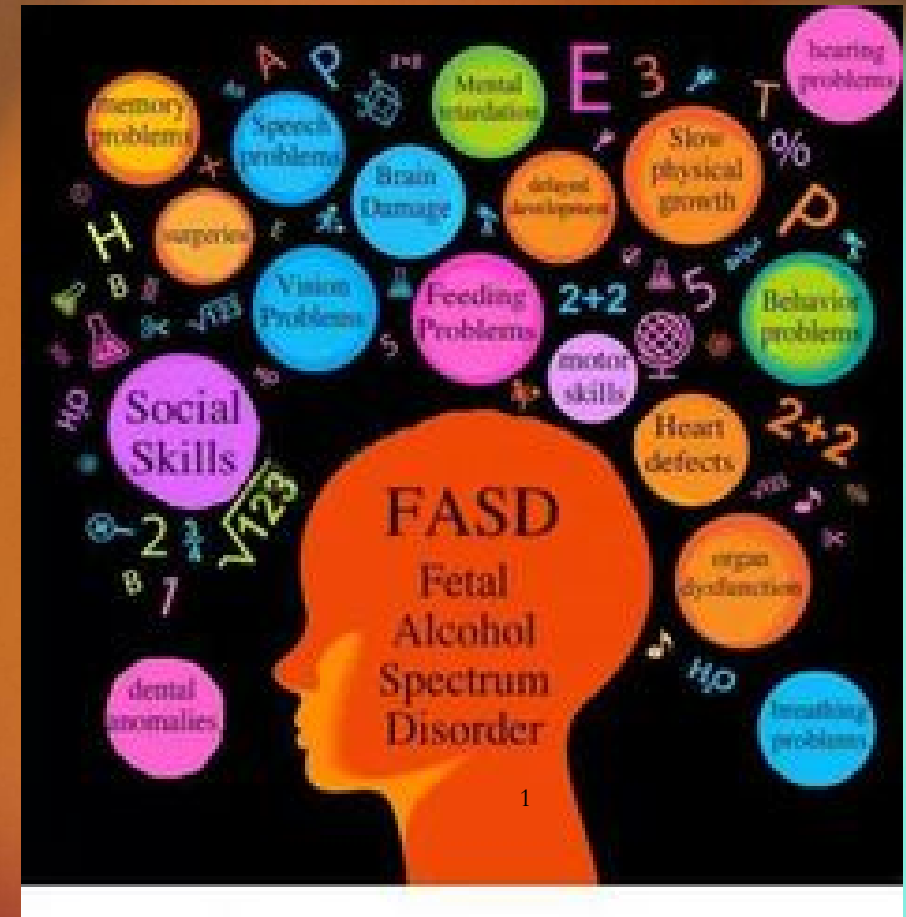


Fetal Alcohol spectrum disorders

Hawaii update

Legislative Briefing 9.17.19



Hawaii FASD Action Group: prevent FASD & create FASD-informed services for people and families affected by FASD

Prenatal Alcohol Exposure

- Life-long brain damage
- Mostly “invisible”
- Affects the entire body (CNS)
- No two people alike
- At least twice as common as autism

Fetal Alcohol Spectrum Disorders



FASD is Underestimated

- Often diagnosed as autism, AD/HD, learning disabilities*
- ~85% missed or misdiagnosed in sample of foster and adopted children**
- Stigma discourages reporting of maternal alcohol use *

Multidisciplinary
team best for
assessment



Impact on Society

- 94% Mental health issues (multi-morbidities)
- 80% Difficulty with independent living
- 80% Difficulty with employment
- 70% Trouble in school
- 60% Trouble with the law
- 50% Adults abuse alcohol/drugs
- 45% Legal problems with sexual behaviors



West Australia youth detention study

99 children assessed

88/99 (89%) at least one severe cognitive impairment

36/88 (41%) diagnosed with an FASD

Created policies to identify and modify treatment among all who worked with these youth



Trends

- Alcohol use during last 3 months of pregnancy¹
Hawaii: **4.8%** (2000); **7.6%** (2013); **8.7%** (2015)²
- Unplanned pregnancies¹
Hawaii: **45%** (2008); **50%** (2009-2015)³



Cost of FAS in the U.S. (2002)

- \$2M Lifetime cost (One person)
- \$4B Annually



Lupton, C., Bird, L., & Harwood, R. (2004). Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics*, 127C(674):42-50. In SAMHSA DHHS Publication No. (SMA) 06-4236 (2007).

Hawaii FASD Action Group Priorities

1. Train All communities: health care providers, employers, schools, counselors, psychologists, substance use and mental health providers.
 - (Trained over 650 people; Hosted two conferences in Hawaii).
2. Initiate a long-term training for treatment providers to screen people at high-risk for FASD and modify treatment.
 - (GIA Failed 2019; Resubmitting)



Priorities, cont.

3. Allow DD services to individuals with normal IQ and low adaptive functioning (e.g., FASD).

- (Discussions with DOH/DHS)

4. Expand Medicaid services for children and adults with FASD.

- (SB242 failed in 2019)

5. Initiate surveillance projects on prevalence of FASD to inform programs and policies

- (No action)



Priorities, cont.

6. Redefine ways to confirm maternal drinking during pregnancy.
 - **(Resolution died in 2019)**
7. Create multidisciplinary teams for assessment & treatment recommendations (Univ. Washington model)
 - **(Unsuccessful attempt with DOH and DOE 2017)**
8. Fund family support groups with childcare
 - **(No action)**



Mahalo nui loa

*“Individuals with FASD are born into an impossible world
We must make the world possible for them.”*

K.K. . Yabusaki, 3/20/19



Terra Daniel – Parent/Member of FASD Action Group

Link to FASD Awareness Day Video:

<https://www.youtube.com/watch?v=iRY3s-1OOao&app=desktop>



PR%oF

Alliance

Legislative Briefing
September 17, 2019

Background

- Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) was founded in 1998
 - First affiliate of NOFAS
 - Our work has always been focused on systems change/public policy
 - Board has made commitment to support policy advancement
-

Minnesota at a glance

- 5.6 million population
- 70,000 birth annually
- Population is concentrated in Minneapolis/St. Paul with a few cities in northern and southern Minnesota
- Strong commitment to health, but stubborn disparities exist





Waivers

- CADI – Community Access for Disability Inclusion
 - BI – Brain Injury
 - CAC – Community Alternative Care
 - DD – Developmental Disabilities
 - EW & AC – Elderly & Alternative Care Services (65+)
-



Keys to Success in MN

- Deep commitment to bi-partisan approach, understanding that FASD impacts us all
 - FASD is common, costly, and preventable: a win/win for legislative policy
 - Legislative champions in leadership
 - Developed a strong advocacy base of "noisemakers"
-

Making the case

- Your state is already spending this funding with poor outcomes
 - Multiple foster care placements
 - Correctional system
 - Special education costs
 - Clear that preventing FASD can SAVE the state funding
 - Modest investment can make a significant impact
 - Human rights issue
-

FASD Appropriation

- During Governor Carlson administration in 1990's statewide task force was established.
 - This task force produced a set of recommendations AND a fiscal appropriation with about \$8 million going to state agencies including health and human services, education, corrections, public safety and planning.
 - Funds gradually were absorbed by other programs.
 - MOFAS, now Proof Alliance established in 1998.
-

FASD Appropriation continued

- MOFAS/Proof Alliance deep commitment to public policy
 - General fund sole source appropriation made in 2004
 - Public/Private partnership
 - Increases under both Republican and Democratic Governors
-

**What is
included?**



**Public
Awareness /
Prevention**



**Intervention &
Family Support**



Screening & Diagnosis



Community Grants



Professional Education & Training

Additional State Funds - DHS

- Funding for long term recovery supports for women with substance use disorders who are pregnant or who have young children
 - Demonstrated that for very modest funding, community resources can be leveraged and outcomes have saved the state money
 - Because of advocacy and demonstrated results we are able to fund up to four community to provide this service which is a huge gap to preventing FASD
-



DHS funding

Para Training

Foster Care Training

Examples of Progress

MDH funding

Mandated Reporting





Big Dreams

- Brain injury definition, waiver
- FASD waiver
- Requirement for first responders
- Universal screening during pregnancy, early childhood
- Universal screening when children are in out of home placement
- Information transferred from maternal to infant records
- Increased funding for prevention and support services



Questions