

***Effective Practice & Clinical Strategies across the
Continuum of Child Welfare Services for
Addressing the Needs of Children with Fetal
Alcohol Spectrum Disorders & Other Conditions
Related to Prenatal Substance Exposure***

August 2nd, 2016

CWLA National Conference

Hyatt Regency, Orange County, California

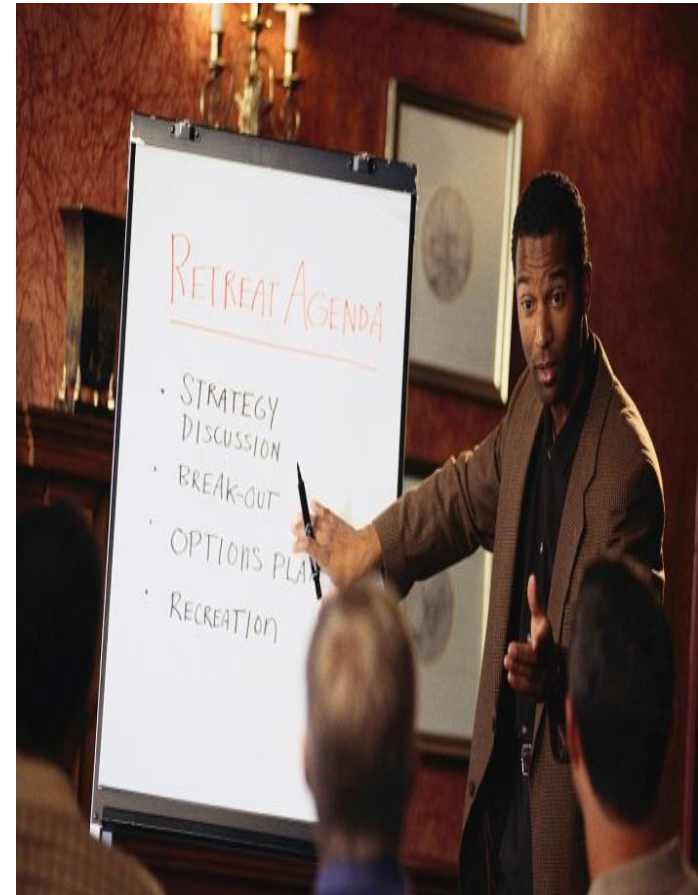




9/30/2016

PART A

8:30 – 10:00



PART A

- ✓ Opening/Welcome/Setting the Stage
 - Julie Collins, Director of Standards for Practice Excellence, CWLA
- ✓ Panel - National and State Perspective
 - Speakers: Eileen Elias, Senior Policy Advisor and Director, JBS International, Inc., Disability Services Center. She is the Chair of CWLA's Mental Health Advisory Board (MHAB) and Shannon Cross-Azbill LCSW, Clinical Director, Alaska Division of Juvenile Justice, Anchorage, Alaska
- ✓ Q and A

PART A

- ✓ Panel – New Federal Collaboration
 - Speakers: Jacquelyn Bertrand, Ph.D., Senior Scientist, Centers for Disease Control and Prevention and Sharon Newburg-Rinn, Ph.D., Social Science Research Analyst, Data Team, Children's Bureau
- ✓ Q and A



PART B

10:30 – 12:00

PART B


- ✓ Panel – Effective Practices & Clinical Strategies
 - Speakers: Douglas Waite, MD, is Assistant Professor of Pediatrics at Mount Sinai Hospital and Medical Director for the Keith Haring Clinic at Children's Village in Dobbs Ferry, New York. Dr. Waite is also a member of the CWLA Mental Health Advisory Board; Gwendolyn J. Messer, MD, FAAP, Medical Director, Children's Research Triangle, Chicago, IL; and Dan Dubovsky MSW, FASD Specialist, former SAMHSA FASD Center for Excellence
- ✓ Q and A
- ✓ Closing and Next Steps

FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

Overview of FASD and Co-Occurring Psychiatric Disorders

Eileen Elias, MED

**Director, JBS International Disability Services Center
CWLA Mental Health Advisory Board Chairperson**

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Overview

- This Supersession highlights the lack of evidence-based studies and the pressing need for specialized interventions that address the diagnostic and treatment challenges faced by children with psychiatric disorders within the FASD population.
- My presentation is supported by the JBS published white paper: *Improving Awareness and Treatment of Children with Fetal Alcohol Spectrum Disorders and Co-Occurring Psychiatric Disorders*
(<http://www.jbsinternational.com/site/Pages/services-disabilities.aspx>)
 - The paper was funded by the Centers for Medicare and Medicaid Services (CMS) Community Alternatives to Psychiatric Residential Treatment Facilities Grant.

WHAT DOES CO-OCCURRING DISORDER MEAN?

- The term *co-occurring disorder* describes the presence of a psychiatric disorder and a disorder such as FASD that is related to substance use.
- Co-occurring disorders can also include the presence of a developmental disability, a co-occurring emotional/psychiatric disorder, and FASD.
- Robust studies of evidence-based interventions for populations with co-occurring disorders are lacking.

FASD HISTORY

- FASD emerged as a description of a continuum of disorders associated with fetal alcohol syndrome (FAS) in the last 20 years; FAS itself was identified in the 1970s.
- FAS was originally thought to be associated with distinctive facial features and cognitive deficits. It is now understood that FAS can be present in those with average intelligence and no physical markers, which complicates the diagnosis due to the absence of symptoms.
- FASD comprises various disorders that require a multidisciplinary team to properly diagnose it.

FASD HISTORY

- FASD is not included in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as a full diagnostic category but is listed as a disorder that requires further study (American Psychiatric Association [APA], 2012); this is a step on the way to full inclusion as an identified diagnostic disorder.

PREVALENCE OF FASD

- It is estimated that 1 in 100 babies in the United States is born with a neurodevelopmental disorder as a result of prenatal exposure to alcohol (PAE) (May & Gossage, 2001).
- FASD is frequently cited as the most common preventable birth defect.
- The presence of FASD predisposes children to a variety of co-occurring psychiatric disorders (i.e., a psychiatric disorder that co-occurs with a disorder such as FASD that is related to substance use).

EXPERIENCE OF CHILDREN WITH FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS

- Children who receive an FASD diagnosis face various developmental, behavioral, and educational challenges.
- Because FASD is a birth defect that primarily affects the brain, early identification of FASD is critical to ensuring that the child's needs are addressed throughout his or her lifespan.
- Children affected by FASD may be defiant, aggressive, or out of control.
- These symptoms can, in part, be attributable to central nervous system (CNS) damage brought on by prenatal exposure to alcohol (PAE).
- Children who are affected by CNS damage due to PAE may experience maladaptive behaviors that lead to referrals for diagnostic evaluation and possibly a mental health diagnosis by behavioral health staff.

FASD CHALLENGES

- A challenging aspect of FASD is the psychiatric disorders that often accompany it. Mood disorders, major depression, psychosis, and personality or conduct disorders can co-occur with FASD.
- The fact that FASD can co-occur with psychiatric disorders is often why FASD is underdiagnosed in children receiving treatment in Psychiatric Residential Treatment Facilities (PRTFs) and other institutions.
- In 2005, Congress funded state-based demonstration projects to determine whether children with serious emotional disorders who would normally be served in a PRTF could be treated successfully in a community-based setting. Nine states (Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia) were funded to provide community alternatives to inpatient treatment in PRTFs.

FASD CHALLENGES

- Mindful of the cognitive deficits experienced by children with FASD, the Alaska demonstration focused on modeling new behaviors that ameliorate symptoms of serious emotional/psychiatric disorders and ease transitions into employment and independent living.
- By pairing each child with a mentor and bringing all the providers and social service agencies involved in the child's care together for training and education, the Alaska demonstration maintained these children in the community, even though they met criteria for inpatient hospitalization.
- By highlighting Alaska's successful demonstration, this Webinar makes the case for developing interventions for children with FASD and co-occurring psychiatric disorders, while documenting the lack of treatment-based evidence-based practices, especially when an individual is hospitalized in a psychiatric facility.

DIAGNOSIS OF FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS

- Against the difficulty of diagnosing FASD and the under-recognition of psychiatric disorders in children with FASD is the very real knowledge that early diagnosis of FASD is a main protective factor, leading to twofold to fourfold decreases in adverse life outcomes (e.g., trouble with the law, confinement in jail or for treatment, repeated inappropriate sexual behavior, substance abuse) (Streissguth et al., 2004).

DIAGNOSIS OF FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS

- Early diagnosis must be followed by interventions that target the emotional/mental, behavioral, and educational needs of children with FASD and co-occurring psychiatric disorders.
- Because psychiatric disorders often accompany FASD in children, understanding the roles of trauma and protective factors can be integral to preventing and intervening in FASD and the psychiatric disorders with which it occurs.
- An early diagnosis of FASD and co-occurring disorders can have the potential to break the cycle of trauma and substance abuse that, if undiagnosed, can appear across generations.

DIAGNOSIS OF FASD AND CO-OCCURRING PSYCHIATRIC DISORDERS

- According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA), FASD is chronically underdiagnosed because “distinguishing FASD from other developmental disorders is tricky, and evolving diagnostic standards are not yet accepted by everyone” (NIAAA, 2011).
- What has been suggested in the literature is that an individual with FASD and a co-occurring disorder is not diagnosed with FASD, but rather he or she may receive a diagnosis of multiple mental illnesses as the primary diagnosis.
- Bertrand (2009) compiled five behavioral interventions that show promise, and APA, in its draft language for DSM-5 (APA, 2012), surveys behavioral therapies and pharmacotherapies. The provisional inclusion of FASD in DSM-5 (in its Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure section) is driving more research and heightenng the FASD profile.

THERAPIES

- The behavioral deficiencies that appear in patients affected by FASD may be addressed, but their neurocognitive deficiencies caused by PAE may be ignored. If neurocognitive effects are ignored, then traditional pharmacological therapies will be ineffective and, thus, inappropriate for the individual.
- Such inappropriate treatments may increase risk of unnecessary psychiatric and medical hospitalizations and other adverse events.
- To obtain an accurate FASD diagnosis, a multidisciplinary team that consists of clinicians who understand the child's behavioral, psychological, and social needs should determine appropriate interventions that can be tailored to the child and family (NOFAS, 2006).
 - The Alaska demonstration showed that this strategy was effective in helping children with FASD seek treatment and stay in their home environment.

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Questions

Contact Information

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REFERENCES


- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders* (DSM-5). Arlington, VA: Author, 2012. Retrieved from <http://www.dsm5.org/proposedrevision/pages/proposedrevision.aspx?rid=574>
- Bertrand, J. Interventions for children with FASD: Overview of findings from five innovative research projects. *Research in Developmental Disabilities*, 30(5): 986–1006, September 2009.
- Disney, E.R., Iacono, W., McGue, M., Tully, E., & Legrand, L. Strengthening the case: Prenatal alcohol exposure is associated with increased risk for conduct disorder. *Pediatrics*, 122(6): e1225–e1230, December 2008.

REFERENCES

- May, P.A., & Gossage, J.P. Estimating the prevalence of FASD: A summary. *Alcohol Research & Health*, 25: 159–167, 2001.
- National Institute on Alcohol Abuse and Alcoholism. NIAAA advances research on fetal alcohol spectrum disorders. *NIAAA Spectrum*, 3(3), September 2011. Retrieved from <http://www.spectrum.niaaa.nih.gov/archives/v3i3Sept2011/features/fasd.html>
- National Organization on Fetal Alcohol Syndrome. *FASD Interventions*. Washington, DC: Author, 2006. Retrieved from <http://www.nofas.org/wp-content/uploads/2012/05/intervention.pdf>

REFERENCES

- Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., & Young, J.K., Risk factors for adverse life outcomes in FAS and FAE. *Journal of Developmental and Behavioral Pediatrics*, 25(4): 228–238, 2004.
- Substance Abuse and Mental Health Services Administration. *Fetal alcohol spectrum disorders: Tips for elementary school teachers*. Rockville, MD: Author, 2004. Retrieved from <http://fasdcenter.samhsa.gov/documents/WYNKTeachersTips2.pdf>



Understanding and Addressing the Mental Health Needs of Children in Child Welfare with Fetal Alcohol Spectrum Disorder

Shannon Cross-Azbill, LCSW

Division of Juvenile Justice

State of Alaska

Alaska FASD Diagnostic

Teams



- Total cost to go through the Diagnostic Clinic is \$5000 per individual. \$2000 is billable through Medicaid. \$3000 of the costs are an Advocacy from the State in order to help sustain the Diagnostic Clinics. Alaska has been able to keep this in the State Budget despite the budget deficits Alaska is experiencing.

- Six Active Diagnostic Clinics

Nome's team is assembled and are waiting on their provider agreement with the state.

- FY 2016:
- 110 have gone through FASD Diagnostic Clinics
- Average age between 7-10 years old




Alaska's Medicaid Waiver Demonstration Project (2007-2012)

- Targeted group:
 - **Birth up to 21 year olds** placed in or at risk of placement in Residential Psychiatric Treatment Centers (RPTCs) with:
 - ***A diagnosed or suspected Fetal Alcohol Spectrum Disorder (FASD)***
- 3-M model: Modeling, Mentoring, Monitoring



Alaska Medicaid Waiver Demonstration (2007- 2012)

- **Service delivery components:**
 - Plan of Care Coordinator
 - *Interdisciplinary team coordinator for RPTC transition plan and integrated plan of care*
 - *Supervision of Mentor and plan implementation*
 - Training and Consultative Services
 - Respite Care
 - Modeling to youth:
 - *Social skill acquisition*
 - *Independent Living skills*
 - Modeling to family and other caregivers and providers
 - *Effective interventions with youth and providers*
 - *Behavioral supports*
 - Mentoring to success
 - *Independent choices*
 - *Building relationships*
 - Daily oversight/monitoring of service plan



Alaska Medicaid Waiver Services Offered (2007- 2012)

– Treatment and Intervention Mentors (TIM)

- Direct service personnel, with whom the youth and family was comfortable, provided intensive skill development by role modeling positive behavior
- Connected youth to other positive role models
- Built early intervention into the plan by monitoring for development of new issues and behaviors so they could be addressed immediately
- Provided advice, counsel, guidance, and one-to-one encouragement
- A form of teaching that included walking alongside the person and inviting him or her to learn from your example
- Participated in activities **with** the person rather than connecting the person with activities and then gave the person the responsibility to follow through

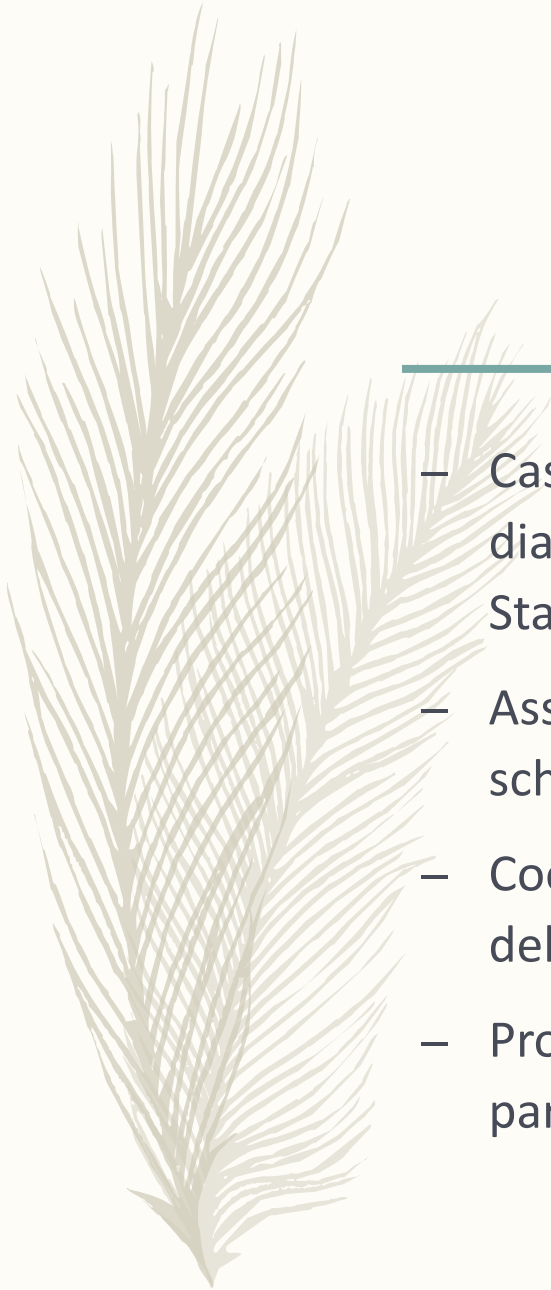


Current Services Offered: Complex Behavior Collaborative (CBC)

- The CBC helps providers meet the needs of clients on Medicaid with complex needs who are often aggressive, assaultive and have difficulties being supported in the community.
- Clients typically have cognitive impairment with complex behavior management and also has one or more complicating issues which can include chronic mental illness and FASDs.
- Available treatment has been exhausted without success for the individual
- Goal is to help clients live as independent as possible in the community
- Offers consultation and training to providers and clients' natural supports, including family members
- Consultation is onsite, which has included going to rural areas to train providers and families to better work with and support the client

Case Management

- Case Management Services to individuals previously diagnosed with an FASD by a FASD team supported by a State Provider Agreement
- Assists with following through with referrals, maintaining schedules, and coordinating services
- Coordinate assessments, treatment planning and service delivery
- Provide advocacy and support to the parents and foster parents of a child with an FASD





Individualized Service Agreements (ISA)

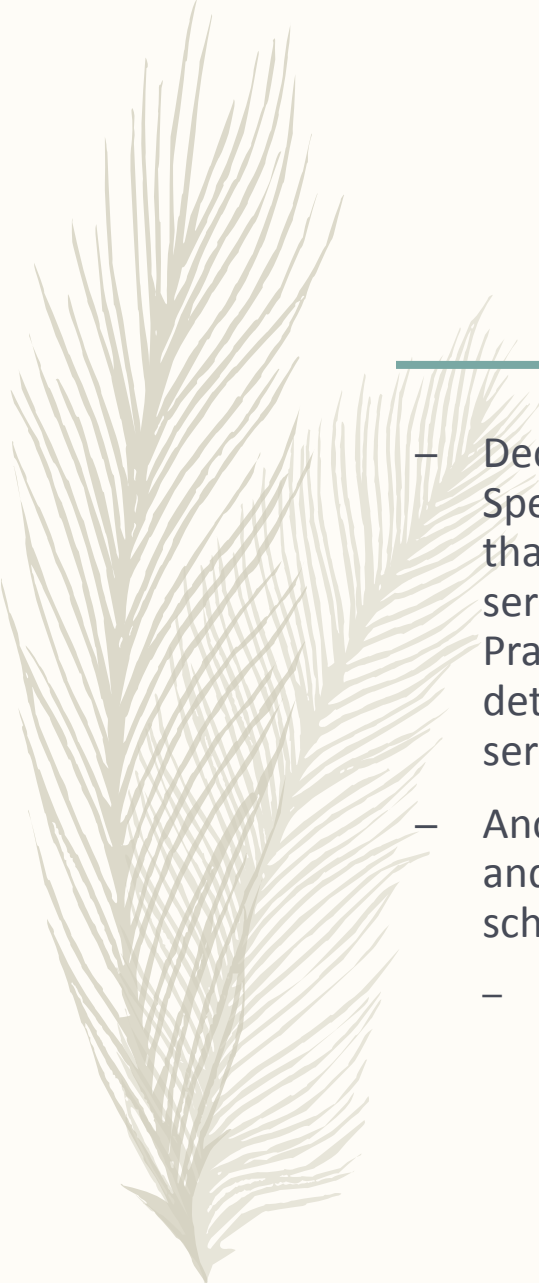
- ISAs are flexible funds for eligible youth who are either non-resourced, or can be utilized to pay for services that insurances will not reimburse.
- Department of Health and Social Services was allotted 1.8 million dollars for FY11. Funding has continued to be available
- Office of Children's Services and Division of Juvenile Justice also have ISA funds they utilize
- Client Eligibility
 - A resident of the state
 - Under 21 years of age
 - Been assessed by a MH professional and meets criteria for SED
 - Is at imminent risk of being removed from the home
 - Been assessed to meet residential level of care
 - Has been approved by DHSS for services



Teen Friendship and Dating Program (TFDP)

- A new program designed by the UAA Center for Human Development to teach adolescents with Fetal Alcohol Spectrum Disorder and/or Autism Spectrum Disorder how to develop and maintain healthy relationships and prevent interpersonal violence.
- TFDP sessions are held twice a week over a 10-week period in groups of 6-8 co-ed participants. Each session is approximately 1.5 hours for a total of 30 hours over 20 sessions. Session topics include: feelings, types of relationships, personal boundaries, communication, meeting people and first impressions, planning social activities, the dating process, personal safety, sexual health, and gender differences. Caregiver is provided feedback after each session.

Alaska Schools

- 
- December 2015, Alaska adopted regulations to include FASDs for Special Education, adding FASDs to the list of health impairments that may render a student eligible for special education and related services as with Other Health Impairments. Allows Advanced Nurse Practitioners (ANP) to diagnose FASD and other health impairments to determine student eligibility for special education and related services
 - Anchorage and Soldotna/Kenai School Districts have trained teachers and Administration on FASDs, implementing lead teachers within the schools
 - Provide 5 Parent Support Groups with more birth parents are now attending
 - *Parenting groups are helping parents reach out more readily for diagnosis*



Other Available Services

- Stone Soup Group (SSG) offers support to families of children affected by prenatal alcohol exposure. They offer specialized parent navigation, classes and trainings.
- Alaska Youth & Family Network is staffed mainly by fellow parents (may be birth, foster, grandparents , adoptive parents or caring adult) of children with mental health issues, substance abuse, autism or FASDs.
 - Parent Navigators help support and educate parents as well as help them navigate the system
- FAScinating Family Camps (two camps a year are offered with some scholarships to assist with family travel)



Alaska FASD Partnership

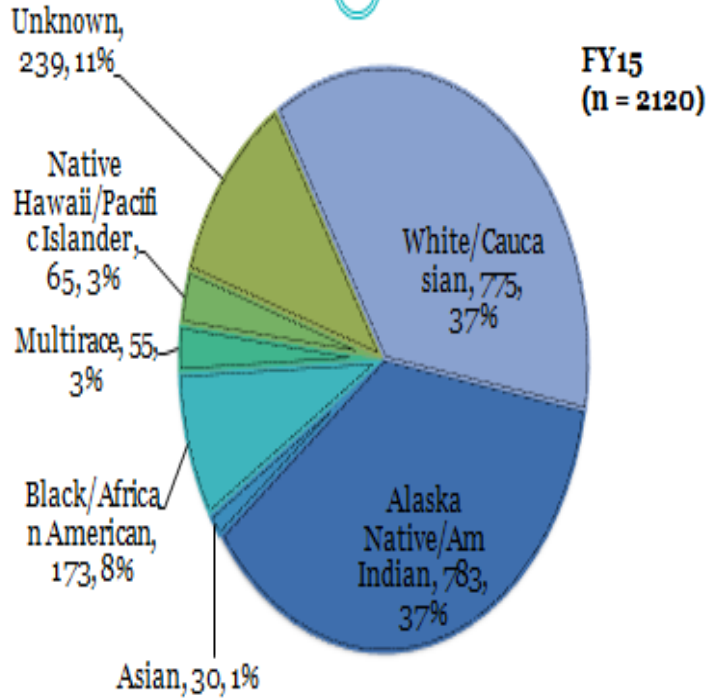
- The mission of the Alaska FASD Partnership is to promote awareness, prevention, and effective life-long interventions for those affected by prenatal exposure to alcohol and their families.
- The Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership is a coalition of over 110 individuals and organizations committed to addressing issues related to FASD in Alaska.
- The Partnership is guided by a steering committee of individuals, organizations, and state 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.

A large, light green feather graphic is positioned on the left side of the slide, extending from the top to the bottom. It has a central rachis with many fine barbs radiating outwards, creating a soft, textured appearance.

Trainings Offered Throughout the State

- FASD 101
- FASD 201
- Into Action: Brain Based Approach to FASD & Other Neurobehavioral Disorders
- CDC's FASD Core Competencies
- ACE Interface: Building Resilient Communities
- Trauma Informed Care 101
- Shelter from the Storm: Trauma Informed Care
- What Fills Your Teapot?: Secondary Trauma and Self-Care
- Youth Mental Health First Aid
- Alaska QPR Gatekeeper Suicide Prevention

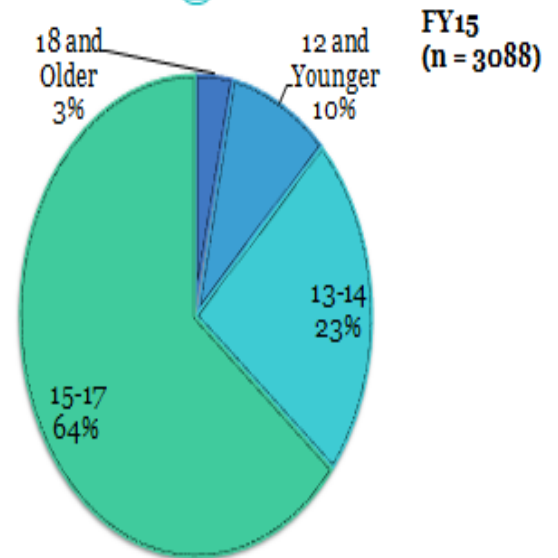
DJJ Referrals by Race



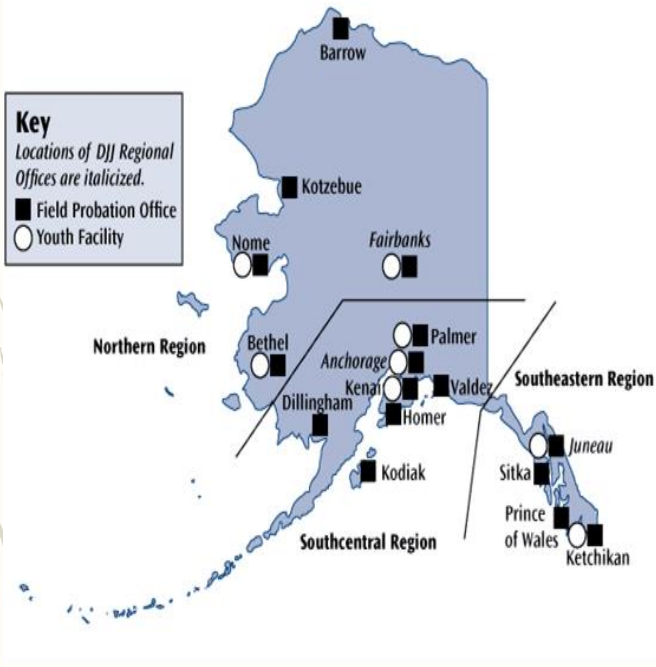
Division of Juvenile

State of

DJJ Referrals by Age

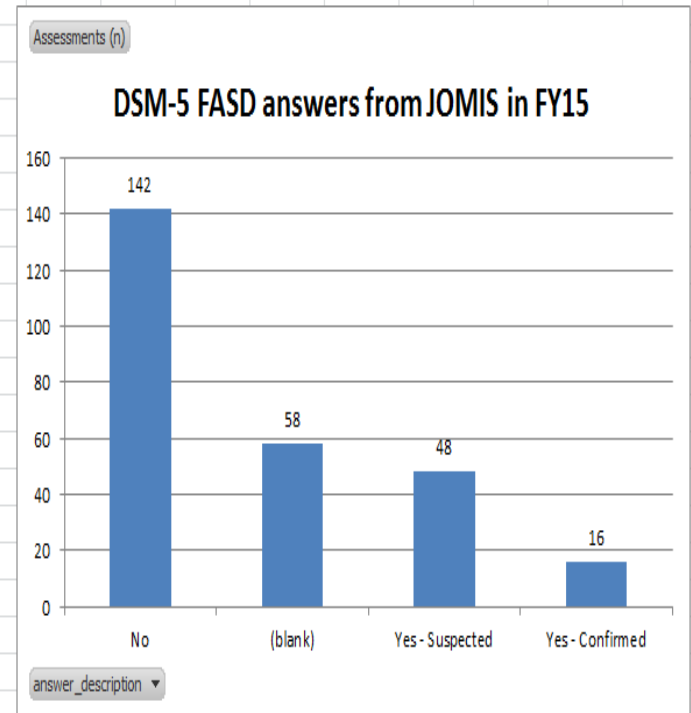


DJJ Statewide Map of Office and Facility Locations



Division of Juvenile Justice, State of Alaska

FASD answer	Assessments (n)
No	142
(blank)	58
Yes - Suspected	48
Yes - Confirmed	16
Grand Total	264



Division of Juvenile Justice: Efforts to Better Treat Those with Mental Health Issues and FASDs

Medication-Induced Movement Disorders and Other Adverse Effects of Medication - indicate diagnoses in narrative

Other Conditions That May Be a Focus of Clinical Attention - indicate diagnoses in narrative

4 Was there prenatal alcohol exposure?

5 Treatment accommodations/modifications needed for (if IQ known, please note in narrative):
 Cognitive/processing impairments
 Prenatal alcohol and/or drug exposure
 TBI

6 Identified treatment target needs
 Aggression reduction
 Community/social support
 Domestic violence tx
 Distorted cognitions
 Education (higher education)

ALASKA DJJ JOMIS TEST

S. Cross-Azbill ACTIVITIES SEARCH HELP

Assessment Panel

Jomis, Jimmy Q DOB 10/1/1998 ID 51279

Assessment Assessment Date Staff

24 Was there prenatal alcohol exposure?

25 Treatment accommodations/modifications needed for (if IQ known, please note in narrative):
 Cognitive/processing impairments
 Prenatal alcohol and/or drug exposure
 TBI

26 Identified treatment target needs
 Aggression reduction
 Community/social support
 Domestic violence tx
 Distorted cognitions
 Education (higher education)
 Education (IEP)
 Emotional/self-regulation skills
 Family interventions
 Fire starting behavior ed/tx
 Gang prevention/intervention/ed
 Health related education/support

Division of Juvenile Justice: Efforts to Better Treat Those with Mental Health Issues and FASDs

ALASKA DJJ
JOMIS TEST

J.MARCHETTI Security Mode Status: OFF ADMINISTRATION ACTMTIES SEARCH HELP

Case Plan

Jomis, Jimmy Q DOB 9/1/1998 ID 51279

Date Created

Tx Admit or Prob Ordered

Date Signed

Type/Status

Strengths/Other Considerations

As identified by the YCA, Jimmy is very athletic and is also quite smart.

Due to his prenatal exposure to substances, Jimmy has some cognitive processing

Risks/Needs

1. YLS - Offenses/Dispositions - 1
2. YLS - Family / Parenting - 4
3. YLS - Education / Employment - 3
4. YLS - Peer Relations - 2

Parties to the Activity

Person Name	Relationship
Jomis, Jimmy Q	Juvenile
Ausman, Lavon C.	Mental Health Clinician
Cross-Azbill, Shannon L	Nurse

	Risks/Need	Long Term Goal	Date Completed
1	YLS - Family / Parenting - 4	Jimmy will develop coping strategies do diminish antisocial b	<input type="text"/>
2	YLS - Leisure / Recreation - 4	Identify pro-social activities that are of interest and engage in	<input type="text"/>
2	YLS - Personality / Behavior - 3	Develop empathy for others and identify the harm caused by	<input type="text"/>



Innovative Interventions: Neurofeedback

- The goal is to promote some brain frequencies and diminish other frequencies to improve or decrease certain behaviors.
- The person then plays a video game or watches a movie with their brain being in control.
The brainwave activity is “shaped” toward a more desirable, regulated performance.



Innovative Interventions: Neurofeedback

Movement, Orientation, Recognition,
Ability to understand spoken and/or
written language

**Parietal
Lobe**

**Frontal
Lobe**

**Occipital
Lobe**

Visual processing

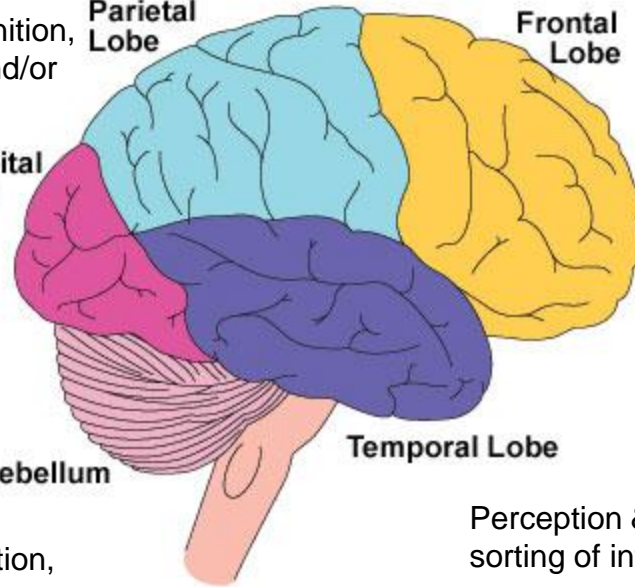
Cerebellum

Temporal Lobe

Motor coordination,
Behavior, memory

Reasoning, planning, problem
solving, organization, attention,
behaviors, emotions

Perception & recognition of auditory stimuli,
sorting of information, short term memory





Innovative Interventions: Neurofeedback

- What is Neurofeedback?
 - Biofeedback using the EEG
- • Neurofeedback is a brain-training technique (targets specific areas of the brain for different functions and different disorders)
- • We observe the brain in action
- • We feed the information back to the trainee
- • The trainee attempts to meet certain goals
- • Gradually, the brain adjusts its function
- • The brain begins to use its new-found skills
- • Once learned, the brain remembers





Fetal Alcohol Spectrum Disorders: Federal Collaboration

Presentation at the 2016 Child Welfare League of American Conference
Advancing Excellence in Practice and Policy: What Works for Families
Affected by Substance Use

August 1-3, 2016
Orange, California

*Sharon Newburg-Rinn, Ph.D., Social Sci. Research
Analyst*

Children's Bureau /Office of the Commissioner of ACYF, ACF, U.S.
Department of Health and Human Services, Washington, DC

Jacquelyn Bertrand, Ph.D., Psychologist,
National Center on Birth Defects and Developmental Disabilities,
Centers for Disease Control and Prevention (CDC),
U.S. Department of Health and Human Services,
Atlanta, Georgia



What we know

FASDs Field

- “Clinical wisdom”
- Clinic based studies
- 1.3 million children with an FASD + children with other exposures



From child welfare field

~415,000 children in care



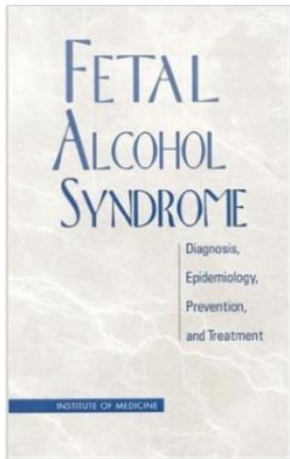
- ❖ Estimates vary by source & methodology, but up to 2/3 of families have substance use/abuse issues
- ❖ Majority of children come into the system at age 3 years or younger, so many of these children may be prenatally exposed
- ❖ Single epi study in King County WA: rate of children with FAS substantially greater than published estimate for general population
- ❖ 86% of a sample children in IL child welfare agency with an FASD were unidentified or misdiagnosed

Why is alcohol so serious for child welfare?

- Unlike other substances, prenatal alcohol exposure disrupts development of the brain, including formation of brain cells, establishment of synaptic connections and physiological brain function.
- The prenatal brain damage caused by in utero exposure to alcohol results in lifelong disabilities affecting the child, family and community.
- More than 50% of U.S. adults drink alcohol
- For most recent data available, treatment admission rates were **higher for alcohol abuse than for any of the major illicit drugs** in 42 of the 48 reporting states.

Importance of alcohol impact

“



Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”

Institute of Medicine, 1996

Likely reasons for less attention to prenatal alcohol exposure



- ✓ Alcohol is readily, legally, obtained. It is normalized in a way that other drugs are not.
- ✓ In child welfare, alcohol may often be thought of in terms of immediate safety of the child/youth. “Is the parent unable to be a good parent due to alcohol use”?
- ✓ Neonatal Abstinence Syndrome (NAS) rarely occurs with alcohol. The dramatic and disturbing images of a newborn who experiences NAS leads to emphasis on other drugs by lawmakers and the general media.

Detection is an issue in child welfare

- ✓ The majority of fetal alcohol spectrum disorders are hidden disabilities -- most children do not have apparent dysmorphic facial features; even when they do, these features are not noticeable to the untrained eye.
- ✓ Many affected children will have good **basic** language and social skills (e.g., vocabulary, syntax, interest in social contact, etc).
- ✓ Majority of individuals with an FASD do not have intellectual disability.
- ✓ At a general level, many behavioral characteristics of children with FASDs mimic those of trauma.

Why identify in child welfare system?

- Establish burden & resource needs
- Ongoing monitoring for trends
- Platform for Epi and risk factor studies
- Improve the health and developmental outcomes for this very vulnerable population of children by:
 - Providing appropriate services & facilitate successful reunifications and family outcomes
 - Avoid cycles of abuse/neglect
 - Reduce multiple placements and therapeutic placements



Don't we have this information in AFCARS and NCANDS? Umm no.

Ongoing monitoring: In theory, NCANDS (National Child Abuse & Neglect Data System) and AFCARS (Adoption & Foster Care Analysis and Reporting System) allow: Child “abused” alcohol + Child age = zero). But:

- Many state systems don't differentiate alcohol/drugs
- Policy determines data obtained/entered.
- “Pick Lists” of removal reasons: Enter only most urgent safety reasons, so alcohol exposure lost from the record.
- Both agencies agree: Need more detail on what local agencies currently do so we can advise on ways to improve systems and services.



Exploratory Project: DC-Child and Family Services Agency



Objective: Gain a better understanding of the policies, practices and procedures of a child welfare agency to identify and care for children that have possibly been prenatally exposed to alcohol and/or drugs.

Tactics:

1. Key informant interviews-transcribed & coded with ATLASi
2. Caregiver focus group interviews-transcribed & coded with ATLASi
3. Electronic case notes review

Informants

- Administrators
- Investigators
- Clinical staff (records)
- Permanency CWs
- Education/training
- Data management
- CMS Pediatricians
- Foster & adoptive parents
- Respite providers
- Therapeutic caregivers

Sample Topics

- Policy
- Knowledge of PSE
- Education of PSE
- Current practice
- Education/training needs
- CE opportunities
- Current cases
- Previous cases
- Work with Sp Needs

What they told us

Administrators (N=9):

- ❖ Currently no policies address identification or education regarding children with prenatal substance exposure. Things tend to be informal and vary across case workers,



“Every one knows drugs are bad.”

“This information could be very useful when working with a family.”

What they told us

Investigators/Clinical staff (N=7):

- ❖ Estimated 10 to 30 percent of cases involved prenatal substance exposures
- ❖ Heavy reliance on positive toxicology reports to identify
- ❖ Only 0-3 year old developmental screener asks about prenatal exposures



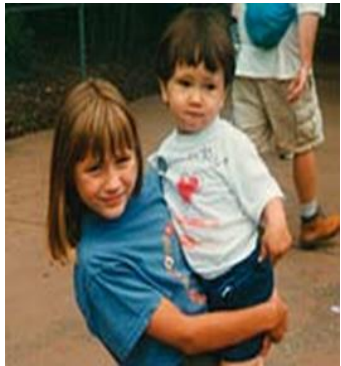
“...my concern with them being pre-exposed was like ‘is the parent still using or not?’”

“It’s not something that’s on my radar.” It’s not a reason for removal or impacts immediate safety”.

What they told us

Permanency staff (N=8):

- ❖ Learned about the topic “on-the-job” and from mentors and supervisors or from own pregnancy; perpetuates misinformation
- ❖ May be appropriate staff to query mother after a rapport is built, not initially



“If it’s not in the computer, it didn’t happen.”

*“...need to know the symptoms, if you don’t,
you
can’t connect the dots”*

What they told us

Educators/trainers (N=7):



- ❖ Trainings tend to be developed around the “hot topic” of the day, (e.g., trauma informed services; consumable marijuana)
- ❖ Education would be helpful- *“In school you’re told drugs are bad, don’t use during pregnancy. But they never tell you why.”*
- ❖ Need local resources so that care can be provided, no reason to identify if there’s nothing to be done

What they told us

Caregiver focus group (N=7):

- ❖ Initial training only talked about not drinking during pregnancy, not the effects on the child to watch for
- ❖ Mother of child with ARND diagnosis: *“It would have been really helpful to have some information on what to look for. We wasted so much time and energy getting to a diagnosis.”*
- ❖ Mother of child with FAS: *“didn’t intend on being a therapeutic foster parent, but had to become one by default”*
- ❖ *“Zero information on treatment and strategies has been provided to deal with the results of the diagnosis.”*



What we found in the file notes

- ❖ No single data element for prenatal exposure to alcohol or other drugs
- ❖ Most useful information is contact in **contact notes** and **court reports** – but time consuming, tedious and not very efficient
- ❖ Diagnostic information tends to be embedded in medical visit notes, not a separate data element
- ❖ Multiple opportunities to document both exposure and diagnoses



Preliminary findings

- **Alcohol can be devastating substance to children through parental substance abuse, prenatal exposure and their interaction**

- **The relative harm from in utero exposure to alcohol is greatly under appreciated, both in terms of**
 - Harm relative to other drugs
 - Contribution of child's disabilities to family function

- **Child welfare agencies would be well served to identify children with prenatal exposure to alcohol to:**
 - Accurately diagnosis and provide appropriate interventions
 - Improve parenting & family function
 - Reduce repeated cycles of abuse/neglect

Where we go from here

- Establish 5 year Interagency Agreement
- Pursue AFCARS & NCANDS data elements
- Convene Technical Working Group (TWG)
- Replicate DC-CFSA project nationally
- Develop trainings and resource materials for child welfare professionals to improve identification & care
- Evaluate for efficacy & effectiveness
- Establish identification of children with prenatal exposures, especially alcohol, as routine in the child welfare system





Your Input???

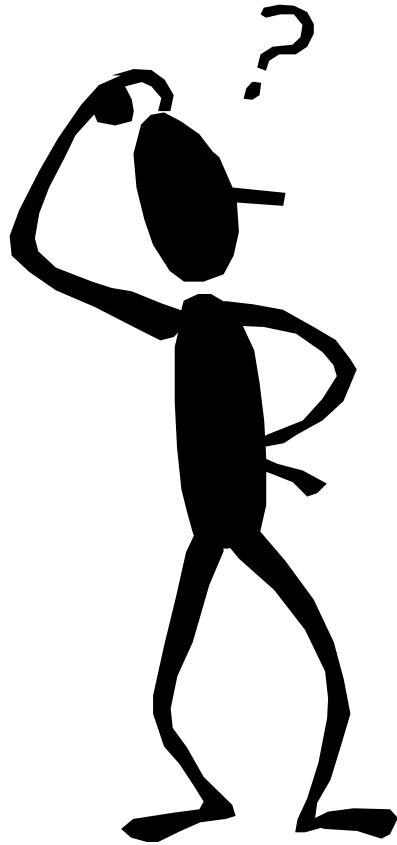
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