



Hawaii Fetal Alcohol Spectrum Disorders (FASD) Action Group

# FASD: Invisible No More

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<https://youtu.be/gc2LAbrijnQk>

# Objectives

- Brief Overview
- Impacts
- Strategies

\*Plug In...FASD Virtual Mini Conference September 2021  
@hawaiifasd (Facebook and Instagram)



# FETAL ALCOHOL SPECTRUM DISORDERS

- FASD encompasses a range of effects on the brain and body of individuals prenatally exposed to alcohol.
- FASD is a lifelong disability.
- Individuals affected by FASD display various daily living challenges and are often misdiagnosed and misunderstood.
- FASD-informed education and interventions are critical for the success of individuals and their families.

# FASD Facts

- Of all substances, alcohol produces the most serious neurobehavioral effects on the fetus
- Impacts schools, foster/adoptive care, mental health/substance abuse services, and the justice system
- Many individuals are unidentified
- Lifetime social & health care costs for children born w/FASD is ~\$2 million, ~\$6-8 billion annually in U.S.



# Prevalence and Rising Concerns

- 2018 conservative estimate: 1 in 20 (5%) first graders are affected by FASDs
- FASDs are at least twice as common as autism
- 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



May, P.A., Chambers, C.D., Kalberg, W.O, Zellner, J., Feldman, H., et al. (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities, 319(5):474-482. doi:10.1001/jama.2017.21896

Hawaii Health Data Warehouse, Hawaii State Department of Health, Pregnancy Risk Assessment Monitoring System, Drinking alcohol last 3 months of pregnancy for years 2000-2013. Report created 2/8/17.

# Diagnostic Barriers

- Difficult to obtain verification of alcohol consumption by bio mom
- Invisible disability  
(misdiagnosed or undiagnosed)
- Need more awareness of FASD in the state
- Currently no comprehensive diagnostic team in Hawaii (Multidisciplinary assessments needed by MD, Psychologist, SLP, OT)



# Issues with Missed & Misdiagnosis

- Invisible disability (no visible features)
- Misdiagnosis leads to inaccurate and possibly even treatment that is harmful
- Even if the person has co-occurring issues/dxs, if the FASD is not recognized the treatment will not be optimal



Dubovsky, D (2018) Raising the Focus on and Funding for FASD in Hawaii (Powerpoint slide)



# Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

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

# How is FASD diagnosed?

~There is no simple test

~FASD is usually diagnosed by a team of trained professionals (assessing CNS impairment, speech, sensory, etc)

~Confirmed maternal use during pregnancy

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~Kapiolani-Dr Jeff Okamoto

~Hawaii Community Genetics



# *IMPACTS*



# Possible Areas of Impairment

- Executive functioning
- Memory
- Abstract concepts
- Judgement
- Generalizing information
- Cognitive pace (Slower information processing)
- Auditory pace
- Impulsivity
- Perseveration
- Language and communication
- Sensory processing
- Not able to use consequential thinking (cause and effect)



# Adaptive Functioning Impairment

- Easily influenced by others
- Excessive demands for attention
- Naive and gullible
- Social inappropriateness
- Difficulty communicating needs
- Emotional regulation
- Organization of daily tasks
- Difficulty with independent living
- Navigation (ie., using public transportation)
- Occupational functioning
- Financial management



# Secondary Issues Arise

- Attachment difficulties
- Fatigue and frustration
- Anxious and fearful
- Overwhelmed and shut down
- Rigid, resistant, argumentative
- Feelings of failure, low self-esteem
- Withdraw, avoidance, and isolation
- Few friends (increase risk of negative peer group)
- Opposition and defiance
- School concerns
- Family problems
- Truancy, avoidance, trouble with the law
- Depression and other mental health concerns
- Substance use

# Adverse Life Events

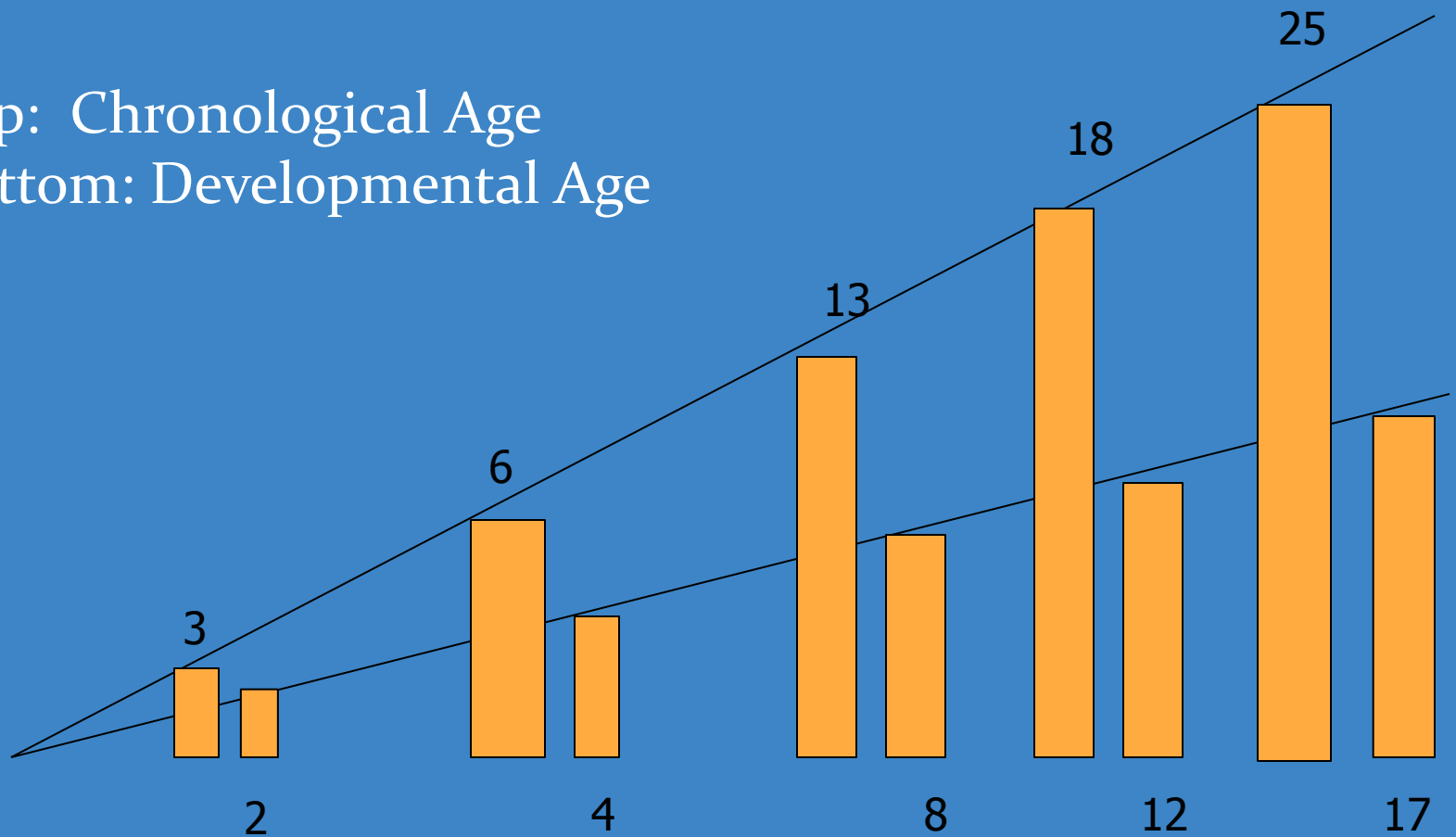
- 94% Mental health issues
- 80% Independent living
- 80% Maintaining employment
- 70% School challenges
- 60% Encounter with the law
- 50% Abuse alcohol/drugs
- 45% Legal problems with sexual behavior



Matson, et al. (2017) Fetal alcohol spectrum disorders. (power point slide). Retrieved from NOFAS Northern California: A Silent Epidemic Fetal Alcohol Spectrum Disorders Conference.

# Dysmaturity: Chronological vs. Developmental Age

Top: Chronological Age  
Bottom: Developmental Age





# Common Strengths

- Intense and determined
- Curious
- Concrete, contextual learner
- Friendly, generous, loyal, loving
- Music (playing instruments, composing, etc.)
- Creativity (art activities)
- Doing work on the computer
- Working with hands (woodworking, crafting...)
- Good with animals



# Strategies

*Try Differently, Not Harder*



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## First Step: Be in the Right Frame of Mind

Having behaviors	Experiencing symptoms
Won't or defiant	Can't
Refuses to sit still	Under or over stimulated
Resisting or doesn't care	Doesn't get it
Lying (Confabulation)	Memory deficits
Doesn't Try	Tired of failing



# The Basics...

- Get informed
- Not all strategies are transferable from one individual to another
- Compassion for each other (both for the caregivers and providers)
- Caution:
  - Tough love does not work
  - Do not get into a power struggle
  - Observe, do not assume



# Hawaii FASD Conference

## FASD: Integrating Trends and Applications

\*September 9, 16, 23, 30 @ 12pm-1:30pm Zoom

\*Registration Open Now till 9/8/21

<https://hawaiifasd.org/fasd-virtual-conference-2021/>

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