as behavior that suggests disobedience, non-compliance, or aggressiveness. If justice professionals are not aware how FASD may impact an individual, they may not want to get to know their client or work with them any more than the basic minimum to "get by" (Fraser, 2008, p. 8).

The conference report summarized the challenges facing efforts to encourage justice system adaptation to the needs of persons affected by FASD. An important issue is the "lack of awareness of FASD among justice system professionals." Additional challenges are: "(1) that FASD is an 'invisible disability'; (2) the short time-frame that individuals spend with criminal justice professionals; and (3) that it is difficult to order or conduct an FASD diagnostic assessment" (Fraser, 2008, p. 8).

Recent documentation of the prevalence and costs to society of FASD

Facial features typical of FAS make it easier to document than the other far more prevalent but hidden FASD conditions. Therefore, even in publications discussing the general issues presented by FASD, the available statistical data is often limited to studies of the prevalence of FAS. The Alaska Department of Health and Social Services has found that among states tracking FAS rates, Alaska has the highest prevalence in

the nation (Alaska Department of Health and Social Services, 2010). Corrections officers in Alaska estimate that 27% of the inmate population has FAS (Behavioral Health Research and Services, 2006). The federal Centers for Disease Control (CDC) reports that the FAS prevalence in the general population of the United States is 0.2-1.5 per 1,000 births; in the American Indian/Alaska Native population it is 3-5 per 1,000 births; in the population of the children in foster care it is 15 per 1,000 births; and in the population of children in a (Canadian) juvenile justice treatment facility it is 200 per 1,000 births (Briacombe et al, 2009, p. 11).

The CDC also reports studies showing that the estimated prevalence of all FASD conditions in the general population of the United States is 9-10 per 1,000 live births (Briacombe, et. al, 2009, p. 11). The Alaska Department of Health and Social Services states that about 180 babies born each year in Alaska have "suspected FASD." (Alaska Department of Health and Social Services, 2010). In 2008, there were 11,438 births (Alaska Bureau of Vital Statistics, 2010) yielding an estimated prevalence of FASD in Alaska of approximately 16 per 1,000 live births. The prevalence of births of children affected by FASD on the North Slope or other rural areas of Alaska is not documented.

A study by the Fetal Alcohol and Drug Unit at the University of Washington of 661 clients diagnosed at their clinic with FAS from 1973 to 1995 showed that "[s]ixty percent of the adolescents and adults and even 14% of the children had trouble with the law." (Streissguth, 1997). This over-representation of persons affected by FASD in the justice system, justifies substantial efforts to accommodate the cognitive disabilities presented by fetal alcohol exposure.

The incredibly high costs to society from this situation are illuminated by the federal Centers for Disease Control recognition of a 2004 study, which found that "[i]n 2002, the estimated [average] lifetime cost for one individual with FAS

was \$2 million" (Briacombe et al., 2009, p. 12,). The CDC admits that the costs to society from all FASD conditions are "unknown" (Briacombe, et al., 2009).

Accommodations used in the Barrow court for persons who may be affected by FASD

The following ideas are offered as a work in progress. The justice system in Barrow is always interested in approaches relevant to our situation and I have found that each conference I attend presents new ideas and a deeper understanding of how to best adapt to the realities presented by FASD. These are some techniques that seem to work for us in our rural court environment:

own ring Instead of completing the hearing quickly by assuming that there has been effective communication with counsel before the hearing, I take the time to completely explain to local participants what is going on. It is sometimes necessary to take a break in the hearing to allow an individual affected by FASD to process what he or she has heard before yet more information is discussed.

ear, rete age the ing I try to avoid legal jargon as much as possible. I often use a more informal tone, since a person affected by FASD may really be relating to the whole experience like a middle school (or far younger) student, instead of the high school student or adult that the person appears to be.

ber ral ors In addition to sensitivity to the possibility of FASD, I need to respect cultural influences that can affect many court participants. For example, more traditional persons in many Alaska Native cultures do not look directly at an authority figure, as a sign of respect. Shy youth on the North Slope will sometimes not respond to a question except by raising their eyebrows, meaning, "yes." Local people on the North Slope often require a longer time to formulate an answer to a ques-

tion even if they understand perfectly what was said, as within this culture a thoughtful answer is valued above a quick answer.

Adapt commonly used forms to have 1) concrete language, 2) more white space, and 3) opportunities for a defendant to put initials by each condition

For example, my criminal forms do not simply state "OR Release." Alaskan practitioners know that this statement means a person is released without posting any bail, but one should not assume a defendant, especially one affected by FASD, understands this. The current version of my four-page form appointing counsel, setting dates and bail conditions, says:

OWN RECOGNIZANCE. I can get out on my "own recognizance." This means: I don't have to give any money right now. I promise to come back to court or jail. I also promise to follow all the promises in this form. The police could arrest me if I do not come back to court or follow all the promises.
My initials: [_____]

Using more white space, 14-point type, and the requirement to initial each rule are efforts to make sure that the whole process is not simply a "blur" of words. Both the Court and the defendant must focus on each point.

Use the same system for conduct agreement/conditions of probation forms in a juvenile delinquency case

These cases are less formal than the adult criminal cases and Alaska's Division of Juvenile Justice emphasizes the value of "restorative justice." The Division has been supportive in our implementation of a shortened version using concrete language of its Conduct Agreement/Conditions of Probation form. For example, the current form used at Barrow includes the following rules:

1. I won't drink alcohol. [_____]
2. I won't use illegal drugs like marijuana. [_____]
3. I will take a "PBT" or "UA" test when the police or the probation officer asks me to. [_____]

Be receptive to "third party custody" arrangements (including, when available, electronic monitoring) in criminal cases rather than using higher bail, when such arrangements will provide adequate structure for a defendant. Such arrangements will reduce overcrowding in the jails, are more humane and constructive for defendants affected by FASD, and reduce costs to society.

When sentencing laws provide enough flexibility, reduce the amount of jail time (or the level of care for a juvenile delinquent) and increase the amount of supervision time. The attorneys involved in a case can often reach this result through plea bargains that reduce the severity of a charge, enhancing judicial discretion in fashioning a meaningful sentence or juvenile disposition. A person affected by FASD could adapt well to the structure of a jail or juvenile institution, but the person is also more likely to learn negative behaviors from others in the same environment. Another reason supporting the use of sentencing alternatives for persons affected by FASD is that jail beds and placements at juvenile institutional facilities provide more structure than needed at greatly increased cost to society (Wartnik, 2007).

When FASD is suspected, include a recommendation in a sentencing judgment or juvenile disposition order that can assist professionals working with the individual. The recommendation for adult defendants could read something like: "This defendant may have a FASD condition. The Court THEREFORE RECOMMENDS that anyone working with the defendant use concrete language, with the realization that basic concepts will need to be repeated frequently."

- For defendants who might qualify for community custody and who have issues of alcohol/substance abuse and limited employment skills: Classification to a halfway house for alcohol/substance abuse counseling and employment training.
- For defendants likely to remain in jail and have alcohol/substance abuse issues: Defendant should participate in any alcohol/substance abuse counseling provided to the defendant

by the Department of Corrections, which may include a residential therapeutic community within the jail.

- For defendants with more severe cognitive impairments: Prior to release from jail, the Department of Corrections should explore long-term structured living arrangements that might be available for this defendant upon completion of the jail term.

Keep bringing up the issue of FASD, especially in child welfare and juvenile delinquency cases

If a FASD condition is suspected, encourage the social worker or juvenile probation officer to obtain a FASD diagnosis. The greater resources available in these cases and the greater amount of time that a youth is in custody, as compared to adult defendants, make it more likely that an evaluation might be arranged. The earlier the evaluation can occur, the more useful in the life of the person: Having an evaluation prior to the age of 6 is the second most beneficial "protective factor" for patients 12 years and older (Streissguth, Barr, Kogan, & Bookstein, 1997). Efforts to bring up the subject of FASD are also necessary in other types of cases when a participant is suspected of having the condition (Malbin, 2004).

Schedule periodic review hearings in certain cases

More frequent interaction with an authority figure like a judge is a great way to enhance structure for juveniles and adults involved in the justice system. Therefore, we have monthly or quarterly review hearings in some cases. The hearings are an opportunity to make sure a treatment program is working, to celebrate successes, and (once again) to warn of consequences of not following the rules.

Acknowledge and support, on record, initiatives by other professionals to assist FASD-affected clients

For example, one officer in Barrow had a number of probationers who were obviously affected by FASD who were not doing well. Rather than immediately filing petitions to revoke probation, the officer started the "Breakfast Club." Each of these defendants had to come into the office at 8:00 a.m. to plan his or her activities for that day. The next day they would come in and report on the previous day's activities and plan the current day. The officer found that after about three

weeks of this additional structure in their lives, they would get the message on complying with probation or show that they were not able to do so.

Caring social workers or juvenile probation officers may have gone through the steps necessary to qualify a young adult affected by FASD for federal Social Security disability payments. In Alaska, youth in custody may build up a significant trust fund from dividends received from the state and/or native corporations. Such trust funds become available in a lump sum on the 18th birthday. Most youths need guidance in managing these government or private funds, and appointment of a conservator provides great benefits for such youth. If the mental problems are severe enough to prevent normal decisions about living arrangements and medical care decisions, the court may also need to appoint a guardian.

Another adaptation I have made is to attempt to identify suspected FASD cases even though an actual FASD diagnosis is rare in my court. I keep in mind (and put on record) that I cannot "diagnose from the bench." Yet there are indicators that I use to tell me if a person is probably affected by FASD:

1. Comes from an alcoholic family.
2. Frequent contact with the justice system—especially with similar kinds of cases; back in court repeatedly for bail or probation violations.
3. Impulsive behavior is demonstrated in current situation and/or prior record.
4. Often a "follower" in criminal incidents, but is the one who is getting caught.
5. History of problems with school, including having an IEP or dropping out early.
6. Has a lot of mental health diagnoses (FASD may be the most basic one that has been missed).
7. Short stature.
8. Facial appearance—however, for adults this factor is not very useful.

9. Multiple foster home placements (in the unusual case in which such information is available to me).
10. History of inappropriate sexual behavior (when such information is available to me).

Encourage the individual to learn more about FASD and attempt to reduce feelings of guilt and blame of the birth mother

Bringing up the issue of FASD at a court hearing can sometimes lead to some very sensitive moments, especially when parents are in court to support a person with a possible FASD. Here is the approach I use for both adolescents and adults:

It looks like you might have a challenge in your life called FASD. It's not your fault; it just happens that your brain may work a little differently because your mother may have been drinking while you were inside her. You might want to learn about it and mention it to people working with you so that they can do a better job in helping you understand things. Remember that your mom could have been drinking before she even knew that she had you inside her.

(Based on suggestions from Olson, 2009; Kelly, 2010).

Special programs at the Barrow Court

Barrow
Misdemeanor
Resources
Project

The Alaska Mental Health Trust Authority (Alaska Statutes 47.30.11-47.30.61) uses the income from the one million acres of Alaska's land Congress granted to the Territory of Alaska "to be held in public trust to help effectuate the creation and operation of mental health care facilities in Alaska" (*Weiss v. State*, 1997).⁸ The beneficiaries of the Trust are persons with various mental health conditions, including developmental disabilities (Alaska Statute 47.30.056(c)(2), (d), (e), (f), & (g)). The Trust programs may also include "prevention or early intervention services for individuals at risk of becoming Trust beneficiaries. The Trust considers prevention of these conditions, where possible, as part of its mandate" (Alaska Mental Health Lands Trust, 2010).

⁸ The lands were granted in the U.S. Congress' Alaska Mental Health Enabling Act (1956).

The Trust has been aware that there are a significant number of persons involved in the justice system in Alaska who have FASD or other mental health challenges that result in excessive jail time. In fact, "approximately 42% of individuals incarcerated in the Alaska Department of Corrections qualify as Trust beneficiaries" (Alaska Mental Health Trust Authority, 2010). The Trust approached the Barrow Court as a site to try initiatives to specifically deal with this issue in a rural setting. The Trust's first approach at Barrow was to encourage formation of a therapeutic court program. It paid for a consultant who (after consultations with the judicial officers, social workers, juvenile probation officers, prosecutor, defense attorney, police and others) prepared manuals for both professionals and defendants. Despite these substantial efforts, this attempt did not work in our small community: We have only one prosecuting attorney, one resident defense attorney, one superior court judge and one magistrate. Considerations of both time and personnel made it impossible to have the type of specialized "team" and "premeetings" before each court hearing that therapeutic courts require. The extremely low number of clients demonstrated that the complexity of the program did not appeal to North Slope defendants.

With considerable input from the justice community in Barrow, the Trust's efforts have now evolved into the Barrow Misdemeanor Resources Project (BMRP). An adult misdemeanor probation officer/case manager (administered through the statewide Alcohol Safety Action Program [ASAP]) staffs this program. The case manager's duties are broader than other probation officers administered by ASAP. Since well over 90% of the crime on the North Slope is alcohol-related, and since we also have a relatively high percentage of domestic violence assaults, misdemeanor (and felony) probation conditions routinely include treatment requirements. The case manager attends misdemeanor arraignments and sentencings as well as other court hearings. Most referrals to the case manager state that the defendant is to meet with BMRP soon after the hearing (or completion of jail time) "for assistance

in complying with probation conditions." The case manager meets with the defendant in the BMRP office across from the courtroom. The case manager interviews the person to gain information for a mental health screening tool she has developed based on models used in other programs, reviews the probation conditions, and then assists the defendant in contacting local treatment programs for assessment.

The assistance from BMRP may end after the interview if the defendant does not appear to have mental challenges. However, if the initial interview reveals mental health concerns, including suspected FASD, the case manager undertakes a broader range of involvement. The defendant is assisted in contacting treatment programs, referrals may be made to other support services, and family counseling about guardianship/conservatorship may be given. The case manager schedules ongoing appointments with the defendant to monitor progress. The effort is to make the criminal justice process more understandable with extra attention and explanation, and to keep the defendant affected with FASD from needlessly facing petitions to revoke probation and more jail time by providing greater structure that helps maintain the defendant's ability to make appointments and comply with treatment recommendations (G. Hooper, personal communication, September 1, 2010). The adult probation officer has also requested assistance from the BMRP caseworker for felony probationers needing special assistance because of mental health concerns.

Compliance hearings

The flexibility of a therapeutic court program to conduct relevant hearings and have reasonable, swift sanctions for those with FASD make such programs a very desirable option,⁹ but Barrow's small justice community does not have the available staff to support a full therapeutic court program. However, this reality does not prevent us from using therapeutic

⁹ See, for example, the Community Resources Project/Mental Health Court in Anchorage, Alaska and the Community Wellness Court in Whitehorse, Yukon Territory, Canada.

court principles. For about 2 years, District Court Magistrate Karen R. Hegyi maintained a program of monthly compliance hearings, inviting the superior court judge to join her on the bench to hear from treatment providers and misdemeanor defendants whose probation conditions included treatment conditions. Unlike a traditional therapeutic court, however, there were no premeetings before the monthly compliance hearings. Treatment providers sent compliance forms in before hearings. These were reviewed by the magistrate and cases were ranked. Defendants doing well were first. As each name was called, the defendant would come up and treatment provider(s) would give a summary of progress in treatment. Completion of a program resulted in a standing ovation, good progress met with applause, spotty compliance was met with silence and the prosecuting attorney would inform persons not making adequate progress that a petition to revoke probation would be filed. (If the defendant shows compliance, the prosecutor would withdraw the petition).

The value of ongoing contact between the judicial authority figure and the defendant is one of the basic techniques of the nationwide therapeutic court movement, especially for defendants with mental challenges such as FASD (Hora, Schma, & Rosenthal, 1999). Barrow's compliance hearing program is currently in vacation mode because of workload considerations from the clerk's office and the concern of a treatment program's former administrator that the monthly reporting could harm the program's treatment relationship with the client. We anticipate addressing these issues and rejuvenating this program within the next few months.

The journey continues: Some recent cases involving persons affected by FASD

Tom *Tom has never been evaluated for Fetal Alcohol Spectrum Disorder despite his lengthy juvenile justice history, a series of misdemeanor convictions, and his felony weapons charge*

involving a dangerous standoff with police officers. Tom is now 24 years old, but he started using alcohol and marijuana when he was 12. Raised in a North Slope village, he was placed in another village in foster care from age 11 to 14. Several males in his extended family had committed suicide. Police investigations found at least probable cause that he was involved with a great deal of dysfunctional behavior as a juvenile: at age 8, deliberately setting a fire; at 10, breaking windows; at 14, stealing items from the counseling center in Barrow, assaulting another youth, stealing a bike and trying to steal a four-wheeler; at ages 15 to 16, being identified as someone who took snow machines and arranged for other youth to do so. All these incidents were dismissed or handled with counseling by the juvenile probation officer.

Tom was formally adjudicated a juvenile delinquent at 16 after he chased another youth while in possession of a baseball bat. He was referred to a residential alcohol/substance abuse treatment program in Southeast Alaska and did fairly well. But then, as a 19- to 20-year-old adult he was convicted three times of misdemeanor domestic violence assaults against his girlfriend. He reported to treatment providers that during this period of time he also had eight major snow machine accidents. He had periods of employment: 2 years as a stockman in an auto parts store, 4 months as a laborer, and 28 months as a tour guide.

At the age of 22 he received his first felony conviction for having an illegal weapon (a sawed-off shotgun) during an incident in which he possessed the illegal weapon and a rifle, was intoxicated and highly agitated, and engaged in a 3-hour standoff with police officers until he was allowed to talk with his ex-girlfriend. Based on the plea agreement, I sentenced him to 24 months with 18 months suspended and put him on probation for 3 years with probation conditions including no possession or consumption of alcohol and treatment requirements. By the time of the sentencing hearing he had served the jail time.

His probation officer allowed him to travel to Anchorage shortly after the sentencing. When he returned, the probation officer searched his baggage and found two bottles of whiskey, a probation violation. He told his probation officer that he knew he should not have brought in the alcohol, but he figured "his chances of getting searched were only about 5% so it was worth the risk." I added some community work service to his sentence. He is currently before the court for another petition to revoke probation for failing to complete the court-ordered domestic violence intervention program. The probation officer, prosecuting attorney, and defense attorney agreed to extend his probation for enough time to complete all treatment and to require him to travel to Fairbanks, Alaska to complete (and pay for) domestic violence intervention treatment, alcohol/substance abuse treatment, and a psychiatric evaluation. I recommended that the psychiatrist be someone familiar with FASD.

The fact that Tom was in foster care from ages 11 to 14, the dysfunction in his birth family, and his ongoing offenses as a juvenile strongly suggest a cognitive impairment such as Fetal Alcohol Spectrum Disorder, but he never had the benefit of this type of assessment. The child welfare and juvenile justice systems (and the Court) had ample opportunity to conduct such an evaluation but missed it. At last, as an adult, he is being referred for an appropriate mental health evaluation.

Jane *Jane's case demonstrates the limits of service delivery when a client turns 18 and insists on leaving an available structured placement.* Jane was involved in the child welfare system, and the FASD evaluation arranged by the social worker yielded a diagnosis of FASD "static encephalopathy-alcohol exposed." Her behaviors were quite difficult for care providers to deal with and she lived in institutional placements for extended periods of time. As she approached her 18th birthday, she was placed in a therapeutic foster home. The foster parents were working with her to finish her high school diploma. But she insisted that she leave the custody of the social workers as soon as she turned 18. When all persua-

sive efforts failed, the state moved to close the case at the 18th birthday. Custody remained open only long enough to have a conservatorship established for her.

Tragically, she was sexually assaulted while in Anchorage shortly after her release from custody. She returned to her birth mother in a North Slope village, but had problems in the village and became suicidal. She was immediately transferred to the Fairbanks Memorial Hospital for care. When the hospital released her, she was provided temporary housing, and she received transition to adulthood services in Fairbanks from a specialist at the Office of Children's Services. But she insisted on going to locations frequented by alcohol and drug abusers and spending time there. Only after she was again physically assaulted did she begin to realize that she needed more assistance than the conservatorship. A temporary guardian is now in place (pending the permanent guardianship hearing) with the ability to find adequate housing and require Jane to take advantage of the placement.

Mary *Mary is someone for whom the structure provided by a loving adoptive family has given her a reasonable chance to live a full life as an adult.* I had handled the termination of parental rights proceeding of Mary's birth parents some twenty years ago. One part of the evidence was videotaped testimony of a child psychologist about the many complicated problems Mary would face as she grew up because of her exposure to alcohol during her mother's pregnancy, and how the birth parents would be unable to cope with them because of their own instability. I granted the termination of parental rights. Mary was very blessed to have a Barrow couple file an adoption petition within a few months. I insisted that the couple watch the videotaped expert testimony before I would grant the adoption. The couple watched the video and proceeded; I granted the adoption. I have noticed that Mary has never been in the Barrow court¹⁰ and has had appropriate employment. She

¹⁰ She has had traffic tickets and a minor misdemeanor in South Central Alaska.

appears to be doing fine, with the structure that had been provided by the adoptive parents and her employment.

John *John had the benefit of a tentative FASD diagnosis while in the juvenile justice system. But his desire to live with his family in an Arctic village resulted in an environment that did not provide the structure he needed. His impulsive criminal behavior has landed him in jail, again.* John came before me in a juvenile delinquency case for burglarizing the store in his home village near Barrow. His dysfunctional family situation and the lack of other options on the North Slope that would meet his needs required placement outside the North Slope. One benefit of the placement was that the Division of Juvenile Justice was able to arrange for a mental health evaluation that concluded he had "Axis III: . . . Possible Fetal Alcohol Effect/Fetal Alcohol Syndrome." Just after his 18th birthday, he was back in front of me with an adult felony case for burglarizing the same village store. He had learned something from the previous burglary juvenile case: He wore gloves and turned off the store's electricity so that the surveillance camera did not work. But he was quickly turned in and the stolen items were recovered. When he was arrested, he was still wearing socks he'd stolen from the store.

The probation officer noted the diagnosis and recommended approval of an agreement for limited jail time and a suspended imposition of sentence that would give John the opportunity to have the felony taken off his record. She showed her understanding of FASD in her additional recommendation that if the defendant violated probation there should be a prompt response so that he will understand the connection between his actions and the consequences. I accepted the plea agreement and the defendant was out on probation immediately, since prior to sentencing he had already served the 60-day jail sentence required by the plea agreement.

Back in the village after the jail time, John wanted to get a job with a local construction company. The construction staff lived

in the village's small hotel. When he approached them about the job, they told him to apply online. He said he did not have a computer and they let him use the computer in their area of the hotel. When he left, he was wearing some Carhartt overalls that he had seen inside the hotel, which had an iPhone in the pocket. The staff called the police. When the officer arrested John, he was still wearing the Carhartts, with the iPhone still in the pocket. Now he faced a petition to revoke probation with a possible maximum sentence of five years in the old case, as well as a new charge of burglary in the first degree with a maximum of 10 years and a "presumptive sentence" of 4-6 years. He faced an immediate sanction, because he remained in jail continuously since his arrest; however, the investigation and plea negotiations for the two cases lasted 5 months. I accepted the plea agreement resolving both cases, which mandated dismissal of the new case and a permanent felony conviction with a 2-year flat sentence for the probation revocation in the earlier case. I included a recommendation that because of the diagnosis of "probable FASD," corrections staff should use concrete language and repeat basic concepts. I also recommended that the defendant be transferred to a halfway house.

Joseph *This young adult was diagnosed with FASD as a youth and his behaviors prevented an adoptive placement. He was not able to cope with living in a community setting and his social workers placed him in a residential psychiatric facility for treatment that lasted about one year. He now has chosen to live in Anchorage and he has just started residing in an assisted living program that will be available for almost the next 3 years.* Joseph was one of several children in a highly dysfunctional family that generated a child welfare case resulting in termination of parental rights. He was 6 years old at the time. Both parents were severely alcoholic. When he was 11, Joseph was diagnosed with the FASD "static encephalopathy-alcohol exposed." His behaviors prevented a permanent adoptive placement. The social workers had to place him in a residential psychiatric program in the rural hub community of Bethel in Southwest Alaska, which had staff that understood his FASD

condition and worked well with their native clients. He completed the program in approximately 1 year.

As he approached his 18th birthday, professionals obtained the services of a court-appointed conservator for him. Joseph wanted to move to Anchorage and, with assistance from the transition to adult life specialist in the Office of Children's Services, he was accepted to an assisted living program where he can live with some structure until his 21st birthday. With the income he has coming in from Social Security and native corporation dividends, along with the structure of the assisted living program, he has an ideal situation for beginning his life as an adult. His case is now being transferred to Anchorage, but I had the gratification of seeing these arrangements put in place for him.

The journey continues: Ideas for the future at Barrow

In addition to continuing to implement adaptations in the court setting, it is important to consider additional projects to make our rural community more responsive to the needs of persons affected by a FASD.

Service providers in our community have identified the difficulty of finding opportunities for diagnosis of FASD as a stumbling block in providing support to individuals with obvious challenges in dealing with their life experiences (Ruiz, personal communication, September 9, 2010). Having the diagnosis when it is justified holds the promise of more effective treatment and adequate structure to avoid the justice system altogether.

Efforts are underway to form a FASD diagnostic team in Barrow. Dedicated professionals active in a FASD diagnostic team in Anchorage have offered to assist Barrow professionals in establishing a FASD diagnostic team for the North Slope. They have proposed a model of having quarterly 4-day trips (including weekend days) to Barrow to conduct evaluations as a team alongside local professionals. We could have a "FASD Clinic"

just like the existing "Orthopedic Clinic," "Diabetes Clinic," and other specialty clinics provided at our local hospital facility with specialists from Alaska Native Medical Center in Anchorage. Having such a team would slowly reduce the tremendous backlog of undiagnosed individuals, including young children, teenagers and adults, resulting in more effective service delivery, greater understanding by the person and his or her caregivers about behavioral issues, and enhanced ability to access benefits. On a statewide basis, this model would encourage development of traveling FASD diagnostic teams to serve rural hub communities similar to Barrow.

Adopt innovations such as the "Probation Icon Project" for juvenile justice cases

The FASD Youth Justice Program in Winnipeg, Manitoba has developed sheets of peel-off icons symbolizing each juvenile probation condition. When the juvenile probation officer is explaining the conditions to a FASD-affected youth, the youth is encouraged to peel off the appropriate icon and place it by the corresponding probation condition. When the youth is done, the youth leaves with the copy of the conditions with the icons on it. The probation officers testing this approach feel that the level of comprehension is greatly increased (Robson, 2009). The Alaska Division of Juvenile Justice is receptive to adapting the use of peel-off icons to its Conduct Agreement/ Conditions of Probation (Murray, personal communication, October 28, 2010). The first step will be to develop icons that fit the Alaska Division of Juvenile Justice probation conditions.

Encourage development of programs to support birth mothers to care for a child with FASD, when at all possible, while preserving safety for the child

The value of such programs in providing meaningful support for birth mothers and their families has been confirmed by research (Olson, Oti, Gelo, & Beck, 2009). Programs in Washington such as Families Moving Forward and the Parent Child Assistance Program provide such a model. Dr. Sterling Clarren, a leading physician in the field of FAS for over 30 years, has predicted that such programs would reduce the incidence of FASD by half, since birth mothers given such support tend not to have additional FASD-affected children (Clarren, 2010). Barrow's Children and Youth Services program¹¹ is currently developing such an initiative using

¹¹ Jointly sponsored by the North Slope Borough, the Native Village of Barrow and the Alaska Office of Children's Services.

the Teaching-Family Model of providing a great deal of support within the family to eliminate or at least greatly reduce time that a child must be separated from the child's family (Dunbar, personal communication, October 22, 2008).

The Barrow Superior Court is in the process of becoming the first rural Alaska court to implement the Alaska Department of Corrections' Probationer Accountability with Certain Enforcement (PACE) program. Modeled on a successful program in Hawai'i, the program identifies certain felony probationers for special enforcement procedures in which even technical probation violations result in immediate petitions to revoke probation, warrants are served on an expedited basis, and a court hearing is held within 72 hours (Halpin, 2010). The hearing results in a very prompt but limited sanction. The sanction might be the immediate service of a few days in jail (Telkamp, personal communication, October 13, 2010). Such an effort will assist probationers affected by a FASD or similar cognitive impairments to realize that violating probation conditions has a consequence of jail time by having the limited consequence occur immediately after the violation.

Such placements would be more humane, suitable, and far less costly to the citizens than locking persons affected by FASD in jails or locked juvenile institutions. The Lakeland Centre for Fetal Alcohol Spectrum Disorders in Cold Lake, Alberta, Canada has issued a report describing a large number of Canadian programs that provide structured living for persons affected by FASD. One program of particular interest is the Whitecrow Village FASD Society in Nanaimo, British Columbia, Canada, which provides a wonderful model of a structured living and outreach program administered by and serving adults with FASD (Warner & Kissinger, 2010). Two programs that have lost their funding also demonstrated the feasibility of structured living specifically targeted for adults and adolescents affected by FASD: the Phoenix House program for adult offenders in a halfway house in Vancouver, British Columbia, and the Kids Kare

and Education program in Washington State for adolescents in state custody.

Bread for the journey

As hopes for a North Slope justice system that is more caring and more appropriate for its citizens with fetal alcohol spectrum disorders and other mental health challenges become more real, it is useful to keep some basic realities in mind.

FASD is not a racial issue; it is a medical condition caused by maternal drinking during pregnancy that can happen anywhere on earth among persons of any race. Unfortunately, the medical community may misdiagnose or overlook the FASD condition and provide a psychiatric diagnosis that leads to ineffective and inappropriate treatment. Instead of realizing the FASD condition exists, the professional may give a diagnosis limited to conditions such as Attention-Deficit/Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder, and/or Conduct Disorder only (Dubovsky, 2008). On the other hand, a person with a FASD may also have a number of other mental health conditions along with the FASD.¹² Effective intervention will only occur if the treatment providers pay attention to FASD and the other conditions as well.

Even if facial appearance changes over time, a person does not "outgrow" FASD. With a structured life, the person may adapt and become a productive citizen (Kleinfeld & Westcott, 1993). In court, an affected person may be quite verbal, give answers indicating that the person has "understood," and could, if asked, repeat back what was said. But an adult or teenager affected by FASD may have the understanding and behavior of

¹² "Attention-Deficit/Hyperactivity Disorder, Schizophrenia, Depression, Bipolar Disorder, Substance Abuse Disorder, Sensory Integration Disorder, Reactive Attachment Disorder, Separation Anxiety Disorder, Post Traumatic Stress Disorder, Traumatic Brain Injury, Medical disorders (e.g. seizure disorder, heart abnormalities.)" (Dubovsky, 2008).

a middle school student or younger. A person affected by a FASD may be able to follow a direction one day and be unable to do so the next, not due to recalcitrance, but simply because of the way the person's brain functions (Rathbun, 1993).

The challenges for persons affected by FASD are present across the justice system. A defendant may lack the intent required for certain crimes, yet be convicted of them. A defendant might be very suggestible during police questioning, leading to false confessions and wasted resources (and increased danger to the community) when the investigation is shut down too soon. Victims and other witnesses affected by FASD may have a great deal of difficulty in a trial when asked to describe what has happened (Conry & Fast, 2000). Probationers or parolees may have special difficulties in following the rules, leading to more court time and jail commitments for violations of bail, probation and/or parole. Parents in child welfare cases may have special difficulties in satisfactorily completing case plans.

Delivering adequate training about FASD to justice system professionals can be challenging, given work loads and shift work. The problems become more acute when dealing with the vast area of a jurisdiction like Alaska. Even when persons have been trained, the turnover in these positions fosters the need for ongoing training despite the costs involved.

Even if judicial officers and other justice system professionals understand FASD and its effect across a person's life span, the traditional justice system has many roadblocks for those wishing to adapt. Research on the effect of FASD shows that an affected person has difficulty relating consequences to previous actions (Conry & Fast, 2000), yet cases drag on for months because of workloads and efforts to protect rights, greatly diminishing the impact of any consequences imposed. The experience of families raising a child affected by FASD shows that it is most productive to have an affected person concentrate on a very limited number of goals

(Jones & Cunningham, n.d.), yet bail orders and case plans may have a dozen rules and a document like the judgment for a felony probationary sentence in Alaska has 12 to 30 general and special probation conditions. Pressures to complete hearings promptly to move the docket and leave court clerks free to work on progressively more difficult data entry requirements make it difficult to slow down a hearing and provide the explanations needed by an affected person. The very real possibility that a person affected by FASD will be overwhelmed by too much information provided at one time justifies taking a short break in a hearing when possible to maximize the ability of the person to understand it.

A person affected with FASD almost always needs enhanced structure—the “external brain.” But the available tools may be excessive in structure and expense—like a jail cell—or provide reasonable structure, but only for a relatively short period of time—like a halfway house, alcohol treatment program, or juvenile treatment program. Also, knowing how much structure is needed for a particular individual is difficult: Professionals (including judicial officers) can become chronically frustrated with the frequent situation that we do not know how intensely a particular individual is affected by FASD.

Conclusion, but not the end of the journey

Failure to adapt to the legitimate needs of persons with the “invisible disability” of FASD needlessly encourages the development of “secondary disabilities” (Streissguth, Barr, Kogan & Bookstein, 1996) that lead to excessive involvement of affected persons with the justice system, increased confinement, and tremendous time demands for all the professionals involved, including peace officers, probation officers, and social workers. Tribal courts face the same challenges as they resolve cases within their jurisdiction. Society as a whole bears a great burden of cost. By helping

affected persons avoid disproportionate entanglement with the criminal justice system, these costs would be reduced.

Accommodating persons with a cognitive disability like Fetal Alcohol Spectrum Disorder is both a human rights issue and a due process issue (Evensen, 2010). Despite the pressures on time and energy, courts must do their best to be understandable, and to be respectful of such persons appearing before them. Failure to do so implicates ethical requirements for both attorneys and judges to insure that persons involved in the justice system understand what is happening to them (Huguelet, 2010).

Fetal Alcohol Spectrum Disorder impacts the entire justice system in ways that are difficult for any one person to grasp. Those who realize this fact feel somewhat lonely and overwhelmed as the overall justice system adapts slowly to accommodating the human rights of cognitively impaired persons. But there are some rays of hope. The Canadian Bar Association's (CBA) 2010 resolution 10-02-A "Fetal Alcohol Spectrum Disorder in the Criminal Justice System" shows admirable understanding of the issues raised by FASD (Canadian Bar Association, 2010). The resolution recommends that the CBA:

1. support the initiative of Federal, Provincial and Territorial Ministers responsible for Justice with respect to access to justice for people with FASD and urge all levels of government to allocate additional resources for alternatives to the current practice of criminalizing individuals with FASD;
2. urge the federal, territorial and provincial governments to develop policies designed to assist and enhance the lives of those with FASD and to prevent persistent overrepresentation of FASD affected individuals in the criminal justice system; and
3. urge the federal government to amend criminal sentencing laws to accommodate the disability of those with FASD.

Similar efforts in the justice community in Alaska and the rest of the United States would result in a more humane, effective justice system which would lead to a noticeable

reduction in the needless human and financial costs of our current treatment of persons affected by a Fetal Alcohol Spectrum Disorder. As Canadian Judge Mary Ellen Turpel-Lafond stated at the September, 2008 Whitehorse conference on access to justice of persons affected by FASD, improving effective "access to justice" for individuals with FASD "is the desire in fact to understand and keep them out of the justice system and to ensure that the justice system is not used as a substitute for appropriate social services and supports for some of the most vulnerable citizens" (Fraser, 2008).

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14

Understanding FASD: Disability and Social Supports for Adult Offenders

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Fetal Alcohol Spectrum Disorder (FASD) can affect people of all backgrounds, ethnicities, religious persuasions, and socioeconomic groups, and represents a significant factor in predicting involvement in the correctional system. The following discussion is focused on the issues facing the corrections system and offenders or former offenders with FASD, as well as issues facing society on the release of people with FASD back into the community. The strong correlation between the disability, unmet multifaceted needs and incarceration of people with FASD, along with the stigma and hard realities of incarceration, necessitate a thoughtful perspective to improve the chances of success for this population.

Adults with FASD experience a range of disabilities that contribute to the likelihood that they will enter the correctional system. These include the primary brain deficits of cognitive and behavioral problems, gullibility, inhibition and poor judgment; secondary disabilities, such as substance abuse and mental illness; and deficits in the social determinants of health, such as poverty and racism. However, the judicial and correctional systems are generally not prepared either to identify FASD, or to address the disabilities of FASD among the offender population. Screening and assessment for the spectrum in these systems is limited, and at present there is no system in place to screen for FASD in adult prisons in Canada (Chapman, 2008). Although there are overtures in some jurisdictions to address the latter deficit, the needs of adult offenders with FASD are currently not adequately met in the corrections system (Chapman, 2008; Miller, 2005; Boland, Chudley, and Grant, 2002). It is important that the correctional system recognizes and identifies affected individuals, because people with FASD are vulnerable and their disabilities contribute to their getting into trouble with the law (Moore and Green, 2004; Streissguth *et al.*, 2004). Moreover, research has indicated that identifying FASD at any age improves options for interventions and helps to reframe problematic behaviors (Malbin, 2004).

14.1

Fetal Alcohol Spectrum Disorder (FASD) is a Disability

The term “disability” has a variety of definitions. For the purposes of discussing the interrelationship between FASD, social services and incarceration, disability occurs when individuals have activity limitations that create barriers to their participation in society. In the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO), three broad health domains are noted: body functions and structures; activities or the execution of actions; and participation, or life involvement (Cieza *et al.*, 2009). Using this international framework, it is appropriate to view FASD as a brain dysfunction that causes impairments (Olson *et al.* 2009) in all three main areas of functionality.

Fetal alcohol exposure (FAE) results in a continuum of impairments that cause affected people to be functionally disabled in a variety of ways. There are both primary disabilities and secondary disabilities associated with FASD. *Primary disabilities* are those that are directly caused by exposure to alcohol before birth, while *secondary disabilities* arise out of the interplay between primary disabilities, psychosocial factors, and environmental influences. Other factors that contribute to the barriers experienced by people with FASD are deficits in the social determinants of health.

Incarcerated people with FASD are an especially vulnerable subgroup of the affected population. Offenders may never have received a diagnosis, and they commonly have a pattern of repeated trouble with the law. People with extensive criminal histories are frequently considered high-risk offenders, and factors contributing to their criminality, including brain damage caused by FASD, may not be taken into account by the justice system. The incidence of primary and secondary disabilities caused by the prenatal exposure to alcohol is very high in offenders with FASD, and interventions to ameliorate adverse outcomes generally have not been employed (Fast and Conry, 2004). The interrelationship between the primary and secondary disabilities of FASD can lead to behavior that results in incarceration, and as a result affected people will require the same societal accommodation and supports that are available to people with other disabilities. Offenders with FASD are disabled. FASD can be viewed as a disability with societal challenges and needs for support similar to those of other chronic impairments that result from injury, such as spinal cord injuries.

14.1.1

Primary Disabilities Associated with FASD

The effects of prenatal alcohol exposure (PAE) include damage to brain structures that results in deficits in cognition, development, and behavior. PAE can also cause separate medical conditions, such as seizure disorders, skeletal problems, cardiovascular disease, dental problems, and reactions to medications (Paley and O'Connor, 2009). All of these conditions influence an individual's ability to function and participate fully in society.

In particular, the diminished cognitive function in FASD results in major deficits in an individual's ability to meet the demands of daily life. Poor short-term memory can result in information and instructions being quickly forgotten; and while long-term memory may be unaffected, information storage is often disorganized and therefore information becomes difficult to retrieve (Grant *et al.*, 2004). Effective executive function (EF), or the integration of basic cognitive processes, is often lacking in people with FASD. Deficiencies in EF affect multiple areas of functioning, including work and school performance, social interactions, parenting, daily living skills, and ability to plan, organize and learn from mistakes (Grant *et al.*, 2004; Connor *et al.*, 2000). The scores on intelligence tests of people with FASD may or may not be abnormal, but many people with FASD are not able to perform at the level predicted by their IQ scores (Malbin, 2004; Kodituwakku, 2009; Fast and Conry, 2009; Chudley *et al.*, 2007; Wass, Persutte, and Hobbins, 2001). These factors, combined with insufficient inhibition and poor cause-and-effect reasoning, can lead to life-long difficulties in adapting to social expectations and functioning socially (Rasmussen *et al.*, 2008).

14.1.2

Secondary Disabilities Associated with FASD

Secondary disabilities are conditions, behaviors or situations that develop after birth. Secondary disabilities associated with FASD include mental illness (depression, anxiety and psychoses), substance abuse, restlessness, trouble at school, homelessness, and unemployment (Paley and O'Connor, 2009; Chudley *et al.*, 2007). Secondary disabilities cause significant upheaval in people's lives. Trouble at school can lead to delinquency and then to trouble with the law, which can in turn cause difficulty in attaining and retaining employment and lead to further encounters with the legal system. According to Streissguth *et al.* (2004), adolescents and adults with FASD have a 60% risk of getting into trouble with the law. Incarceration can result in a loss of housing and possessions, and association with other criminals can lead to stigma and victimization.

These problems are also referred to as “neurobehavioral.” Malbin (2004) states that the observable behavioral effects of FASD need to be recognized as the result of the physical changes in the brain and their impact on brain processing. Dysfunction in behavior includes poor judgment, poor impulse control, conduct problems, poor problem-solving skills, learning problems, fine motor skills deficits, hyper-reactivity to stress, sexual promiscuity, resistance to change, difficulties in forming lasting relationships, gullibility, victimization, and an inability to understand or conform to social norms (Paley and O'Connor, 2009; Chudley *et al.*, 2007; Rasmussen *et al.*, 2008; Aragon *et al.*, 2008). Some of these behaviors develop over time as protective reactions to feelings of frustration (Malbin, 2004). Aragon *et al.* (2008), indicate a link between a lack of services due to undiagnosed FASD and the development of secondary disabilities in adolescence and adulthood. Other research suggests that the early evaluation and identification of exposed people is vital to anticipating the confounding occurrence of secondary

disabilities (Schonfeld, Mattson, and Riley, 2005). Among offenders with FASD, secondary disabilities are a key aspect of their involvement with the justice system.

14.1.3

The Social Determinants of Health and FASD

Housing, sanitation, nutritious food, health care, employment, access to services, justice and human rights are vital for everyone, and are known as the “social determinants of health.” These are the economic and social conditions in which people are born, grow up, live and age, and the wider economic, social and political systems established to deal with illness (World Health Organization, 2008). Research indicates that social determinants of health have a greater influence on an individual than behavioral risk factors.

Social determinants of health influence both the incidence of FASD and the outcomes of people affected by it. There are a number of factors that lead to FAE. The mother’s alcohol consumption during pregnancy is the direct cause; however, women do not live their lives in a vacuum. Trauma, poverty, inadequate nutrition and housing, gender inequity, racism, addiction, abusive relationships and other conditions affect their health, personal options and behavior. Children born with FASD in such environments face serious environmental and social adversities that place them at risk for adverse outcomes (Streissguth *et al.*, 2004; Rasmussen *et al.*, 2008). Adults with FASD have frequently grown up in unstable environments and have experienced difficulty in meeting their basic needs; many have been separated from biological parents and lived in multiple foster homes (Olson *et al.*, 2009). They often have experienced learning problems and unemployment, and may have ended up in jail (Streissguth *et al.*, 2004). Studies indicate that FASD-affected children have lower health-related quality of life than children who have survived cancers and other significant physical disabilities (Stade *et al.*, 2006). High-quality caregiving and a stable home environment are important factors in successful outcomes for people with FASD, yet positive and stable family environments are not typical for this population (Olson *et al.*, 2009). The negative outcomes associated with FASD are thus related to the very high rates of environmental risk factors and the inadequacy of family resources for affected children (Olson *et al.*, 2009). Offenders with FASD represent the output of an environment that is characteristically rated low on social determinants of health.

The principal health risks such as trauma, physical and sexual abuse, racism, poverty and housing instability are rarely addressed in FASD prevention (Reid, Greaves, and Poole, 2008). In order to improve the health of people with FASD and lower the prevalence of the spectrum, the contributing social influences on alcohol use need to be attended to (Gearing, McNeill, and Lozier, 2005). All of these factors are important to address, as they contribute to sustaining a disadvantaged life situation. When added to the secondary disabilities such as substance abuse, unemployment and incarceration, social and environmental risk factors are increased. Attending to the social determinants of health should help to reduce not only the occurrence of complex conditions but also the societal costs associated with FASD.

14.1.4

Human Rights and FASD

FASD is best considered within a broader disability context wherein participation in society is accommodated and functionality is managed through service provisions, much as would occur for someone with a progressive degenerative disorder. Canadian law, as detailed in the Charter of Rights and Freedoms, recognizes that individuals are equal under the law and entitled to equal protection and benefit, without discrimination based on age, race or ethnicity, religion, skin color, gender, mental or physical disability (Canada, Charter of Rights and Freedoms, 1982). The purpose of equality rights is to respect the dignity, worth and value of all Canadians, and to ensure that laws and government action are based on circumstances and needs, and not on negative stereotypes. One of the roles of government is to facilitate equal access to services and supports for citizens. The impairments caused by FASD necessitate that affected individuals receive the supports they need to participate equally in society.

14.1.5

Incarceration and FASD

The prevalence of FASD is difficult to assess. Current estimates of the percentage of the overall population that is affected range from 2% to 5% in North America and Western Europe, with the spectrum generally under-recognized (Malbin, 2004; Fast and Conry, 2004; May *et al.*, 2009). There is a higher incidence of FASD in certain regions and groups. Typically, rural, isolated and remote areas have a higher incidence, but the precise numbers are unknown (Bohjanen, Humphrey, and Ryan, 2009). Canadian FASD research suggests that rates are also higher in some Aboriginal communities (Boland *et al.*, 1998). In particular, the prevalence of FASD is significantly higher among incarcerated people in Canada, and an estimated 10-fold greater than among the general population (MacPherson and Chudley, 2007).

The problems that people with FASD have in adhering to social norms of behavior can result in their being considered socially deviant instead of disabled. Children with FASD are viewed as victims of the birth defects caused by alcohol exposure (Donohue, 2008). Adults with FASD in the correctional system are regarded in an entirely different way, as deviants who have violated social norms (Donohue, 2008). Research indicates that the disabilities caused by FASD become de-medicalized as the affected person develops into an adult (Donohue, 2008; Golden, 1999). The term “de-medicalization” refers to affected people coming to be regarded as in charge of their lives and perpetrating social wrongs through choosing to display challenging behaviors, rather than as people with physical and mental limitations caused by damage to the brain (Golden, 1999). This change in perspective results in adults with FASD being considered fully responsible and then being relegated to the criminal justice system (Donohue, 2008). However, the child with FASD inevitably matures into the adult with FASD, because the

14.2.1

Treatment Programs

The brain deficits in offenders with FASD, combined with the secondary disabilities associated with the spectrum, cause problems in functioning that make traditional prison treatment programs ineffective. It is an expensive use of scarce resources to have people enrolled in programs that cannot be effective. Moreover, a lack of response to programs by people with FASD can lead to their not being able to access prison programs because they have a history of not being helped by such programs (Fast and Conry, 2009; Chudley *et al.*, 2007; Boland *et al.*, 1998; Burd *et al.*, 2003). The literature calls for corrections to do a better job with offenders with FASD. One way to accomplish this goal is to effect a change in offenders' behavioral skills and social circumstances before they are released into the community. The research calls for programs in prisons to address affected people's abilities (Chapman, 2008; Debolt, 2009; Alberta Health Services, 2009; SAMHSA, 2007). In addition, the prison programs need to be client-centered in order to assess each individual's strengths and weaknesses and to develop appropriate skills training and treatment. In order to attend to the different needs and functional abilities of people with FASD, existing programs in the corrections system require restructuring. Notably, this can be accomplished through focusing on meaningful outcomes, such as building adaptive skills.

The rehabilitation of offenders is an evaluative and capability-building process (Ward and Marshall, 2007). Current research indicates that rehabilitation programs, and the release plans developed for individuals, need to include constructive conceptions of positive lives (Ward, 2002). It is important to assess individuals' life histories to better understand their psychological dispositions and vulnerabilities, as well as the internal and external factors that may prevent them from meeting their primary needs (Ward, 2002). The multiple and comprehensive requirements of people with FASD in the correctional system require interdisciplinary teams to deliver programs (Evans and Brewis, 2008; Egger, Binns, and Rossner, 2009). The research on PAE conducted in schools indicates that a structured environment which is heavily oriented around order and routine is beneficial for people with FASD; developing integrated programs in the corrections system could help to address these requirements for adults (Chapman, 2008; Bell, Trevethan, and Allegri, 2004).

14.2.2

Recidivism and Alternative Sentencing

Numerous studies have noted the high rates of recidivism among offenders with FASD (Boland, Chudley, and Grant, 2002; Malbin, 2004; Fast and Conry, 2004; Chudley *et al.*, 2007; Mitten, 2003). Recidivism among FASD-affected people occurs for many reasons. The brain structural deficits that cause difficulty with school and socializing continue to cause problems in the correctional system. People with FASD have difficulty adhering to parole conditions, which is a primary

reason for the recidivism problems for this group (Fast and Conry, 2004; Chudley *et al.*, 2007). Moreover, research indicates a link between a lack of community living skills and high rates of recidivism (Eggers *et al.*, 2006; Lindstedt *et al.*, 2004). For offenders with mental illnesses, a lack of community services after release can exacerbate their illnesses and contribute to recidivism (Sneed *et al.*, 2006).

Considering the primary and secondary disabilities of people with FASD, a strong argument can be made for addressing recidivism among offenders with FASD through purposeful sentencing, improving skills, and attending to other issues such as mental illness. Research into chronic offenders acknowledges that high-needs offenders, such as people with FASD, are more likely to return to prison (Government of Canada, 2007), and that receiving services to meet those needs may act to reduce recidivism. However, this research also suggests that the criminal law paradigm is a less than appropriate way to deal with disabled offenders (Government of Canada, 2007).

Incarceration is based on principles of deterrence and rehabilitation, along with denouncing unlawful conduct. Incarceration is designed to deter people from breaking laws, and rehabilitation is intended to return offenders to the community in a better state than before the crime. These principles assume that offenders have the capacity to understand the nature and consequences of unlawful behavior and to enact changes in their behavior and personal circumstances. The brain damage caused by FASD makes deterrence from future crimes and rehabilitation unlikely, if not impossible (Malbin, 2004). Alternatives to incarceration for people with FASD, such as diversions, conditional sentences and sentencing circles, need to be considered (Fast and Conry, 2004; Fast and Conry 2009; Roach and Bailey, 2009; Mitten, 2004). The literature calls for environmental accommodations for affected people within the correctional system, much as would be considered standard for persons with other disabilities (Malbin, 2004). Chudley *et al.* (2007) have recommended alternative sentences and parole conditions that consider the disability caused by FASD.

Currently, the justice system in Canada may consider FASD as either a mitigating or an aggravating factor in sentencing offenders. An analysis of Canadian case law indicates a lack of consistency in the approach to offenders with FASD (Roach and Bailey, 2009; Justice Canada, 2009). In certain cases, offenders were found unfit to stand trial, some were sentenced as youths to adult correctional facilities, while others were labeled as dangerous offenders (Roach and Bailey, 2009; Justice Canada, 2009). FASD may be considered or mentioned by the court, but the brain impairments are frequently not given substantial weight during sentencing (FASD Ontario Justice Committee, 2007).

For offenders with FASD, it is essential for the justice system to focus on achieving long-term positive outcomes. Alternatives to incarceration are recommended in the literature for offenders with FASD who are not a risk to the public (Fast and Conry, 2009; Mitten, 2003; Debolt, 2009; Roach and Bailey, 2009). Suggestions for incarceration alternatives include holistic community-based programs that address both substance-abuse problems and mental health issues (Mitten, 2003). According to the research, the most purposeful sentences for people with FASD

may be those that effect change in the person's life or social circumstances, rather than strictly aiming to change the person's behavior (Fast and Conry, 2009). Another factor to consider in the sentencing of FASD-affected offenders is their susceptibility to victimization while in custody (Chudley *et al.*, 2007; Jones, 2007). Incarceration is not appropriate for many affected people because of the brain deficits caused by PAE, which impair learning and reasoning and influence behavior. Inmates with mental illnesses may accumulate disciplinary sanctions during incarceration, and thereby reduce their opportunities for parole (Baillargeon *et al.*, 2009). In addition, the negative social networks extant in prison increase the probability of re-offending through post-release affiliations.

Reducing recidivism by offenders with FASD will require adjustments within the correctional system. Canadian government research acknowledges that incarceration is an inefficient and ineffective way of addressing recidivism in chronic offenders for whom prison is not a deterrent (Government of Canada, 2007). This research recommends that, for chronic offenders with cognitive impairments, investing resources in health and social systems may yield better results than repeated processing through the criminal justice system (Government of Canada, 2007). Chudley *et al.* (2007) have called for the allocation of appropriate resources within social services to improve the outcome and quality of life for affected people. Addressing the lack of fit between the abilities of people with FASD and release requirements will also reduce the costs of recidivism associated with FASD, and improve outcomes (Alberta, Government, 2007–2008; Every *et al.*, 2000; Canada Government, 2009; Canada, Government, 2007).

The criminal justice system is currently limited in its ability to impose the type of sentencing that would be beneficial to people with FASD. Court jurisdictions were not intended to recommend the community-based holistic supports and services that help people with FASD live effectively in the community (Roach and Bailey, 2009).

14.2.3

Release Planning

Statutory release from custody is governed by a federal law that allows offenders who are not considered dangerous to serve the last one-third of their sentence in the community on parole to the Correctional Service of Canada (CSC). Parole is granted to offenders to facilitate rehabilitation and ease transition into the community. The criteria for granting parole includes the risk to society, the prisoner's post-release plan, criminal record, behavior in prison, and information provided by psychiatrists/psychologists, police, victims, and family. The CSC is responsible for preparing offenders for consideration by the National Parole Board. Upon release, prior offenders are required to report to a parole supervisor and to adhere to a variety of conditions, including curfews, restrictions on travel, movement and behavior, as well as prohibitions on alcohol consumption and associating with certain individuals. Should the conditions of release be violated, the offender may be returned to custody (Correctional Service of Canada, 2008).

Before an offender is released from custody, the individual must agree to a correctional plan, which outlines the procedures to maintain a law-abiding lifestyle in the community. The plan details restrictions on movement and commitment to participate in employment and programs. Each plan is individualized to the person's needs and focuses on specific issues, such as job training and substance abuse. Successfully re-engaging prior offenders in the community requires adequate supervision and effective community programs (Correctional Service of Canada, 2008). The inherent limitations faced by people with FASD can result in significant barriers to reintegration into the community for this group.

Community reintegration programs for offenders with brain damage, including those with FASD, are vital to success. However, the research identifies a general need for community reintegration programs in the corrections systems (Egger *et al.*, 2006), and a lack of continuity and program consistency between correctional sites and community settings. This can result in people with FASD "falling through the cracks" in service provision if bridging and transitions between the two environments are not in place.

Prior to the release of an offender with FASD into the community, planning for that eventuality is critical. Both pre-release and post-release plans for affected individuals need to be developed (Eggers *et al.*, 2006; Sneed *et al.*, 2006). Any treatment needs of individuals, such as for mental illness and substance abuse, need to be started while the person is in custody and then continued in the community upon release (Magaletta *et al.*, 2009). Establishing contacts with a team of service providers in the community is therefore essential for affected people before release (Eggers *et al.*, 2006). It is also important that probation and parole orders be interpreted to offenders with FASD. Otherwise, their learning disabilities may preclude adherence to the guidelines and increase their risk of re-offending (Fast and Conry, 2004). Research recommends that affected people receive comprehensive but simply written and meaningful discharge planning before being released into the community (Debolt, 2009).

Housing for offenders with FASD upon release appears to be a key to succeeding in the community. Stable housing for adults with FASD upon release from incarceration will also improve the delivery of necessary services. The correctional system has an opportunity to maximize the chance of successful reintegration for offenders with FASD by tailoring services and supports, programs, sentences and probation or parole orders to reflect the needs and functionality of the individual.

14.2.4

Correctional System Needs

The challenges facing the corrections system in addressing the functional disabilities caused by conditions such as FASD are increasingly being recognized by both researchers and governments. The complexity is in altering the existing system in such a way as to enable the needs of FASD-affected offenders to be successfully met within the corrections context, and then extending these services into the community upon the person's release. The FASD literature calls for purposeful

sentencing that is focused on outcomes, and effecting changes in the behaviors and skills of this population while they are in custody.

A recent formal evaluation of federal Canadian correctional programs revealed that targeting the specific needs of offenders is both relevant and effective (Correctional Service of Canada, 2009). Offenders who participated in correctional service programs, such as for substance abuse, exhibited changes in behavior and were more likely to be granted a discretionary release than those who did not participate in programs (Correctional Service of Canada, 2009). Program participation was also associated with a reduction in re-admissions into the correctional system. However, the evaluation also revealed that the correctional system is significantly lacking in its ability to deliver programs to offenders with learning deficits, cognitive disabilities, and mental disorders. The report formally recommended developing a strategy to address the programming needs of such offenders (Correctional Service of Canada, 2009).

Studies indicate a need to develop a clear approach to FASD in the criminal justice system, and to develop clear practice guidelines (Cox, Clairmont, and Cox, 2008). FASD research calls for specific units to be established within the correctional system that are environmentally sensitive to the offenders' behavioral profile (Fast and Conry, 2009; Chudley *et al.*, 2007; Boland *et al.*, 1998; Bell, Trevethan, and Allegri, 2004; Burd *et al.*, 2003). Founding FASD units would enable the corrections system to address the cognitive and behavioral impairments of offenders with FASD. Training corrections personnel about FASD and its effects is also vital since, unless they have an awareness of the condition, such personnel are unlikely to recognize that potentially difficult behaviors are not deliberately chosen but are, rather, a result of brain impairment. Corrections system staff require both a knowledge of FASD impairments and the skills to interact effectively with offenders with FASD (Fast and Conry, 2009; Chudley *et al.*, 2007; Boland *et al.*, 1998; Bell, Trevethan, and Allegri, 2004; Burd *et al.*, 2003). In these ways, the neurobehaviors caused by the impairment can be addressed through modifying the social and physical environment experienced by affected people.

In addition to training for corrections personnel, programming is needed that targets meaningful and relevant roles for FASD-affected offenders after release. Corrections is an environment that can be viewed as both a barrier and a facilitator to participating in society. Because people do get released, it can play a vital role in preparing people to re-enter society (Canada, Criminal Code of Canada, RSC, 1985). Certain aspects of correction culture—structure, repetition, habit—are positive environmental supports that can enhance this pre-release preparation. Working with the FASD-affected population in prisons is an opportunity to connect with individuals who might otherwise “fall through the cracks” in the system.

14.3

Interventions and Social Supports for Adults with FASD after Release

Viewing FASD as a disability under the WHO International Classification of Functioning (ICF) framework allows us to see FASD as a condition that can benefit

from many of the same strategies and principles used in developing services for other disability groups, such as those with acquired brain injury or spinal cord injury. In the case of FASD, there is some research indicating that the disabilities (both primary and secondary) may not be in a stable state (Moore and Green, 2004; Paley and O'Connor, 2009; Kodituwakku, 2009; Rasmussen *et al.*, 2008; McGee *et al.*, 2008). (This point will be discussed later, because it has implications for the design of a community service network.) Drawing on the prevention model (Caplan and Grunebaum, 1967), secondary prevention (which is sometimes called “treatment”) and tertiary prevention (which can be viewed as “rehabilitation”) are the focus of the activities both within corrections system and in the community.

Appropriate interventions and accommodations are vital for people with FASD if they are to remain in the community after being released from the correctional system. One major issue here is to establish seamless and continuous support from the correctional system to the community. Providing continuity in services requires that the correctional system establishes methods and policies to interact with community partners who will help individuals function and access services in the outside world. The limited knowledge regarding adults with FASD, and the challenges that they face in the community, dictates that interventions be specifically tailored to their individual profiles, but still be within the principles of general social service offerings.

14.3.1

Client-Centered Lifelong Multisectoral Supports

A client-centered approach recognizes that the specific characteristics and circumstances of individuals must influence service need and service delivery. The clients are the best persons to describe their experiences of reality, and as a result it behooves service providers to spend the necessary time to learn about the client's life experiences (Law, 1998). An essential element of client-centered practice is facilitating clients in solving their problems (Law, 1998). In the client-centered approach, clients may be involved in making choices about their rehabilitation, rather than having pre-established external decisions imposed on them. The approach allows for flexibility in program delivery and recognizes the particular requirements of the individual.

A client-centered approach has multiple advantages in delivering interventions for people with FASD, because of the highly variable nature of the brain deficits associated with the disorder. The needs of individuals with FASD depend in part on the extent of brain damage by PAE and on the secondary disabilities. Interventions that focus on the individual will be most able to address specific requirements (Chudley *et al.*, 2007; O'Connor and Paley, 2009; Bertrand, 2009). The literature recommends the establishment of multidisciplinary teams to work with community partners to maximize the interventions for individuals, based on their needs and abilities (Grant *et al.*, 2004; Chudley *et al.*, 2007). By tailoring interventions to the needs of the individual, personally beneficial programs and treatments can be provided (Lindstedt *et al.*, 2004; O'Connor and Paley, 2009).

The disabilities caused by FASD do not self-correct over time, and the FASD research indicates that lifelong interventions are necessary for affected people (Paley and O'Connor, 2009; Grant *et al.*, 2004; Chudley *et al.*, 2007; O'Connor and Paley, 2009; Bertrand, 2009). As a result, people with FASD need multisectoral coordinated services that are accessible across their lifespan (Grant *et al.*, 2004). The involvement of multiple service providers in comprehensive interventions has a variety of benefits. Service providers generally follow different mandates to deliver services, which can result in a "silo" approach. Affected people can be lost to follow-up and monitoring if left alone to negotiate the support system. A comprehensive approach that offers coordinated care across multiple systems, including corrections, is important to maximize success for people with FASD (Paley and O'Connor, 2009). Furthermore, traumatic brain injury research reveals that rehabilitation involving an interdisciplinary team leads to improved function and independence (Evans and Brewis, 2008). Successful initiatives are multidisciplinary and multisectoral, and also involve partnerships with community agencies to provide services (Olson *et al.*, 2009; Brown, 2004).

There are multiple barriers to accessing community services for adults with FASD. Affected individuals may not realize they are in need of formal support, and therefore do not seek it out (Debolt, 2009). In addition, they may not possess sufficient cognitive faculties to negotiate separate application processes, and adhere to the variety of system requirements developed for people without brain damage. For offenders with FASD, other impediments include a lack of coordination between the correctional system and programs available in the community (Hartwell and Orr, 1999). The literature identifies a need for community programs for newly released offenders, in part due to the prevalence of waiting lists for entry into treatment programs in communities (Brown, 2004). Further, establishing connections between the services that people receive in the correctional system and in the community will assist in informing service providers about the specific needs and goals of individual offenders (Magaletta *et al.*, 2009).

14.3.2

Employment and Housing

For adults with FASD, an additional impediment to successful community establishment after release from prison is trouble finding employment and other forms of support (Brown, 2004). Other barriers include deficient work skills, gaps in employment records, difficulty accessing transportation to employment or community services, and the availability of health care, child care, and medication (Brown, 2004; Magaletta *et al.*, 2009; Fonfield-Ayinla, 2009).

The availability of stable housing for newly released offenders with FASD is also crucial to success in the community. Homelessness worsens secondary disabilities, such as mental illness and substance abuse, even in people without the brain deficits caused by FASD (Fonfield-Ayinla, 2009; Zlotnick, 2009; Shand, 2004). Moreover, offenders may be released into unfamiliar communities, and with few financial resources (Brown, 2004). It is well known that limited financial resources

have a negative influence on the ability to find and maintain a stable home. As a result, developing a comprehensive approach to intervention across multiple systems of care, including stable housing, is strongly advocated for people with FASD (Paley and O'Connor, 2009; Grant *et al.*, 2004; Chudley *et al.*, 2007; Bohjanen, Humphrey, and Ryan, 2009).

Secure and stable housing has multiple benefits for adults with FASD, and acts as a cornerstone to success in other programs. Housing can help people with FASD to protect against, cope with, and minimize secondary disabilities, such as mental illness (Burd *et al.*, 2003; Brinda, 2006). Stability in housing also assists them in adhering to treatment goals (Debolt, 2009), and reduces recidivism in offenders with mental illnesses (Lindstedt *et al.*, 2004; Case *et al.*, 2009). The difficulties of affected individuals in tracking finances, controlling impulses and following rules necessitates support to ensure stability in housing, such as access to a case worker who can assess the person's needs and ensure that they are met (Brinda, 2006).

The variable and particular effects of FASD on individuals require that programs cover a wide range of housing options appropriate to the range of abilities and functionality, including specialized support and more independent programs. For a newly released offender with FASD, housing within the community is preferred over placement in halfway houses, due to the negative influence of other criminals on affected individuals (Brinda, 2006). Following a client-centered model for providing housing to newly released offenders with FASD is beneficial. A comprehensive umbrella program to provide housing for people with FASD has been recommended in recent research. Such a program would have the capacity to maintain housing stability while accommodating the changing needs of individuals.

14.3.3

Training and Programs

Social and vocational skills training is important for people with FASD. Adults with FASD may have significant social and vocational skill deficits because the impairments caused by PAE do not improve over time, and may even intensify (Moore and Green, 2004; Paley and O'Connor, 2009; McGee *et al.*, 2008). Moreover, even if individuals have received social skills training during their incarceration, repetitive training is vital due to problems in short-term memory and information storage and retrieval (Grant *et al.*, 2004).

The deficits in social problem-solving skills in adults with FASD also require specific interventions. Social problem-solving is affected by impairments in working memory, initiating and planning tasks, and organization and monitoring behavior. Interventions aimed at providing appropriate training and adequate academic and social support can improve the individuals' skills (McGee *et al.*, 2008). Research into interventions in anger management and social skills programs for adults with FASD after release from prison suggests that the management of high-risk situations can be successful with appropriate interventions (Brinda, 2006).

Integrated treatment programs to address mental illness and substance abuse for people with FASD are important. The literature clearly indicates that the secondary disabilities of mental illness and substance abuse are common in people with FASD. Furthermore, mentally ill offenders are at risk of social isolation on release, which is known to worsen substance abuse-related problems (Hartwell and Orr, 1999). Considering that many offenders with FASD are affected by mental illness and addictions, linking treatment for these conditions will help to reduce feelings of isolation. Research into the experiences of mentally ill offenders strongly advocates for an integrated mental health and substance abuse treatment to improve outcomes (Magaletta *et al.*, 2009; Roskes and Feldman, 1999).

Treating mental illnesses or substance abuse in people with FASD requires certain accommodations. Treatment approaches that focus on changing behaviors that are symptoms of FASD disability are inappropriate and ineffective (Malbin, 2004). Research indicates that, like people who have received a traumatic brain injury, those with FASD can be more sensitive to the medications used to treat mental illnesses, and may react to such medications in unexpected ways (Paley and O'Connor, 2009; Fast and Conry, 2009; O'Connor and Paley, 2009). People with FASD may also be resistant to medications and psychosocial therapy (O'Connor and Paley, 2009; Hellems *et al.*, 2008). These atypical reactions to typical interventions require that service providers monitor individuals closely in order to ensure that medications are prescribed and administered effectively, and that any negative side effects are minimized.

Interventions provided for people with FASD after release from corrections must be tailored to address the needs that are specific to people of their age and gender. Youth require access to education, vocational and life skills training, social skills training and to stable housing. Adaptations to the learning problems associated with FASD require environments of reduced stimulation, the use of visual schedules, repeated instructions, and positive behavioral support (Bohjanen, Humphrey, and Ryan, 2009). Women require access to birth control and child care, as well as certainty in release planning to aid in re-establishing relationships with their children (Pedlar *et al.*, 2008). It is also important to screen for alcohol use in women during pregnancy (SAMHSA, 2007). The social and life skills training for women and men with FASD should reflect particular life circumstances, gender roles, culture and behaviors, such as anger management and parenting skills.

14.3.4

External Executive Function Support

People with FASD require the assistance of designated people to act as transitional navigators or advocates, mentors, advocates, and trustees. The problems that affected people have in learning, reasoning, judgment and adaptive skills frequently result in their becoming lost in the system, without assistance. They may have a limited insight into their lack of abilities, and over-represent their capabili-

ties to themselves and others (Chudley *et al.*, 2007). The FASD research recommends that an "external brain" in the form of formal caregivers and advocates be established to help affected individuals adapt, function, and meet their social needs (Chapman, 2008; Chudley *et al.*, 2007; Boulding, 2007; Kellerman, 2003). Access to stable and funded contacts for service providers helps to improve adherence to recommendations and retain participants in programs (Grant *et al.*, 2004; Debolt, 2009). Assistance in financial management is also necessary, and affected people should benefit from the establishment of trustees to manage their personal finances (Chudley *et al.*, 2007). The experience of disability can be minimized with integrated approaches to optimize the person's capacities, strengthen their access to available resources, and improve their interaction with the environment (Stucki and Celio, 2007).

Accommodating the disabilities caused by FASD requires whole system modifications to the person's social and political environment. The ability of affected people to function in society can be improved through coordinated multisectoral targeted interventions, and the establishment of an "external brain" composed of caretakers, advocates, and trustees. Alterations in the environment to support and enhance the functionality of the person disabled by FASD need to be made at the community level, through programs and services provided by governments and community agencies.

One essential aspect of providing interventions to adults with FASD is to follow individuals through the system. When multiple systems of care provide services, it is vital to establish a process to follow the individual across services, to communicate between providers, and to ensure that the individual does not fall through any gaps in the services. Research indicates that, without follow-up, individuals can become lost in the system (SAMHSA, 2007; Hartwell and Orr, 1999). Recent FASD-associated literature calls for a full continuum of services to be available to affected individuals across the lifespan (Malbin, 2004; Olson *et al.*, 2009; Paley and O'Connor, 2009; Fast and Conry, 2009; Chudley *et al.*, 2007). Developing official procedures to follow affected people from the correctional system through the services supplied by multiple providers is critical.

14.3.5

FASD Costs

The economic costs of FASD are important to consider when evaluating the benefits of multisectoral assisted support across the lifespan for adult offenders with FASD. The overall costs of FASD are difficult to assess, due to the variety of factors that influence individuals. Furthermore, researchers acknowledge that the estimates of costs are minimum values, due to the unavailability of many types of data on individuals (Fast and Conry, 2009; Thanh and Jonsson, 2009; Stade *et al.*, 2009). However, there are several basic categories of cost, including direct short-term and long-term costs of FASD to society, correctional system costs, and costs of homelessness.

Evaluations of the general costs of FASD for Canada and for Alberta indicate considerable expenditures at provincial and federal levels. In Canada, the cost of FASD from birth to 53 years of age is CA\$5.3 billion (at 2007 price levels) (Stade *et al.*, 2009). (For updated figures on the cost of FASD, see Chapter 4.) Over half of these costs are attributed to education and healthcare for affected children. This estimate does not include the costs of incarceration, or the cost of lost productivity among adults. The costs in Alberta of FASD amount to about CA\$400 million annually in long-term costs, and about CA\$143 million annually in short-term costs such as healthcare, education and the justice system (based on 2009 price levels) (Thanh and Jonsson, 2009).

Although the correctional system costs are not exclusive to people with FASD, the corrections system includes many with FASD. The cost of the corrections program in Alberta is CA\$106.31 per person per day (CA\$38 696 per year), while the federal corrections cost is CA\$260.10 per person per day (CA\$94 676 per year) (Alberta, Government 2008–2009). Despite these significant expenditures, the figures do not include all of the costs of FASD to the legal system, as there are also costs associated with the crime itself, policing, and court appearances (Fast and Conry, 2009). Boland, Chudley, and Grant (2002) have advocated that the costs associated with adult offenders with FASD be reduced by identifying affected individuals, so that the system could accommodate their disabilities.

The costs of homelessness are also significant. For example, in 2008 there were approximately 11 000 homeless people in the province of Alberta, while the provincial government spends annually an estimated CA\$ 100 000 per person to deliver programs and services to chronically homeless people, such as emergency medical services. The cost of shifting from managing homelessness to ending homelessness in Alberta would save an estimated CA\$ 7 billion over a 10-year period (The Alberta Secretariat for Action on Homelessness, 2008). Clearly, the avoidance of homelessness in people with FASD would lead to a major reduction in associated costs.

The extent of costs to society from FASD is substantial, even without an accurate breakdown of all the costs associated with the spectrum. The figures indicate, unmistakably, that to assist affected individuals in avoiding the correctional system and homelessness would not only greatly help the person but also have significant and lasting economic benefits to society.

14.3.6

Developmental Disability Assistance

The FASD research recognizes that a significant impediment to improving the community participation of people with FASD is the narrow criterion for disability assistance, which includes developmental disabilities (DD) and financial assistance (Streissguth *et al.*, 2004; Grant *et al.*, 2004; Bertrand, 2009). Chudley *et al.* (2007) have identified the need for access to developmental disability assistance for adults with FASD. Moreover, DD services can help in secondary prevention efforts. Burd *et al.*, (2003) have identified the receipt of developmental disability

services as a protective factor for avoiding the secondary disabilities associated with FASD. The literature clearly indicates the lasting and meaningful solutions that could be developed through providing access to developmental disability assistance to people with FASD, thus improving the quality of their lives. These supports may be just enough to keep some of these adults out of justice systems.

Alberta has developed a vision and innovative approaches to FASD in its ten-year strategic plan. There are a number of important ongoing projects in the province, and recently programs have been funded to address the needs of adults with FASD, one of which is Corrections and Connections to the Community (3C). The program has three components: evaluation, transition, and follow-up. Evaluation occurs within the correctional site, while transition begins with programming and relationship-building prior to release, and then continues into the community. The project also has an assertive follow-up phase.

Existing funded programs should be an exceptional source of data to expand the current knowledge of FASD. The annual reports that they submit to funders illustrate the importance of reporting requirements that go beyond accountability, and actually provide important information.

The above strategies are all reasonable and currently in existence in many areas of the community. The challenge is access to support for those people who are not in the greater urban areas and, more specifically, those returning to remote geographical areas with limited health and social services.

14.4

Policy Considerations for Adults with FASD

- 1) Comprehensive diagnostic capacity. In order to access services and supports to assist people with FASD to be contributing members of society, it is necessary to have access to a diagnosis. Diagnostic services for people who may be affected by FASD are needed for children, youth, and adults in all jurisdictions. The usual diagnostic clinics should also seek to evaluate the functional performance of individuals.
- 2) Seamless and equitable services across the lifespan. The brain impairments caused by FASD are lifelong. Thus, services that transcend the traditional “silo” approach, are multisectoral and connect the separate social, health and corrections systems are vital if people with FASD are to have access. It is important for these services to be available, regardless of the affected person’s chronological age.
- 3) Expand Persons with Developmental Disabilities (PDD) legislation to incorporate the functional disabilities of FASD. Legislation that governs developmental disabilities assistance needs to be expanded to include adults with FASD. The legislation which guides eligibility and available services to people with developmental disabilities varies by province. Currently, the

- leading provinces in Canada for providing inclusive disability support are Manitoba, Ontario, Prince Edward Island, and Saskatchewan. Alberta, British Columbia, the Northwest Territories and Quebec continue to link access to developmental disability support to narrow eligibility criteria: people with an IQ two standard deviations below the norm.
- 4) Transitions from child to adult services be pre-planned and allow for wrap-around services, including follow-up, housing, and supported employment.
 - 5) Sustainably funded services based on functional needs.
 - 6) Ongoing life skills and socialization assistance.
 - 7) FASD prevention efforts to target the social determinants of health.
 - 8) Alternative sentences for offenders with FASD whenever possible.
 - 9) Pre-release and post-release plans for offenders with FASD.
 - 10) Enhance correctional environment to reflect the needs and functionality of offenders with FASD.
 - 11) Reduce reconnecting with justice and correctional systems through provision of training, programs, and ongoing assertive supports.
 - 12) Create a safe and supporting community-based "virtual world." Such a world has destinations, activity programs and shelters in which staff and volunteers understand and can manage the neurobehavioral presentation and profile of individuals with FASD. This world is interconnected and linked to resources and case management options across disparate service sectors.

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PARTNERSHIP MEMBERS

*Abused Women's Aid in Crisis
Advisory Board on Alcoholism and Drug Abuse
Alaska Behavioral Health Association
Alaska Center for Children & Adults
Alaska Children's Services
Alaska Mental Health Board
Alaska Mental Health Trust Authority
Alaska Peer Support Consortium
All-Alaska Pediatric Partnership
Anchorage Coordinated Resources Project
Anchorage School District (Anchorage)
Arctic FASD Regional Training Center
Assets Inc.
Association for the Education of Young Children-SEAK
Big Brothers Big Sisters of Alaska
Boys & Girls Home of Alaska
Camp Fire USA Alaska Council
Central Council of the Tlingit & Haida Indian Tribes of Alaska
Christian Health Associates
Copper Basin Neurodevelopmental Center
Deltana Community Services Partnership
Dena A Coy/Southcentral Foundation
Diocese of Juneau
Fairbanks Community Behavioral Health Center
Family Centered Services of Alaska
Frontier Community Services
Gastineau Human Services
Governor's Council on Disabilities and Special Education
Hoonah Indian Association
Hope Community Resources
Independent Living Center
Kenai Peninsula FASD Program
Ketchikan Indian Community
Kinetictions
Kobuk Valley Consulting
Kodiak Area Native Association
Juneau Family Health and Birth Center
Juneau FASD Diagnostic Clinic
Juneau Partnerships for Families and Children
Lower Kuskokwim School District
Lynn Canal Counseling Services
Nenana City School District
Nome Youth Facility
Nondalton Tribe
Regional Wellness Forum
Set Free Alaska, Inc. (Wasilla)
Southcentral Foundation FAS Diagnostic Team
Southeast Regional Health Consortium
Southeast Regional Resource Center
Southern Kenai Peninsula Communities Project
Sprout Family Services
Stone Soup Group
Tongass Substance Screening
UAA Department of Health Sciences
UAA Center for Human Development
Volunteers of America-Alaska
...and many individuals*

HOW TO BECOME A MEMBER

You are invited to join the Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership, a coalition of organizations and individuals committed to addressing issues related to fetal alcohol spectrum disorders in Alaska. There is no cost for membership and no minimum requirements.

Members will be informed of and invited to participate in the Partnership's efforts – including advocacy, budget and policy issues, public awareness, alternatives to incarceration, substance abuse treatment for pregnant women, supported housing, family support, diagnosis, case management, prevention, training for professionals and paraprofessionals, and other issues related to FASD. You may participate in or decline to participate in whatever efforts you choose.

Please fill out and **MAIL, SCAN** or **FAX** to 907-465-4410.

Organization Individual

Contact Person _____

Organization Name _____

Address _____

Email _____

Phone contact(s) _____

What is your affiliation/interest in FASD?

What services do you provide related to FASD?

Alaska FASD Partnership

**Advocacy • Family Support • Diagnosis •
Case Management • Prevention • Life Skills •
Substance Abuse Treatment for Pregnant
Women • Parent Navigation • Training for
Parents • Public Awareness & Education •
Supported Employment • Supported Housing •
Case Workers • Court Interpreters •
Alternatives to Incarceration • Training for
Attorneys & Judges • Training for Educators •
Traditional Healing • Training for Medical
Professionals • Life-Long Interventions**



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Website: www.hss.state.ak.us/abada/fasd.htm

*The mission of the
Alaska FASD Partnership is to promote
awareness, prevention, and effective life-long
interventions for those affected by prenatal
alcohol exposure and their families.*

Alaska FASD Partnership

The Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership is a coalition of over 75 organizations and individuals committed to addressing issues related to FASD in Alaska.

The mission of the Partnership is to promote awareness, prevention, and effective life-long interventions for those affected by prenatal exposure to alcohol and their families.

The Partnership was formed in early 2010 after a groundswell of stakeholder effort and public comment to the Advisory Board on Alcoholism and Drug Abuse, and its partners, about the need for a more organized effort to address FASD in Alaska.

The Partnership is guided by a steering committee of individuals, organizations, and agencies – including people who experience FASD, family members, and professionals who work in the field. Additionally, the steering committee has members representing the Departments of Health & Social Services, Corrections, Education and Early Development, Labor and Workforce Development, and the Alaska Court System.

Seven workgroups of the Partnership are actively addressing a variety of issues related to FASD, including developing policy and funding recommendations, promoting public awareness, workforce development, collaborations,

research, training, and more. They are:

- Diagnosis and Parent Navigation
- Family and Peer Support
- Prevention & Treatment for Pregnant Women
- FASD and the Education System
- FASD and the Legal System
- Services for Adults with FASD
- Professional Development

If you are interested in joining the Partnership or a workgroup, please visit our webpage or contact us via the information below.



Members of the Alaska FASD Partnership pose at the Alaska State Legislature in 2011 after a day of advocating for policies and funding related to FASD.

Message from the Chair

Waqaa from the Alaska FASD Partnership. We are a group of individuals and organizations coming together to address Fetal Alcohol Spectrum Disorders (FASD) and the concerns associated with FASD. We are individuals, parents, professionals, educators, community, healthcare providers, and voters.



Alaska is an incredible state with diversity in our cultures, languages, and communities. Every year, our state attracts many tourists to witness firsthand the beauty of Alaska – in our lands and our people. Yet, behind this beauty, Alaska leads the way with the highest number of individuals born with FASD, and the highest rates of alcohol abuse and domestic violence. The common factor is alcohol. FASD does not discriminate by culture, education, or economic status. It can happen anywhere alcohol is available.

Although Alaska leads the way with identification of FASD through our diagnostic teams, we can do more to help decrease the incidence of FASDs through education and awareness. If everyone reading this newsletter pledges to learn more about FASD – its causes and the issues surrounding alcohol use – our state has the potential to live more healthy, safe, and happier lives. Join our cause – sign up to become a member of the AK FASD Partnership!

Quyana for your time. If you have any questions, concerns, or would like to join the Partnership, please contact us.

Monica Charles Leinberger

Website:

www.hss.state.ak.us/abada/fasd.htm

Alaska FASD Partnership

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The brain is the organ most sensitive to prenatal alcohol damage. [Dr. Edward P. Riley lecture, September 25, 2002]

Damage to the brain from alcohol exposure can have an adverse affect on behavior. Alcohol exposure appears to damage some parts of the brain, while leaving other parts unaffected. Some children exposed to alcohol will have neurological problems in just a few brain areas. Other exposed children may have problems in several brain areas. The brain dysfunction is expressed in the form of inappropriate behaviors. Their behavior problems should be viewed with respect to neurological dysfunction. Although psychological factors such as abuse and neglect can exacerbate behavior problems in FASD, we are looking primarily at behavior that is organic in origin. To better understand FASD behavior issues, shift perspective from thinking the child "won't" to "can't." (Diane Malbin, MSW, Trying Differently Rather Than Harder,)

Sometimes the person's behavior is misinterpreted as willful misconduct (Debra Evensen, www.fasalaska.com), but for the most part, maintaining good behavior is outside of the child's control, especially in stressful or stimulating situations. Behavior problems in children with FASD are often blamed on poor parenting skills. While good parenting skills are required, even alcohol exposed children raised in stable, healthy homes can exhibit unruly behavior. The most difficult behaviors are seen in children who were prenatally exposed to alcohol and who also suffer from Reactive Attachment Disorder.

Most children with FASD have some attachment issues, may display inappropriate sexual behaviors, show poor judgment, have difficulty controlling their impulses, are emotionally immature, and need frequent reminders of rules. As a result, many will require the protection of close supervision for the rest of their lives.

Fetal Alcohol Spectrum Disorders (FASD)

Alcohol causes more damage to the developing fetus than any other substance, including marijuana, heroin, and cocaine. (Institute of Medicine, 1996)

"Soft Signs"

(Psychological signs of FASD brain damage)

- Immature social development: overly friendly to strangers
- Emotional lability:
- Poorly developed conscience:
- Lack of consistent impulse control:
- Inability to learn from consequences
- Good expressive language skills
- Talented in art, music or mechanics.
- Attention deficits: not always hyperactive, but easily distracted by external stimuli
- Short-term memory deficits
- Inappropriate social interactions
- Difficulty managing money:
- Poor concept of time
- Grandiose ideas and unrealistic life goals, distorted perceptions
- Poor judgment
- Vulnerability and naiveté

"The greatest obstacle our children with fetal alcohol disorders must overcome is chronic frustration from not being able to meet the unrealistic expectations of others." – Dr. Calvin Sumner, nationally recognized expert.

FASD and the Brain



(Photo courtesy of Sterling Clarren, MD)
Brain of a baby with no alcohol exposure Brain of baby with heavy alcohol exposure

How Prenatal Alcohol Exposure Affects Development of the Brain

By Teresa Kellerman

Fasstar Enterprises
Fetal Alcohol Syndrome: Support,
Training, And Resources

www.fasstar.com

Fasstar Information Series Brochure 0408B1

FASD and the Brain

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Alcohol is a "teratogen" (substance that is toxic to the baby's developing brain). Damage can occur in various regions of the brain. The areas that might be affected depend on which areas are developing at the time the alcohol is consumed. Since the brain and the central nervous system are developing throughout the entire pregnancy, the baby's brain is always vulnerable to damage from alcohol exposure.

The regions of the brain that might be affected by prenatal alcohol exposure include:

Frontal Lobes – this area controls impulses and judgment. The most noteworthy damage to the brain probably occurs in the prefrontal cortex, which controls what are called the **Executive Functions**.

Corpus Callosum - passes information from the left brain (rules, logic) to the right brain (impulses, feelings) and vice versa; related to attention deficits, psychosocial function, and verbal learning.

Basal Ganglia – involved in cognitive function; affects spatial memory and behaviors like perseveration and the inability to switch modes, work toward goals, and predict behavioral outcomes, and the perception of time.

Hypothalamus - controls appetite, emotions, temperature, and pain sensation

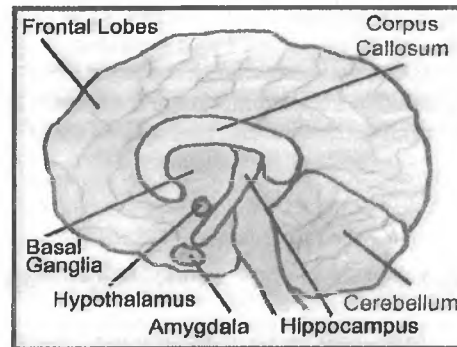
Amygdala – central part of emotional circuitry, senses danger, fear and anxiety; plays major role in recognizing faces and facial expressions, social behavior, aggression, and emotional memory; critical for stimulus-reinforcement association learning.

Hippocampus - plays a fundamental role in spatial and verbal memory retrieval; damage can cause chronic stress, anxiety, and depression; dysfunction is related to symptoms of schizophrenia.

Cerebellum – controls balance, coordination and movement; impacts learning and cognitive skills.

The hypothalamus, amygdala, and hippocampus are part of the **limbic system**, regulating emotions, social and sexual behavior, fight or flight" response, and empathy.

Fetal Alcohol Spectrum Disorders (FASD)



Executive Functions of the Prefrontal Cortex

Effects of alcohol exposure on behaviors related to executive functions of the prefrontal cortex:

- inhibitions: socially inappropriate behavior
- problem solving: inability to figure out solutions spontaneously
- sexual urges: inability to control sexual impulses, especially in social situations
- planning: inability to apply consequences from past actions
- time perception: difficulty with abstract concepts of time and money
- internal ordering: like files out of order, difficulty processing information
- working memory: storing and/or retrieving information
- self-monitoring: needs frequent cues, requires "policing" by others
- verbal self-regulation: needs to talk to self out loud, needs feedback
- motor control: fine motor skills more affected than gross motor
- regulation of emotion: moody "roller coaster" emotions, may withdraw or lash out
- motivation: apparent lack of remorse, need external motivators
- judgment – inability to make wise decisions

Alcohol Exposure by Trimester:

1. During the first trimester, as shown by the research of Drs. Clarren and Streissguth, alcohol interferes with the migration and organization of brain cells. [Journal of Pediatrics, 92(1):64-67]

2. Heavy drinking during the second trimester, particularly from the 10th to 20th week after conception, seems to cause more clinical features of FASD than at other times during pregnancy, according to a study in England. [Early-Human-Development; 1983 Jul Vol. 8(2) 99-111]

3. During the third trimester, according to Dr. Claire D. Coles, the hippocampus is greatly affected, which leads to problems with encoding visual and auditory information (reading and math). [Neurotoxicology And Teratology, 13:357-367, 1991]

Not all damage from alcohol exposure is seen on brain scans, as lesions might be too small to be detected, yet large enough to cause significant disabilities.

Children do not need to have full Fetal Alcohol Syndrome (FAS) to have significant difficulties due to prenatal exposure to alcohol. According to research done by Drs. Joanne L. Gusella and P.A. Fried, even light drinking (average one-quarter ounce of absolute alcohol daily) can have adverse effects on the child's verbal language and comprehension skills. [Neurobehavioral Toxicology and Teratology, Vol. 6:13-17, 1984] Drs. Mattson and Riley in San Diego have conducted research on the neurology of prenatal exposure to alcohol. Their studies show that children of mothers who drank but who do not have a diagnosis of FAS have many of the same neurological abnormalities as children who have been diagnosed with full FAS. [Neurotoxicology and Teratology, Vol. 16(3):283-289, 1994]