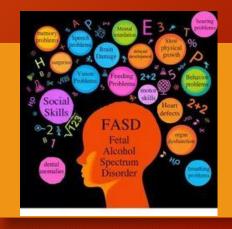


Hawai`i Fetal Alcohol Spectrum Disorders (FASD) Action Group

Fetal Alcohol Spectrum Disorders (FASD): Invisible Disabilities



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Hawaii State Rural Health Association, Project ECHO

Objectives

- >Introduce FASD
- > Rethink intervention strategies

Why talk about FASDs?

- Invisible
- Prevalent
- Increasing
- Costly to family, individual, society

- School-aged children usually identified when referred for learning disabilities or AD/HD
- Care will often focus on co-morbid conditions (autism, AD/HD, learning disabilities, ODD, CD, adolescent depression, bipolar disorder, reactive attachment disorder)*

^{*}Onoye, J. (2018) addressing FASD in Hawaii. Powerpoint presentation 6/6/2018.

^{*}Quality Improvement Center for Research-Based Infant-Toddler Court Teams. www.qicct.org

Invisible, cont.

- Stigma discourages reporting of maternal alcohol use
- < < 5% are ever diagnosed*
- ~85% missed or misdiagnosed in sample of foster and adopted children**

^{**} Chasnoff, I., Wells, A.M., & King L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. Pediatrics, **135**(2), DOI: 10.1542/peds.2014-2171. http://pediatrics.apppublications.org/content/early/2015/01/07/peds.2014-2171



^{*}Onoye, J. (2018) addressing FASD in Hawaii. Powerpoint presentation 6/6/2018.

^{*}Quality Improvement Center for Research-Based Infant-Toddler Court Teams. www.qicct.org

Prevalent

2018 conservative estimate:

One in 20 (5%) first graders are affected by FASDs

 FASDs are at least twice as common as autism



Increasing

- CDC: 2015-2017 (Alcohol use in past 30 days)
 - 1 in 9 pregnant women drank alcohol
 - 1 in 3 engaged in binge drinking
- >55% increase in alcohol sales since mid-March shut down for COVID-19

Cost of FASD

- Human & social costs: Unmeasurable
- 94% Mental health issues (multi-morbidities)
- 95% unable to live independently
- 80% Difficulty with employment
- 70% Trouble in school
- 60% Trouble with the law
- 50% Adults abuse alcohol/drugs
- 45% Legal problems with sexual behaviors

(CDC, 2004; Lange et al., 2013; Lupton et al, 2004; Thanh et al., 2011)

Basic FASD

- Permanent/Irreversible Brain Damage
- Affects the entire body (CNS) --pervasive
- No two people alike
- Overrepresented in certain populations (e.g., homeless, SUD, adoption/foster care, criminal justice system)



Fetal Alcohol Spectrum Disorders



Partial Fetal Alcohol Syndrome (pFAS)

DSM-5: 315.8 (F88)
Other Specified
Neurodevelopmental
Disorder w/ Prenatal
Alcohol Exposure (ARND) (p. 86)

Neurobehavioral Disorder-Associated with Prenatal Alcohol Exposure— Condition for further study (pp. 798-801)



Alcohol-related

neurodevelopmental

disorder

(ARND)

Confirmed

Not required

Not required

Yes

FASD S	spectrum	. (UVV)
		Total I
	Fetal alcohol	Partial feta

(FAS)

(pFAS)

Confirmed

Yes (2 features)

Not required

Yes

peetiant	
	Total FASD
Fetal alcohol	Partial fetal alcohol
syndrome	Syndrome

Confirmed or

Unconfirmed

Yes (3 features)

Yes

Yes

Prenatal Alcohol

Central nervous

Facial anomalies

Growth deficiency

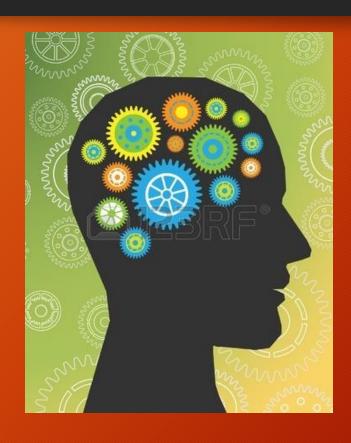
in 3 or more

subdomains

system impairment

Exposure

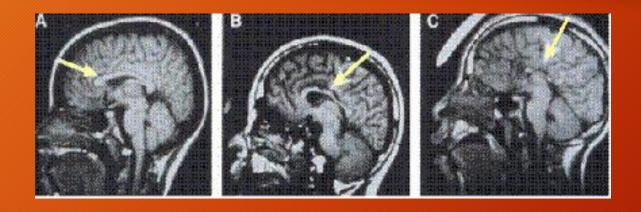
All behaviors begin with the brain



ARRA .
FAS Facial Characteristics:
small eye openings
smooth philtrum
thin upper lip
The second secon

Child with FAS

CNS Damage: Corpus Callosum



The brain of a normal individual (A) and two with FAS (B,C) shows permanent loss of the tissue indicated by the arrows (portions of the corpus callosum).

Secondary Disabilities of FASD

- Fatigue, frustration
- Anxious, fearful
- Overwhelmed, shut down
- Rigid, resistant, argumentative
- Feelings of failure, low self esteem
- Isolation, few friends
- Attachment difficulties—empathy, social cues



Secondary Disabilities, cont.

- School disruptions
- Family problems
- Truancy, run away, avoidance, trouble with law
- Depression, self-destructive, suicidal
- Victimization
- Substance Use







Samantha: 14 yo

- Runs away from home
- Truant
- Uses drugs/alcohol
- Failed 4 schools
- Climbed on roof when upset
- Continues behaviors in spite of consequences
- Aggressive and threatening at times



Samantha, cont.

- Placed in several foster homes from 6 months old, adopted at 2 years
- Fussy baby with many ear infections as young child



Alternative Hypothesis: What if...??

- Mother used alcohol during pregnancy?
- Samantha's behaviors may be affected by brain damage?

Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ ADHD	Int. Dys.	Autism	Polar	RAD	Depres- sion	ODD	Trauma	Poverty
& Mental Health Diagnoses	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Medal	£n i/an	Environ
Easily distracted by extraneous stimuli	Х	Х							ZU	
Developmental Dysmaturity	Х			Х						
Feel Different from other people	Х				Х					
Often does not follow through on	Х	Х					Х	Х	Х	Х
instructions										
Often interrupts/intrudes	X	Х	Х	Х	Х		Х			Х
Often engages in activities without	Х	X	Х	Х	X					Х
considering possible consequences				-			v			v
Often has difficulty organizing tasks & activities	X	Х		Х	Х		Х			Х
Difficulty with transitions	Х		Х	Х	Х					
No impulse controls, acts hyperactive	Х	Х	Х		Х	Х				
Sleep Disturbance	Х				Х		Х		Х	
Indiscriminately affectionate with strangers	Х		Х		Х	Х				
Lack of eye contact	Х		Х	Х		Х	Х			
Not cuddly	Х			Х		Х	Х			
Lying about the obvious	Х				Х	Х				
Learning lags: "Won't learn, some can't learn"	X		Х			Х			Х	Х
Incessant chatter, or abnormal speech	х		х	х	х	х				
patterns										
Increased startle response	Х		Х						Х	
Emotionally volatile, often exhibit wide	Х	Х	Х	Х	Х	Х	Х	Х	Х	
mood swings										
Depression develops, often in teen years	Х	X				Х			X	
Problems with social interactions	Х			Х	Х		Х			
Defect in speech and language, delays	Х			Х						
Over/under-responsive to stimuli	Х	Х	Х	Х						
Perseveration, inflexibility	Х			Х	Х					
Escalation in response to stress	X		Х	Х	Х		Х		Х	

Caring for someone with FASD

- Medical Care
- Medication
- Behavior and Education
- Parent Support and Training
- Alternative Approaches (Biofeedback, animalassisted therapy, art, auditory training, nutrition & supplements)

Shift our interventions

- ➤ Adjust Expectations from "I won't" to "I can't"
- ➤ Build on Strengths
- Supervision = "External Brain"





Mahalo!



Resources

For more information & support:

Hawai'i Fetal Alcohol Spectrum Disorders (FASD) Action Group

www.hawaiifasd.org



Additional Resources

Hawaii Prevention Resource Center

https://www.drugfreehawaii.org/hawaii-prevention-resource-center

American Academy of Pediatrics Fetal Alcohol Spectrum Disorders Program

https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/

Centers for Disease Control and Prevention

https://www.cdc.gov/ncddd/fasd/ and https://www.cdc.gov/ncbddd/fasd/alcohol-use.html

National Organization for Fetal Alcohol Syndrome

https://www.nofas.org