Embracing the Reality *Celebrating* the Passion and Creating the Hope

FASD Southeast Alaska Regional Conference Report • 2010

(Top Photo) Jim and Martha Stey provide music for the presenters after the close of the conference.

(Lower photo) Matt Rorem describes his challenges living with FASD and the challenges of raising his daughter, also with an FASD.

Photo: Kim Andree — Juneau Empire

(Above) Dr. Sterling Clarren, recognized international FASD researcher and educator, presented the keynote address of the conference. He stated, "We need powerful stories coupled with powerful data... Those two things together will bring change. We're starting to see it now... Having a room like this of bright-eyed folks who want to do something about this is huge."

Cover Art Piece

"Life's Journey of Hope and Healing" *by Jenny Jackson* — Whitehorse, Yukon Territory, Canada.

This 6 by 5 foot moose hide hangs from a Yukon diamond willow. It served as a backdrop for the conference

The entire story of a little girl is revealed in three stages. In the painting of a very young child, there is innocence, excitement, and wonder in her face and the beads are in harmony with whites and pink. Growing older, the colors gradually change to deeper pink and purples with turquoise to reveal her developing creativity. Then there is a time of hurt and loss, depicted by brown and beige, with brighter colors telling of her struggle to remember who she is. She gains strength by returning to her spiritual roots and reconnecting to her elders' teachings.

Healing, wholeness and balance return. Nearing the end of her life she reaches down to childhood memories to bring her joy. When she passes dark and beige beads indicate sorrow of family and friends. Sorrow fades leaving gold, brass, and silver indicating happy and loving memories of her.

The work is completed by the constant companion—her Yukon diamond willow walking stick as full of character as was her life.

Photos: K.J. Metcalf, unless noted otherwise. Publication design and layout: M. Stone

Fetal Alcohol Spectrum Disorder (FASD) Southeast Alaska Regional Conference

Juneau, Alaska Feb. 18-20, 2010

Embracing the Reality, Celebrating the Passion, and Creating the Hope

Four hundred people from throughout Southeast Alaska gathered in Juneau Feb. 18-20 for a three-day conference on Fetal Alcohol Spectrum Disorder (FASD). The conference featured an array of national and international leaders in the field of FASD; research, education, and in programs that have proven successful in serving those with an FASD and their families.

While we thought this conference would be successful, we had no idea that it would be as powerful and as extraordinary as it turned out. Extraordinary because those with an FASD and their families courageously found their voices and publically shared their daily challenges in coping with a world that often does not recognize their disability and provides few services. This sharing brought reality, honesty, and courage that raised the level of inspiration and engagement to a new level. This energy helped motivate and invigorate discussion groups to assess the current state of FASD awareness and services and recommend needed improvements.

The purpose of this report is to try to portray a sense of the synergistic energy that resulted in recommendations developed by attendees and presenters to address the most pressing FASD needs in Southeast Alaska.

For a digital copy of this report, please go to **www.hss.state.ak.us/abada**

Why a Conference

Alaska leads the nation in the per capita rate of FASD as well as other first place positions in:

- Consumption of Alcohol
- Incarcerated
- Homeless
- Suicides

Given these embarrassing statistics, we still lack adequate programs, services, and understanding that would help Alaska move out of first place.

Prevention is Key – FASDs are 100% preventable. This was a main theme throughout the conference. However, prevention is more complicated than convincing women and their supportive partners to not drink during pregnancy.

Dr. Sterling Clarren, in his conference keynote address said, " ... the way to greatly lower the occurrence of FASD is to identify and to care for those mothers who, themselves have FASD."

Alice and Martha - This is a true story and is neither the beginning nor the end of the story, but somewhere in the middle. Alice and Martha (not their real names) living on the streets and in the woods of Juneau are chronic alcoholics. They are the victims of abuse, violence, and rape. They have neither permanent homes nor reliable support systems and they are at the mercy of their abilities and environment.

Alice and Martha were both born with brain damage and addicted to alcohol. They have an FASD because their mothers drank while pregnant. Were these mothers and their mothers also born with an FASD? No way to be certain, but most likely - yes. FASDs are so often a multi-generational disability. Although not genetically inherited, they are still passed from one generation to the next.

Alice has given birth to eleven children and Martha has given birth to nine children; twenty children and they <u>all have an FASD</u>. All of the children have been placed in state care. Some of these children are now sexually active, or soon will be .... and the story continues.

In this story, we can identify at least 22 people with an FASD. Each child born with an FASD costs the State of Alaska more than four million dollars during their lifetime. Do the math and it is staggering. That is the easy cost to figure - the human costs and suffering - not so easy.

But, what if we had been smart enough and cared enough to have figured out that Alice and Martha needed supervised housing and an intensive support system? Sure, it would be expensive, but again do the math. There are successful supportive programs that would have given Alice and Martha a high likelihood of a different outcome; a per-

manent home, safety, self-worth, some income, and giving birth to healthy babies that they could raise (avoiding the "empty-nest" syndrome). Providing this supervised level of care for Alice and Martha could have been key to reducing the number of those born with an FASD, and such care could help Alice and Martha live a fuller life.

So, this conference was about those who have an FASD and their families including the Marthas and the Alices, their children, their grandchildren, and the lifetime of understanding, support, services, and care they require and deserve.

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a range of disabilities, from minor to severe, caused when a developing embryo is exposed to alcohol. This prenatal exposure to alcohol causes permanent and irreversible brain damage.

The vast majority of persons with an FASD:

- ***Do not have outward or obvious physical traits that would lead one to think "birth defect" resulting in life-long brain damage.***
- ***May have very good language skills and a near normal IQ, but are unable to remember and learn from mistakes, and can easily be overwhelmed with multiple instructions and obligations.***
- ***Often learn one day and forget the next, do not connect consequences to actions, and act impulsively. Society often views and responds to this behavior as "willful", rather than a brain disability, and punishes accordingly.***
- ***Benefit from being diagnosed when a child and provided a comprehensive support system which can all help avoid or lessen secondary disabilities; mental health problems, disrupted school association, inappropriate sexual behavior, incarceration, substance abuse, homelessness, joblessness, and marriage and relationship problems and violence.***

Recommendations

The conference planning team and community members identified, prior to the conference, the most pressing FASD issues we face in diagnosis, family support, educational systems, housing, incarceration/justice systems, and employment. This list helped the conference presenters and attendees develop recommendations for action.

Overall Recommendations:

Out of the specific recommendations, emerged broader recommendations that touched all issues. The most pressing overall needs are:

1. Increase the Southeast Alaska FASD diagnostic capacity, emphasizing diagnosis of children.
2. Create a system of caseworkers to be assigned to those newly diagnosed with an FASD, emphasizing children and their families.
3. Develop a pilot housing project for those individuals and families with an FASD.
4. Develop support programs for youth, young adults, and adults with a diagnosed or suspected FASD.
5. Advocate for medical professionals, legislators, policy makers, and agencies (Alaska Mental Health Trust Authority and others) to define an FASD as a permanent neurological disorder present at birth. People diagnosed with an FASD should be considered Trust beneficiaries and eligible for Medicaid waivers.
6. Define an FASD as a disability based on functioning cognitive ability and not IQ.
7. Support women with an FASD through their childbearing years, with improved care for those who are identified as chronic alcoholics.
8. Create a non-profit FASD educational, support, and advocacy regional organization.
9. Increase community awareness of FASDs.
10. Increase FASD training for those with an FASD and their families, professional and paraprofessional providers, and volunteers.

It is hoped that the above recommendations will provide a template for individuals, organizations, communities, agencies, and elected officials to advocate for improvements in response to Alaska's unacceptable high rate of FASDs and lack of adequate services. In the following pages, you'll find more specific recommendations in the areas of diagnosis, family support, educational systems, housing, alternatives to incarceration and employment.

"There's so much to learn – it's overwhelming. The most help to me was a greater understanding to help me deal and fight for what my son needs. Knowing that I'm **not** alone. There are many people learning to advocate for my son's needs." *Mother of child with an FASD*

Diagnosis

The key protective factor that will allow a person with an FASD to understand his or her disability, secure effective services and support, and lessen the development of secondary disabilities is early diagnosis. An initial early diagnosis can be made between the ages of 2-4. A follow-up diagnosis needs to be made when the child is more mature at approximately age of 8. Additional diagnoses should then be made during adolescence and, as necessary, into adulthood. An FASD is a lifelong disability.

Alaska is home to 9 functioning FASD Diagnostic Teams in the following communities: Anchorage (2 teams), Juneau, Sitka, Kenai, Wasilla, Fairbanks, Kodiak, and Bethel. Each team is supported by the State of Alaska, Department of Health and Social Services, Division of Behavioral Health. Currently, Behavioral Health maintains provider agreements with the teams and offers a $3000.00 reimbursement for each diagnosis completed, whether or not the diagnosis reveals an FASD. This dollar amount was generated by a thorough evaluation into the cost of a diagnosis offset by Medicaid and other third part billing.

(Above) Carolyn Hartness and Deb Evensen dance to the music at the close of the three day conference.

(Above Right) Jenny Jackson reads her poetry from "Silent No More — A Poetic Voice Breaks the Silence of FASD" as Morgan Fawcett accompanies her on the flute.

(Right) Some of the 400 attending the conference pick up lunches prepared by the Glory Hole Homeless Shelter.

All clinics use the University of Washington, Fetal Alcohol Syndrome Diagnostic and Prevention Network 4-digit diagnostic code. Quantitative, objective measurement scales and specific case-definitions are used to derive the code.

In Southeast Alaska, the Juneau clinic can diagnose 24 clients a year and the Sitka clinic 12 a year. Both clinics take referrals from throughout the region.

1. The Juneau FASD Diagnostic Clinic is operated and coordinated by Central Council of Tlingit and Haida Indian Tribes of Alaska (CCTHITA), Tribal Family and Youth Services. The Juneau interdisciplinary diagnostic team consists of a physician, psychologist, speech and language pathologist, physical therapist, parent navigator, and the clinic coordinator. The team is supported by individuals who volunteer their time and expertise, as well as through the provider agreement with the State of Alaska. The team meets one day a month. Each diagnosis requires a minimum of 4½ hours. Regional awareness of FASDs is increasing resulting in the limited diagnostic capacity being overwhelmed and creating a 3-6 month waiting list for youth, and longer for adults.

2. The Sitka diagnostic clinic is operated by Southeast Alaska Regional Health Consortium (SEARHC) Behavioral Health. As it is with all diagnostic clinics in Alaska, the team is supported through a provider agreement with the State of Alaska. This clinic serves individuals living in Sitka and surrounding communities and primarily offers services to youth. Their clinic is held once a month, with providers convening to determine a diagnosis. They have a waiting list of 3-6 months.

Southeast Alaska is fortunate to be home to two diagnostic clinics supported by a statewide resource network. However, the teams are vulnerable to team member turnover and financial constraints that may threaten a team's success. Early diagnosis is key in supporting individuals who live with an FASD. Without adequate diagnosis the Southeast Alaska region would suffer a significant setback in serving those with an FASD.

Recommendations:

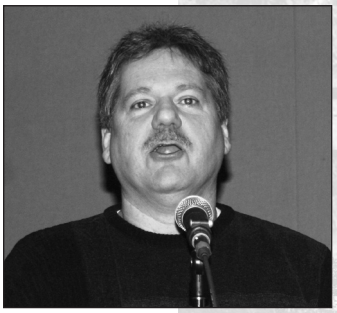
Within the next three years:

1. Double the region's FASD diagnostic capacity.
2. Stabilize the region's FASD diagnostic clinics through increased funding.
3. Fund a case management position for each clinic.
4. Fund a minimum of one parent navigator position for each clinic.
5. Formalize a screening process to facilitate referrals from health clinics and providers to FASD diagnostic clinics.

Family Support

A person with an FASD can go through their entire life-time and never be recognized by them, their family or the larger community as brain damaged. Their chaotic behavior is perceived and responded to as "willful" rather than brain based. These are prime candidates to acquire secondary disabilities: disrupted schooling and school drop-outs,

marginally employed or no employment, substances abusers, victims or perpetrators of violence, incarcerated, and homeless. They can become labeled the trouble makers, become truly disenfranchised, and often are relegated to the default care systems: prison and homeless shelters. They and their families are often in crises – never ending crises.



Leslie Randall (top) and Steve Randall (below) from Ketchikan are parents of an adopted daughter with FASD. They spoke on behalf of parents of children with FASD.

Parents/Guardians are highly likely to notice problems with children and request a diagnosis. The diagnosis may be done by a physician or by the FASD Diagnostic Clinic. The earlier in life a person is diagnosed (as early as two years of age) with an FASD followed immediately with comprehensive services and support for the person diagnosed and their family, chances increase dramatically for a more positive outcome for the life-time of that individual and their family. Ideally, planning should be person-centered and supporting services should be wrap-around. When the child with an FASD enters the formal educational system with a diagnosis they may qualify for an Individual Educational Plan (IEP), under a Learning Disabled (LD) or other health impaired (OHI) designation. The IEP can make a significant difference in their ability to succeed. An FASD alone does not qualify the child for an IEP (see Education).

At the age of 16 the person with an IEP is required to have a transitional plan that, if possible will allow them to live and work independently. Total independent living will likely not be possible for many people, and the plan will likely recognize the level of life-time support in housing, employment and services that they will require.

Usually an adult (age 21 and older) does not have a plan to implement. An adult with a diagnosis has a slight advantage in securing services compared to not having a diagnosis. Families note that after school, people with an FASD often end up incarcerated. Families are often stressed as the parents become caretakers and case managers for the child, youth, and adult (and perhaps their children).

As one parent of a teenager explained it, "Being the caretaker of a child or adult with an FASD is challenging and exhausting. With young children, getting a diagnosis is often difficult. Even after a child is diagnosed, she or he may not qualify for services. Even if the child qualifies, there may an absence of services in her/his community. Once a child leaves school, the situation becomes even more difficult for caretakers. The young adult no longer has the structure provided by a school day, but often is unable to keep a job without adequate services. The correct type of housing to support an individual with an FASD does not exist. At this point, caretakers are getting older and are already exhausted from years of anxiety. Yet, here they are the sole support for their child who is incapable of being completely independent. In all these cases, the parents live

with a high level of stress. Without the appropriate services, parents are continuously overwhelmed, handling one crisis after another."

Obviously, the best support for caretakers would be for their children to receive the early diagnosis and lifelong services that they need. However, the gaps between what a family needs and what services are available are large. Also, there are significant barriers that prevent them from accessing what is available. These gaps will not disappear rapidly. Knowing this, the question becomes, "What can reasonably be done in the next few years to increase support to families caring for someone with an FASD?"

Recommendations:

Diane Casto, Manager, Prevention and Early Intervention Services, Alaska Dept. of Helath & Social Services, speaks on FASD prevalence rates in Alaska.

1. Funding and policy decisions that reflect the overwhelming need for early diagnosis and a need for case managers who would be assigned to a specific youth and adult clients. Currently the system hands the client from one case manager to another at each agency (which may suffer from constant employee turn-over), but there is a need for one place to lend consistency and stability to their lives.

2. Additional certified FASD trainers to inform and educate families, health/care providers, teachers, day care providers, legal system, mentors and elected officials.

3. Develop community based FASD support network where trained volunteers act as mentors to an individual with an FASD.

4. Develop a family-to-family community support network where trained volunteer families "adopt" a family that includes an individual with an FASD.

5. Fund, recruit and train Parent Navigators throughout Southeast Alaska.

6. Develop a regional parent-to-parent support network perhaps based on the Family Empowerment Network (FEN) model (*http://pregnancyandalcohol.org/index.asp?menuID=142&firstlevelmenuID=142&siteID=1*). This will provide both informational and emotional support to families through a hotline, a website, a listserv, trainings, support groups (either face-to-face or via teleconference), and parent-to-parent matching (peer counselors).

7. Extend Stone Soup Group (currently Anchorage based) to Southeast Alaska or create a similar organization to provide FASD information, a website, and coordinate training. There is a great need for a regionally based ongoing training and advocacy.

    - Trainings/workshops should be available emphasizing specific issues such as adolescents and sexuality, socialization skills, stealing and lying, etc.

- The amount of information available on the web and elsewhere can in itself be overwhelming. Therefore, it is necessary to compile a comprehensive informational and regional resource directory so that parents have a reliable place to go for information.

- Hold an FASD camp based on the White Crow L.I.F.E. sessions model *(http://www.whitecrowvillage.org/community/life_sessions.html).*

- Provide opportunities for children and adults with an FASD and their families to reconnect with their culture so that they can gain a sense of identity and decrease feelings of isolation.

Superior Court Judge Michael Jeffery explains how courts could make moderate changes to make some significant improvements in helping those with an FASD comprehend court procedures, with more positive outcomes.

Education

Educating children with an FASD also means educating each and every person who might encounter the child, including family members, neighbors, and professionals, as well as the person with an FASD.

Obtaining educational assistance in the classroom for children with an FASD may begin with a referral at birth from an attending health care provider or not until a child enters an organized educational program. When a student does not respond to the usual behavior management techniques or regular classroom strategies, a referral is made to special education. After an evaluation, the student must qualify for one of the 14 categories of disability listed in the special education law. Because FASDs are not specifically listed as one of the 14 categories, special education teams must look at 504 plans or discuss the Other Health Impairment (OHI) option.

"Over 50% of the children and adults with FASD have an IQ above 70. They do not qualify for special education programs and, if FASD has not been recognized, they are often misdiagnosed or labeled as ADD, ADHD or just plain lazy and stubborn." (Vicky McKinney, Reprinted from FAS Times, Fall '97.) A correct diagnosis makes a huge difference in terms of putting the child's behaviors into perspective.

Transitional planning is scheduled to occur at the age of 16. The child is then supposed to be trained to be able to live "independently". However, almost all individuals with an FASD have an adaptive quotient below 70 (adaptive quotient (AQ), measures ones ability to function day to day without supports in the areas of communication, socialization, daily living, time management, employment, etc.). Russel, D. (2003), *IQ - It Just Doesn't Matter: The Role of Adaptive Functioning in Individuals with FAS/FAE/ARND/FASD.* Vancouver, Canada: FASD Conference: Doing What Works. The most severe cases will or "most will" likely never be able to live independently, and almost certainly not by the time they leave school.

Recommendations:

1. Advocate for a comprehensive school district approach to FASDs (Anchorage School District model based on diagnosis).
2. All childcare providers interacting with children (teachers, bus drivers, etc.) should be required to attend comprehensive training to learn how to work with children who have an FASD.
3. All providers interacting with school-aged children (teachers, aides, support staff, bus drivers, etc.) should be required to attend comprehensive training to learn how to work with children who have an FASD.
4. Provide a life coach, paraeducator, mentor, or case manager to advocate for the student throughout the school day.
5. Ensure that a person who is well versed in educational teaching and behavior options who work with students with FASD, is available to model and assist teachers throughout the school day.
6. Planning should revolve around the child and use person-centered planning as part of a comprehensive wraparound approach.
7. Children should be helped to become comfortable with their cognitive differences and trained to become self-advocates.
8. Transitional planning should begin when the child is 14 and focus on how to work interdependently with their support system as well as developing employment skills and examining career choices.
9. Advocate to have FASD added to the list of disabilities that qualify a child for special education and to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).
10. Provide comprehensive relationship and sex education throughout the lifetimes of each individual with an FASD.

Housing

Supervised, safe, affordable, and life-long housing is one of the most important needs facing most everyone who has an FASD. Evidence suggests that 80% of adults with an FASD, regardless of their IQ, cannot function in the absence of supports well enough to live on their own or maintain employment. (Streissguth, Bar et al. *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FA E)*; Centers for Disease Control and Prevention Grant no. R04/CCR008515)

Supervised, safe, affordable, and life-long housing is one of the most important needs facing most everyone who has an FASD.

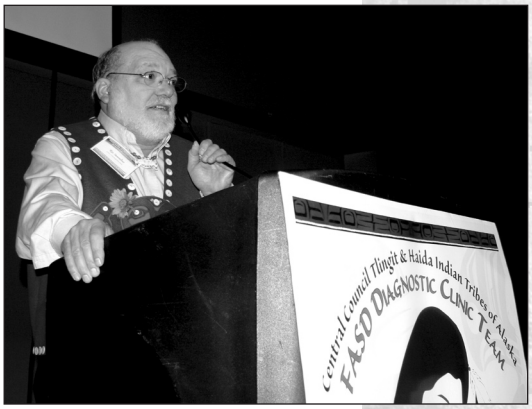
The 7S model of housing should be considered the primary key to broad risk management for adults with an FASD. The 7S model emphasizes housing that is: Safe, Stable, Secure, Supported, Structured, Supervised, and Subsidized.

Juneau does not have a supportive housing program that specifically serves individuals with an FASD. While models exist for various populations (e.g. those with a developmental disability) they do not address

the multiple and unique services needed to support individuals with an FASD. In addition, individuals with an FASD often have IQs that are too high to be eligible for developmental disability programs where an IQ below 70 is required. Too often, people with FASD fall through the cracks.

Recommendation:

A pilot housing project, designed to meet the needs of those individuals and families where an individual has an FASD is a critical need. The idea of developing a pilot interagency FASD housing program should be explored. The structure for supportive housing may be able to be offered through independent, scattered site rentals with in-home supports for persons who do not need constant supervision. It could also be offered among existing supportive housing programs or group homes which may be able to incorporate appropriate cross-discipline services for those who need high levels of support.



Ric Iannolino, coordinator for the Juneau Diagnostic Clinic addresses the conference.

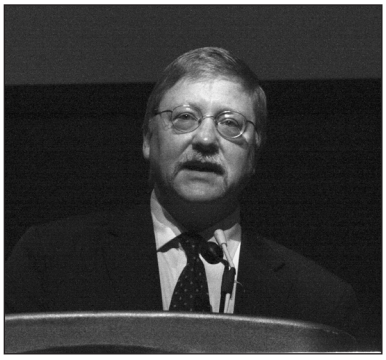
Many agencies already have service delivery systems in place that could be very effective in offering supportive housing (i.e. case management, medication management, peer support, etc.). The important issue is determining how these services and programs can be funded, modified, paired together, and administered with trained staff to successfully provide supportive housing for an individual with an FASD. The endeavor required to develop a supportive housing program for those with an FASD can capitalize on the expertise already available through agencies such as REACH, SAIL, JAMHI, Juneau Youth Services, and Polaris House.

Next steps:

1. Provide ongoing training opportunities to service providers regarding FASDs, their effects on youth and adults, and appropriate interventions.
2. Ensure that transition plans are in place prior to youth aging out of school.
3. Build an FASD coalition, working together with providers of services and other coalitions, such as Juneau Homeless Coalition, to seek solutions to the issue.
4. Bring together existing supportive housing and service providers to explore partnerships.
5. Review/tour successful models operating with this same mission (i.e. the White Crow housing program and the PEERS FASD Collaborative Family Care Homes Project, both in Canada).
6. Work with providers to examine the feasibility of a collaborative pilot project, and the necessary funding streams required.
7. Ensure that the services provided are person-centered (including a person-centered plan) to meet each person's specific needed level of support.
8. Create long-term solutions since the need for support is lifelong, not temporary.

Alternatives to Incarceration

The current systems of care in Alaska are not designed to accommodate the special needs of people with an FASD. Many youth and adults with this "invisible" disability remain undiagnosed, which keeps them out of the care system entirely.



Vance Sanders moderates the justice panel that explores the way that the Alaska courts could better serve those with an FASD.

What services and supports are available, in most cases, ends when schooling ends. Youth and adults with an FASD have little or no support outside of their families, and many do not even have that. When a young person with an FASD reaches the age of 18, he or she is considered an adult, yet most do not meet the functioning definition of adult. At this point in their lives, without support, their chances for success are severely compromised.

The criminal justice system has become the default system of care for many people with an FASD because the behaviors resulting from the disability, such as difficulty understanding consequences, high risk-taking, and a propensity toward alcohol and substance abuse, lead the individual to criminal behaviors. Due to memory difficulties and problems learning from punishment, many people with an FASD are not capable of living up to conditions of release and so end up re-incarcerated. It is common for authorities to misinterpret the behaviors of those affected by an FASD as willful and non-compliant, when in actuality it is the nature of this brain-based disability causing the behaviors.

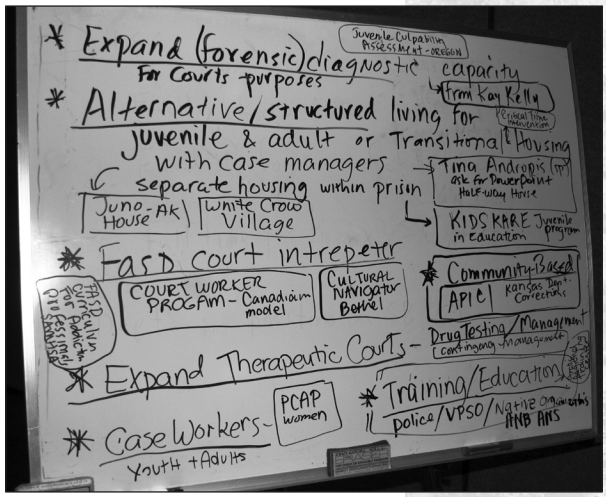
Recommendations:

1. Develop a justice system-wide approach to FASDs. Examine and recommend changes in all aspects of the youth and adult systems, trial, alternatives to incarceration, conditions of parole/probation to provide successful, evidence-based interventions and a true sense of justice for those with an FASD.
2. Expand forensic diagnostic capacity for court procedures so that those with an FASD entering the system can be identified with a better chance of being treated fairly and having access to alternatives to incarceration. Several models offer successful strategies, including Critical Time Intervention (CTI) and Juvenile Culpability Assessment as well as traveling FASD diagnostic teams.
3. Expand Therapeutic/Mental Health Courts and Tribal Courts to specifically accommodate those with an FASD and require that caseworkers receive extensive FASD training to make this alternative work. Implement contingency management and drug testing programs.
4. Utilize FASD Court Interpreters. Due to their disability, people with an FASD are often overwhelmed and confused about court proceedings and then cope by trying to say what they believe the judge or attorney wants them to say. The interpreter would consult with the defendant with an FASD and interpret the process so that the defendant can understand what is expected of him or her. Successful models include the Court Worker Program (Canada),

Cultural Navigators (Bethel), and FASD Curriculum for Addiction Professionals (SAMHSA).

Other suggestions include adapting the Court Services Officer position through the Misdemeanors Resource Project (Barrow); combine ASAP (Alcohol Safety Action Program) and Court Interpreter positions; change ASAP to SBIRT (Screening, Brief Intervention, Recovery and Treatment); research Agape/ Kitsap and PCAP models.

5. Expand FASD Training for justice workers: first-responders, law enforcement, judges, attorneys, caseworkers, and correctional and probation officers. Use curriculum already in place through the Department of Health & Social Services and Arctic FASD Regional Training Center using trainers who are members of each professional group. Create regulations that would require police officers to have cognitive diversity training as a requirement for graduation.
6. Expand case management. Investigate successful models, such as PCAP (Parent-Child Assistance Program for at-risk moms, child-bearing age, 19 years of outcomes) from Washington State, Bridge Home Project, and APIC (Assess, Plan, Identify and Coordinate).



The brainstorming notes from a group of presenters and attendees looking for improvements in the justice system.

Employment

Individuals with an FASD face multiple challenges and barriers when it comes to employment. These challenges derive from both the primary and secondary effects of FASDs. Too often, due to a lack of understanding and training, vocational rehabilitation counselors, job coaches, and employers set up inappropriate expectations for those living with this invisible disability.

A 1996 study of adults with an FASD conducted by the University of Washington found that:

- 50 percent had trouble finding a job.
- 60 percent had trouble keeping a job.
- 18 percent achieved independent living, but most had employment problems.
- About 80 percent had trouble managing money and making decisions.

Streissguth, A., and Kanter, J., eds. 1997. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle: University of Washington Press.

The problem stems from the fact that most of the systems that a teen or adult with an FASD encounters are setup to have the individual learn required skills and then leave the system. The goal for most people diagnosed with an FASD should not be independent employment and living. Instead, it should be interdependent supportive employment and living. When someone with an FASD is succeeding with support and then that external scaffolding is removed, they will likely fail.

Appropriate training can help many people with an FASD find jobs. However, the key to successful employment for individuals with an FASD is an employer who understands FASDs, has reasonable expectations, and provides a supportive environment.

Recommendations:

1. Job training for people with an FASD should begin during high school, with the student's IEP team helping to plan the transition from school to work. Life skills through pre-employment vocational skills programs should be emphasized. Person-centered planning should be used so that the student's desires for her/his future are included.
2. All vocational rehabilitation counselors and job coaches working with those with an FASD need to receive extensive training in FASDs. Models for interacting with an individual with an FASD and an understanding of appropriate expectations need to be central to this training. Appreciation of the role of external supports (e.g. parents that act as an "external brain") and the necessity of those supports being involved in the process (e.g. attending all meetings) should also be emphasized.
3. The business community needs to be educated about FASDs in general, and how to best provide successful employment to individuals with an FASD. This would include the use of specific strategies (e.g. providing mentors, using teams, giving reminders, being available to answer questions, etc.).
4. Current successful employment programs for those with an FASD should be explored. An example of such a program is the Focus Program in British Columbia, Canada, which uses an education and advocacy approach while providing employment and skills training specifically for adults with an FASD. Students and faculty design individual education plans for mathematics and English upgrading, vocational skills training, and personal skill development. Assistance and advocacy work is provided for daily living, the justice system, employment, and social systems that are critical components for student success.
5. Work with the University of Alaska's disabilities counselors and administrators to ensure that they understand the effects of FASDs and that appropriate accommodations be made so that those individuals capable of participating in college level studies have the opportunity to do so. Students may be able to pass the courses for a major they are interested in but may not be accepted since they are unable to pass a general requirement course (e.g. math). Alternatives should be available so that someone can waive a general course that is not necessary for succeeding in the major. Also, students with an FASD should be provided with tutors before any difficulties appear.

Matt Rorem describes his challenges living with an FASD and the challenges of raising his daughter, who also has an FASD.

Finding Our Voices

In *Journey Through the Healing Circle*, presented by Carolyn Hartness she uses a quote from her collaborator Fred Red Crow Westerman, *"We have gathered here with Grandfather, our Creator, the ones who fly, the ones who crawl, the ones who swim, the ones who walk on four legs, and those beautiful spirits...those who have Fetal Alcohol Syndrome and Fetal Alcohol-Related Conditions...who have come to earth as volunteers to teach us what we need to know to heal in our communities".*

The best conference summary came from a young mother who stood in front of the auditorium at the close of the three day conference and explained that her young adopted son had just been diagnosed with FASD. Through tears she told how this conference had given her understanding, skills, support, and hope. She said, "This conference has changed my life and will change the life of my son. When you see my son 25 years from now and see a man whom is succeeding you will know you helped make that possible." The hope is that we will meet that boy in 25 years and say, "Yes, we have supported, cared and nurtured." If so, as Fred Red Crow Westerman stated, we will have learned "….what we need to know to heal in our communities."

Morgan Fawcett relies on his flute playing to help bring calmness and order to his life affected by an FASD.

The healing continued throughout the conference…

"After meeting other teens and adults with an FASD my daughter said to me, 'Mom I'm not embarrassed anymore about having FASD.' " *Parent of an 18-year-old.*

"Hey, I fooled you all. Just because I am pretty good at talking you don't realize that I have FASD. How hard it is for me to remember --- I have severe short-term memory loss. My ability to follow directions and make decisions is very hard for me. When I get instructions I can recall only the last thing said to me… all the rest is lost. If it wasn't for my grandma being my external brain I would be in constant trouble. Another thing that helps me is my flute – it calms my brain. When I'm under stress, like now when I'm speaking in public, I have to play my flute – it calms me and I can better sort out my thoughts --- therefore, my flute is always close by, as is my grandmother." *Morgan Fawcett – Native American flute player and public advocate for understanding FASD.*

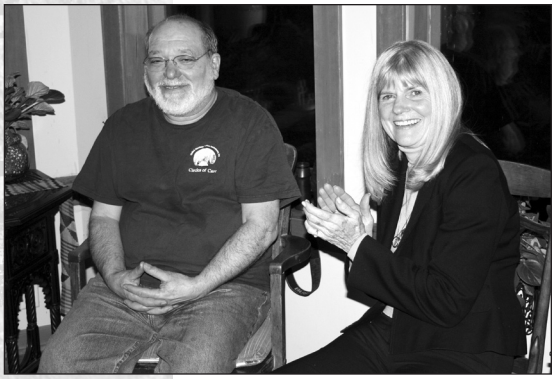
"There's so much to learn -- it's overwhelming. The most help to me was a greater understanding to help me deal and fight for what my son needs. Knowing that I'm **not** alone. There are many people learning to advocate for my son's needs." *Mother of child with FASD.*

Mary Katasse address the conference thanking all for giving hope to her and her son, recently diagnosed with an FASD.

"I discovered that I have FASD too --- I will be better able to meet my FASD clients where they are." *Substance abuse counselor*

"It helped me deal with publically speaking about my own FAS and in learning better ways to deal with my own daughters FASD. My greatest joy was being able to share my story of dealing with my disorder with others." *Adult with FASD and father of daughter with FASD.*

"I wanted to learn more. Connect with others who have FASD. Inspire those with FASD to value the gifts we have." *Clergy with FASD.*



Ric Iannolino and Kathryn "Kay" Kelly enjoy the music after the close of the conference.

"They said I knew it yesterday.
Why don't I know it now?
Yesterday they smiled at me.
Today they don't know how.
Everything is going fine when I do what I should.
Today I don't know what they want.
I'd do it if I could."
Jenny Jackson Mother and author of "Silent No More – A Poetic Voice Breaks The Silence Of FASD."

"This FASD conference has proven to be a 'miracle' for our family! For most of his life I have always known that Matt had a special gift speaking eloquently in public, if only we could get him to discover this gift. We spent most of the past year trying to convince him that he needed to share his story about being a father with FASD raising a child with FASD at the upcoming conference…he came to the conference with great apprehension. His first workshop was the healing circle with Carolyn. He became agitated as I spoke about the difficult process of getting SSI for him. But about 10 minutes later he opened up and spoke about being a dad with FASD with a child with FASD! He spoke beautifully! From then on, his self confidence began to grow. He became like a sponge, absorbing all he could about his disability. He talked to judges who had sentenced him many times, giving them advice about how to help people with an FASD, and they listened. He eagerly attended the remainder of the conference, and with each passing moment, he began to feel the compassion and love of all the people there – including the judges! He felt safe and accepted. The entire experience was so helpful and affirming for him, that he freely shared his story with the entire assembly on the Family Voices Panel. He found his voice and discovered that he truly had the gift to speak eloquently by telling his story! And everyone else who listened to him was awed by the 'gentle giant' and the powerful story of his journey with FASD! Matt's life has been one of constant rejection and ridicule in public settings and private settings outside his home. For the first time he experienced compassion, acceptance, love, safety and all things positive outside the home…" *Laura Rorem*

References:

There is a great deal of knowledge and information available on FASD. We have listed several resources that we feel are a good place to start.

Trying Differently Rather Than Harder by Diane Malbin, MSW
This is a short book (80 pages) that gives concise information about the effects of alcohol on the fetus and how best to help children who have an FASD. Available through http://www.fascets.org/

Fetal Alcohol Spectrum Disorders Center for Excellence
http://www.fascenter.samhsa.gov/

State of Alaska FASD Resources page
http://www.hss.state.ak.us/fas/Resources/default.htm

FAS Alaska - http://www.fasalaska.com/links.html

Attendees were urged to become members in the regional FASD coalition.

Presenters and Speakers:

Rosa Miller, Amalia Monreal, Jenny Jackson, Morgan Fawcett, Deb Evensen, Dr. Sterling Clarren, Carolyn Hartness, Shannon Cross, Barbara Knapp, Dr. Corrie Whitmore, Gil Lucero, Sally Caldwell, Nick Paulie, , Barbara Day-Max, Charlene Lena Takeuchi, Kee Warner, Ken Kissinger, Dr. George Brown, Thea Jefferies, Gail Tharpe-Lucereo, Genevie Casey, Vance Sanders, Honorable Michael Jeffery, Honorable Patricia Collins, Honorable Philip Pallenburg, Tom Wagnor, Karl Gallow, Ed Mercer, Mariya Lovishchuk, Kathryn "Kay" Kelly, Michael Baldwin, the Juneau FASD Diagnostic Team, Sandy Fiscus, Sue Hempel, Margaret Vrolyk, Ben Didrickson, Joe Zuboff, Father Thomas Weise, Teri Tibbett, Doloresa Cadiente, Rebecca Busch, Cheri Scott, Annie Geselle, and Scott Ciamber.

Conference Supporters and Planners

Northern Light United Church, Central Council of Tlingit and Haida Indian Tribes of Alaska, The Alaska Mental Health Trust Authority, Alaska Department of Health and Social Services—Divisions of Behavioral Health and Office of Children Services, Alaska Department of Education—Education and Early Development, Advisory Board on Alcoholism and Drug Abuse, Alaska Mental Health Board, Arctic FASD Regional Training Center, Juneau Youth Services, Gastineau Human Services, Cathedral of the Nativity, Juneau Catholic Diocese, Glory Hole, Resurrection Lutheran Church, Catholic Community Services, Southeast Alaska Regional Health Consortium (SEARHC), Juneau Unitarian Univeralist Fellowship, Driftwood Lodge, Jim Becker, Randy Hurtte, AXA Foundation, Rev. Larry and Rev. Laura Rorem, K.J. and Peggy Metcalf, Don and Marion Gotschall, Buel and Nancy Hixon, Sandi Fiscus, Valley Lumber Company, Dr. Susan Hunter Joerns, Robbie Izzard, Sherri Wes, Lisa and Patrick Pennoyer, Jeri Museth, Geri Mata, Jodi Garrison, Ric Iannolino, Gus Marx, Genevieve Casey, Teri Tibbett, and Deb Evensen. Many of the above people were involved for two years to plan this conference.

Southeast Alaska FASD Coalition
To learn more or become a member, email fasd@unitedwayseak.org

Alaska FASD Partnership
To learn more or become a member email akfasdpartnership@alaska.gov or call 907-465-8920 888-464-8920

Printing cost covered by Advisory Board on Alcoholism and Drug Abuse and Alaska Mental Health Board.

"we have gathered here with Grandfather, our Creator, the ones who fly, the ones who crawl, the ones who swim, the ones who walk on four legs, and those beautiful spirits...those who have Fetal Alcohol Syndrome and Fetal Alcohol-Related Conditions...who have come to earth as volunteers to teach us what we need to know to heal in our communities".

Rosa Miller, accompanied by Amalia Monreal opens the conference with a traditional Auk Tlingit welcome, which helps set the healing tone for the conference.