

## Raising the Focus on, and Funding for, FASD in Hawaii

# Hawaii FASD Action Group Honolulu Hawaii June 5, 2018



Dan Dubovsky  
FASD Specialist

ddubovksy@verizon.net  
215-694-8450



## Timeline

- ▶ Where have we been in Hawaii
    - Trainings
    - Task force
    - Town Hall meeting
    - Development of an FASD State Coordinator
  - ▶ Where are we now
  - ▶ Where do we want to be
    - In awareness
    - In prevention
    - In treatment
    - In State initiative
    - In funding



## What Do We Need?

- ▶ Systems of care at the table
- ▶ Funding
  - From the State
  - From Medicaid
  - From foundations
  - From grants
- ▶ Screening, assessment, and diagnostic capacity



---

---

---

---

---

---

## Incidence and Prevalence of FASD

- ▶ The range of FASD is more common than disorders such as Autism and Down Syndrome
  - Generally accepted incidence of FASD in North America has been 1 in 100 live births
  - Recent studies are identifying a prevalence of between 2% and 5% (1 in 50 to 1 in 20)
  - Much higher percentage in systems of care
  - Majority undiagnosed



---

---

---

---

---

---

## FASD in the DSM-5

- ▶ DSM 5
  - Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure 315.8 (F88)
  - Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (Section III)



---

---

---

---

---

---

## FASD in the ICD-10-CM

- ▶ F88: Other Specified Delays in Development; Other Disorders of Psychological Development
  - ▶ Q86.0: Fetal Alcohol Syndrome (dysmorphic)
  - ▶ Q86; P04.3: Alcohol Affecting Fetus or Newborn Via Placenta or Breast Milk
  - ▶ P04.3: Newborn (suspected to be) affected by maternal use of alcohol
  - ▶ Z13: Encounter for screening for other diseases and disorders
- 

---

---

---

---

---

---

## Importance of Addressing FASD

- ▶ FASD is 100% preventable
  - ▶ Alcohol causes the most serious lifelong neurobehavioral effects on a fetus of any substance of abuse (IOM)
  - ▶ First weeks of fetal development are critical
  - ▶ Close to 50% of pregnancies are unplanned
  - ▶ Most women don't recognize pregnancy this early in fetal development
- 

---

---

---

---

---

---

## Importance of Addressing FASD

- ▶ There are three promising practices for the prevention of alcohol exposed pregnancies
    - CHOICES—a CDC funded program for non-pregnant women at risk
    - Screening and Brief Intervention
    - Parent-Child Assistance Program (PCAP)—a 3 year case management model for women at highest risk
- 

---

---

---

---

---

---

## Importance of Addressing FASD

---



---



---



---



---



---



---

- ▶ The Province of Alberta has done a study of the cost savings of implementing the Parent-Child Assistance Program
- 

### *Canadian Economic Evaluation of PCAP*

---



---



---



---



---



---



---

Summary: Using PCAP data from Alberta, Canada, this is the first study estimating the incremental cost effectiveness ratio and the net monetary benefit of a PCAP program. Results estimate that PCAP prevented approximately 31 (range 20–43) cases of Fetal Alcohol Spectrum Disorder *among 366 clients in a 3-year period*. The net monetary benefit is approximately \$22 million (range \$13–\$31 million). Results indicate that the program is cost-effective and the net monetary benefit is significant.

Authors note that the benefit is likely underestimated as the study did not include benefits from the reduction in unemployment and welfare income dependence rates among PCAP participants.

Thanh, N.X., Jonsson, E., Moffatt, J., Dennett, L., Chuck, A., & Birchard, S. (2015). An Economic Evaluation of the Parent-Child Assistance Program for Preventing Fetal Alcohol Spectrum Disorder in Alberta, Canada. *Administrative Policy and Mental Health*, 42:10–18.

---



---



---



---



---



---



---

## Importance of Addressing FASD

---



---



---



---



---



---



---

- ▶ If FASD is not recognized, people frequently get misdiagnosed
  - ▶ Misdiagnosis leads to inaccurate, and at times potentially toxic, treatment
  - ▶ Even if the person has a co-occurring issue, if the FASD is not recognized the treatment will not be optimal
  - ▶ This can lead to repeated treatment episodes, repeated homelessness, and repeated incarceration
- 

## Importance of Addressing FASD

- ▶ Individuals with an FASD are at high risk of involvement in the correctional system
  - Poor judgement
  - Naïveté
  - Difficulty predicting the consequences of actions due to damage to abstract thinking
  - It is estimated that incarceration costs more than one trillion dollars in the U.S. <https://source.wustl.edu/2016/09/cost-incarceration-u-s-1-trillion/>

---



---



---



---



---



---



---



---

## Importance of Addressing FASD

- ▶ In Hawaii in 2015, there were 6,063 people in prison at an average cost of \$29,425 per inmate for a total of \$178,403,775  
<https://www.vera.org/publications/price-of-prisons-2015-state-spending-trends/price-of-prisons-2015-state-spending-trends/price-of-prisons-2015-state-spending-trends-prison-spending>
- ▶ Another source reported 7400 in prison (state or federal) in Hawaii for a cost of \$217,745,000 [www.prisonpolicy.org](http://www.prisonpolicy.org)

---



---



---



---



---



---



---



---

## Importance of Addressing FASD

- ▶ Individuals with an FASD are at high risk of substance use disorders
  - Genetic vulnerability
  - Family history
  - Peer pressure
  - Living with a hidden disability
- ▶ Substance abuse costs the U.S. over \$600 billion annually  
<https://www.drugabuse.gov/publications/principles-drug-addiction-treatment-research-based-guide-third-edition/frequently-asked-questions/drug-addiction-treatment-worth-its-cost>

---



---



---



---



---



---



---



---

## Importance of Addressing FASD

- ▶ Individuals with an FASD are likely to fail in treatment
    - Evidence based practices in treatment are based on verbal receptive language processing skills
  - ▶ They will often repeatedly fail in treatment
    - Treatment programs repeatedly use practices that are not effective for those with an FASD
    - The individuals are viewed as being non-compliant and unmotivated
  - ▶ Repeated ineffective treatment is very expensive
- 

---



---



---



---



---



---



---



---

## Importance of Addressing FASD

- ▶ The prevalence of Fetal Alcohol Syndrome in the foster care system is 10 times higher than in the general population
  - ▶ Children in foster care are at higher risk for an FASD. As many as 75% of children in foster care have a family history of mental illness, drug, and/or alcohol abuse
  - ▶ *S. J.. Atley, PhD, J.Stachowiak, RN, MN, S. Clarren, MD, Ch Clausen, RN, MN, (2002) Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population, Journal of Pediatrics, Volume 141, Number 5.*
- 

---



---



---



---



---



---



---



---

## Importance of Addressing FASD

- ▶ Child welfare needs to recognize if primary caregivers have an FASD
    - If they do, giving them a list of instructions sets them up to fail
    - If they have an FASD, sending them to parenting classes is a waste of time, money, and energy
    - If they are not recognized, parental rights are often terminated
    - If they want to raise a child, they may have another alcohol exposed pregnancy
- 

---



---



---



---



---



---



---



---

## Cost of FASD

- ▶ Lifetime cost for one individual with FAS in 2002 was estimated to be \$2 million
  - ▶ Cost to the U.S. for only FAS is estimated at \$4 billion annually
  - ▶ In 2016, it was estimated that 20.9% of women ages 18–44 binge drank
    - 43% of women who reported in this age range who reported any drinking reported binge drinking
    - <https://www.cdc.gov/ncbddd/fasd/data-maps-2016.html>



## Rationale for Screening for FASD

- ▶ If we don't identify individuals with FASD, they often experience
    - Many moves as children
    - Repeated abuse and trauma
    - Failure in typical education, parenting, treatment, justice, child welfare, mental health, vocational, and housing approaches
    - Think they are "bad" or "stupid"
    - High risk of being homeless, in jail, or dead



## Rationale for Screening Caregivers

- ▶ FASD is not genetically transmitted, but alcohol use runs in families
  - ▶ If we do not recognize FASD in caregivers, they often
    - Are labeled as neglectful, uncaring, or sabotaging
    - Have children removed from their care
    - Have parental rights terminated
  - ▶ Women may have another alcohol exposed pregnancy



## How Outcomes Can Be Improved by Recognizing an FASD

- ▶ The individual is seen as having a disability
- ▶ Frustration and anger are reduced by recognizing behavior is due to brain damage
- ▶ Trauma and abuse can be decreased or avoided
- ▶ Approaches can be modified
- ▶ Diagnoses can be questioned



---

---

---

---

---

---

---

## Screen for Identifying Individuals with a Possible FASD

- ▶ In response to requests from providers, we developed a screen to identify those who may have an FASD
- ▶ Called the Life History Screen
- ▶ Information on the screen was published in the International Journal of Alcohol and Drug Research
- ▶ There are 32 questions in 9 categories



---

---

---

---

---

---

---

## Life History Screen

- ▶ The questions on the screen are based on clinical experience and statistical analysis
- ▶ Twenty-two residential substance use treatment programs tested the usefulness of the screen
  - Feedback resulted in modifying questions and language



---

---

---

---

---

---

---

## Life History Screen

- ▶ Categories:
  - Childhood History
  - Maternal Alcohol Use
  - Education
  - Criminal History
  - Substance Use
  - Employment and Income
  - Living Situation
  - Mental Health
  - Day to Day Behaviors



---

---

---

---

---

---

---

## Life History Screen

- ▶ The screen is to be given to everyone
- ▶ The screen is not meant to be given to the person to complete
- ▶ How questions are asked is an essential component to training on the screen
  - Some questions may need to be asked after a trusting relationship is formed with the person
  - Some questions may need to be revisited once this relationship is formed
- ▶ Comfort of the interviewer is paramount



---

---

---

---

---

---

---

## Life History Screen

- ▶ We recognize that the screen will most likely identify others with subtle cognitive impairments that impact interventions
- ▶ The screen should **not** be used unless a positive screen leads to modifications in approaches
- ▶ The screen is not diagnostic and should result in a referral for a diagnostic evaluation if available
- ▶ Modifications need to be implemented in the meantime



---

---

---

---

---

---

---

## Keys to Success in Implementing the Life History Screen and Modifications

- ▶ True buy-in and participation of the executive director of the agency
- ▶ Buy-in and participation of the supervisory staff
- ▶ ALL staff need to be trained
- ▶ The process MUST include face-to-face training, follow-up, and ongoing coaching



---

---

---

---

---

---

---

## German Study of the Life History Screen (LHS)

Lisa Schwerg 2018

- ▶ Called the Biographic Screening Interview for Adults with FASD
- ▶ LHS translated into German then back to English to ensure nothing was lost
- ▶ Some items were adjusted to the German culture
- ▶ “B-Notes” were added for hard to understand items



---

---

---

---

---

---

---

## German Study of the Life History Screen (LHS)

Lisa Schwerg 2018

- ▶ Staff was trained on FASD and administration of the screen
- ▶ Sensitivity training was held on how to respectfully interact with adults with FASD in asking sensitive questions
- ▶ Interviews utilizing the screen lasted 5–8 minutes



---

---

---

---

---

---

---

## German Study of the Life History Screen (LHS)

Lisa Schwerg 2018

- ▶ The categories with the greatest predictability for accurate results were:
  - Childhood history
  - Maternal alcohol use
  - Day-to-day behaviors
  - Living situation
  
- ▶ Those with the least predictability were:
  - Criminal history
  - Substance use
  - Possibly because many interviewed were in a substance use program

---



---



---



---



---



---



---

## German Study of the Life History Screen (LHS)

Lisa Schwerg 2018

- ▶ 111 Participants were recruited from:
  - An alcohol and other drug rehabilitation clinic
  - An FASD diagnostic clinic
  - A self-help group for people with FASD
  - Member of FASD–Deutschland diagnosed with FASD
  - Age range was 20–74
  - 66.3% male; 33.7% female
  
- ▶ 90 completed the diagnostic process

---



---



---



---



---



---



---

## German Study of the Life History Screen (LHS)

Lisa Schwerg 2018

- ▶ 87.5% of the people affected by an FASD were correctly identified (sensitivity)
- ▶ 93.7% of the people who did not have an FASD were correctly identified (specificity)
- ▶ 92.8% of participants overall were correctly identified using the screen

---



---



---



---



---



---



---



## Screening for an FASD for Youth

- ▶ The Michigan Department of Mental Health Services for Children and Families wanted to identify youth with a possible FASD
- ▶ I was asked to develop a screening and assessment protocol
- ▶ A protocol for children Birth–Five and one for children and adolescents Six–Eighteen was developed

---

---

---

---

---

---

## Screening for an FASD for Youth

- ▶ A strengths assessment was also developed
- ▶ If a child is assessed as having a possible FASD, an array of interventions is utilized
- ▶ The protocol is being piloted in three counties

---

---

---

---

---

---

## Risk of Sexually Transmitted Infections

- ▶ People with an FASD are at risk for HIV and sexually transmitted infections
  - Difficulty avoiding dangerous situations
  - Difficulty negotiating safe sex
  - Difficulty remembering to use safe sex techniques

---

---

---

---

---

---

## Suicide Risk Among Individuals with an FASD

Whitney and Dubovsky (2010)

- ▶ Literal thinking can lead to a higher risk for suicide
  - Language used in discussing deaths
- ▶ Community response to other suicides
- ▶ Wanting to “go along with the crowd”
- ▶ “If I kill myself, people will be upset”
- ▶ Inability to predict the consequence of death at the moment



---

---

---

---

---

---

---

## Issues in Addressing Behaviors

- ▶ We are a problem based society
- ▶ Professionals get paid for dealing with problems
- ▶ Meetings focus on problems
- ▶ Policies, procedures, and handbooks for many treatment programs focus on negative approaches
  - Consequences for certain behaviors
  - Many rules and what happens when they are broken



---

---

---

---

---

---

---

## Issues in Addressing Behaviors

- ▶ Many individuals with an FASD, as well as many with other disabilities that manifest behaviorally, those with substance use disorders, and those with mental illness have repeatedly heard what they do wrong throughout their lives
- ▶ They rarely hear what they do right



---

---

---

---

---

---

---

## Issues in Addressing Behaviors

- ▶ We need to change our approach
- ▶ We need to incorporate a true strengths based approach to everyone
- ▶ Identifying strengths and abilities needs to be foremost
- ▶ We need to move towards a positive focused system of care

---



---



---



---



---



---



---



---



## Engaging Systems of Care

- ▶ Discuss the likelihood of significant numbers of individuals in each system having an FASD
- ▶ Point out the lack of diagnostic capacity to meet the estimated prevalence
  - So most will not be accurately diagnosed
- ▶ Discuss the cost savings of preventing FASD
- ▶ Discuss the potential cost savings of providing modified approaches to improve outcomes

---



---



---



---



---



---



---



---



## Engaging Systems of Care

- ▶ Work with Medicaid to cover as much of the diagnostic evaluation as possible
- ▶ Discuss the utilization of ICD-10-CM codes to cover mental health issues for those with an FASD
- ▶ Ask each participant what their priorities are
- ▶ Develop a “treatment” plan that addresses those priorities
  - Long term goals
  - Short term goals
  - Steps toward achieving each goal
  - Who will work on each step

---



---



---



---



---



---



---



---



## References

- ▶ Grant TM, Novick Brown N, Dubovsky D, Sparrow J, Ries R. *"The Impact of Prenatal Alcohol Exposure on Addiction Treatment."* Journal of Addiction Medicine 2013; 7(2) 87-95.
  - ▶ Grant TM, Novick Brown N, Graham JC, Whitney N, Dubovsky D, Nelson LA. *"Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress."* International Journal of Alcohol and Drug Research 2013; 2(3) 37-49.
- 

---

---

---

---

---

---

---

## U.S. Resources

- ▶ Centers for Disease Control and Prevention FAS Prevention Team: [www.cdc.gov/ncbdd/fas](http://www.cdc.gov/ncbdd/fas)
  - ▶ National Institute on Alcohol Abuse and Alcoholism (NIAAA): [www.niaaa.nih.gov/](http://www.niaaa.nih.gov/)
  - ▶ National Organization on Fetal Alcohol Syndrome (NOFAS): [www.nofas.org](http://www.nofas.org)
  - ▶ Minnesota Organization on FAS: [www.mofas.org](http://www.mofas.org)
  - ▶ These sites link to many other Web sites
- 

---

---

---

---

---

---

---