

FETAL ALCOHOL SPECTRUM DISORDER (FASD) AWARENESS, PREVALENCE, SUPPORT, AND MANAGEMENT IN NATIVE COMMUNITIES

*Alyce Spotted Bear and Walter Soboleff
Commission on Native Children*

Annika Montag, PhD

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Fetal Alcohol Spectrum Disorder (FASD)

- FASD, a developmental disability that results from prenatal alcohol exposure
- It is a *collection* of different disorders that may involve a number of physical and mental effects
- Leading known cause of learning disabilities
- It is common; conservative estimates are 1-5% but may be up to 10% of the US population
 - More common than autism, Down syndrome, muscular dystrophy, and spina bifida
- Conditions range from mild to severe
- FASDs can't be cured; they are permanent. But they can be treated and managed



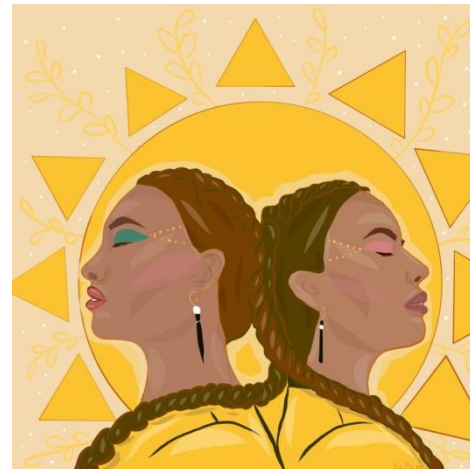
Variable Susceptibility of the Effects of Alcohol

Maternal

- Drinking pattern: timing and magnitude of exposure
- Differences in absorption, distribution, metabolism
- Genetic and epigenetic differences
- Comorbidities, environmental exposures
- Nutritional status and vitamins
- Age and parity

Fetal

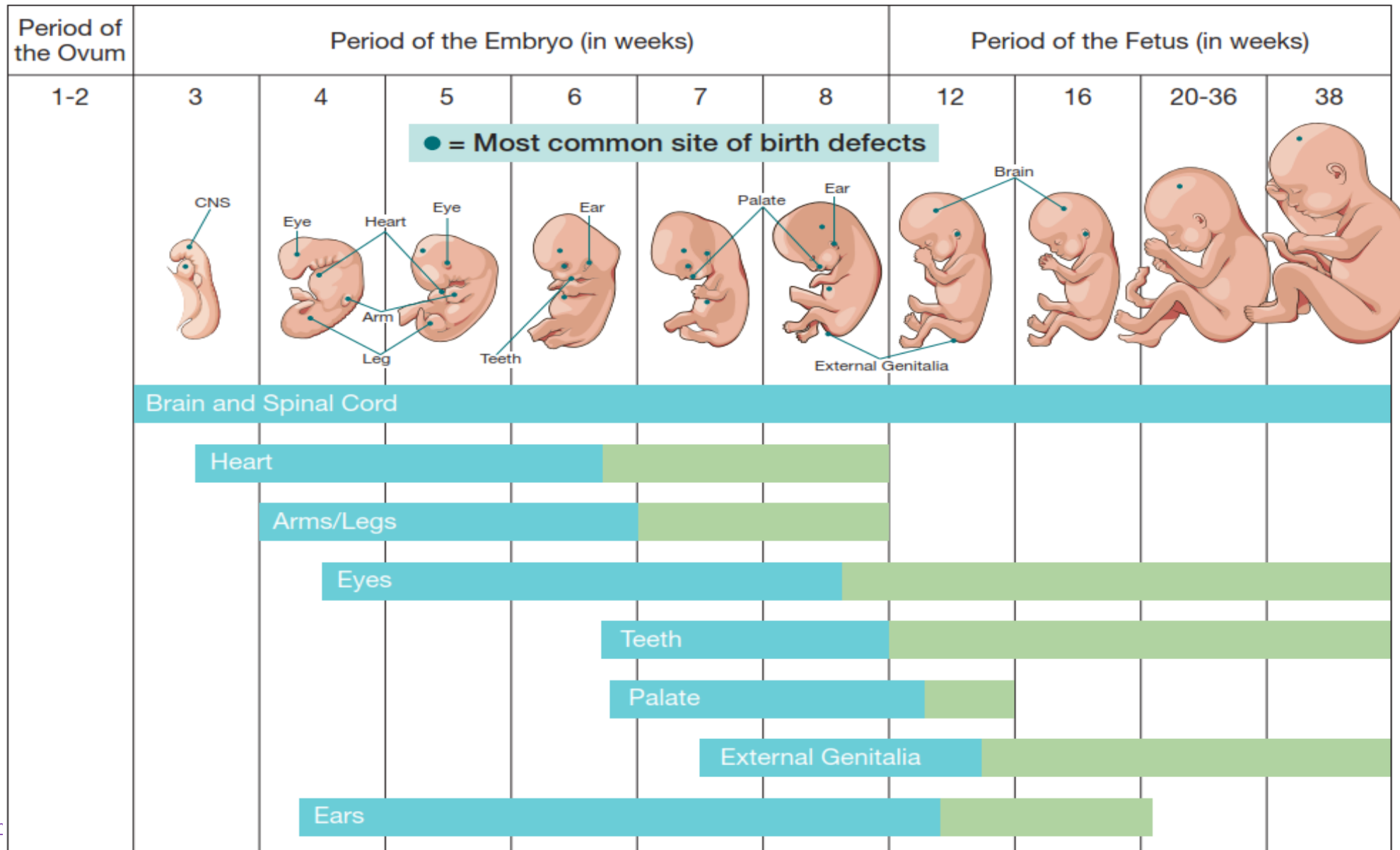
- Genetic differences
- Windows of development



Artist: Tiffany Wolfe

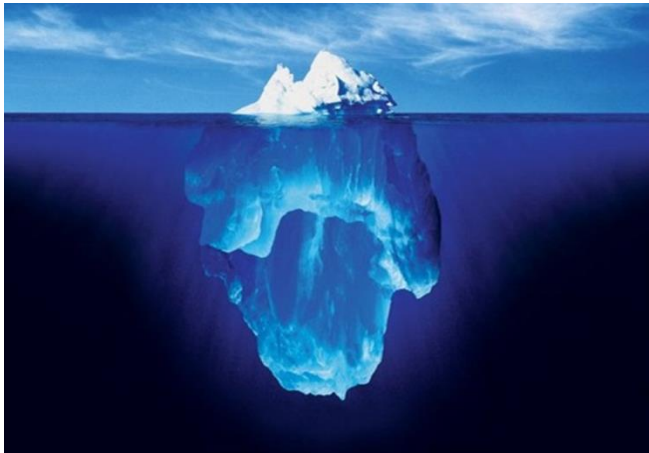


Critical Periods in Human Development



Within FASD are:

- FAS, Fetal Alcohol Syndrome
- PFAS, Partial Fetal Alcohol Syndrome
- ARND, Alcohol Related Neurodevelopmental Disorders
- ND-PAE, Neurodevelopmental Disorders Prenatal Alcohol Exposure



Fetal Alcohol Syndrome

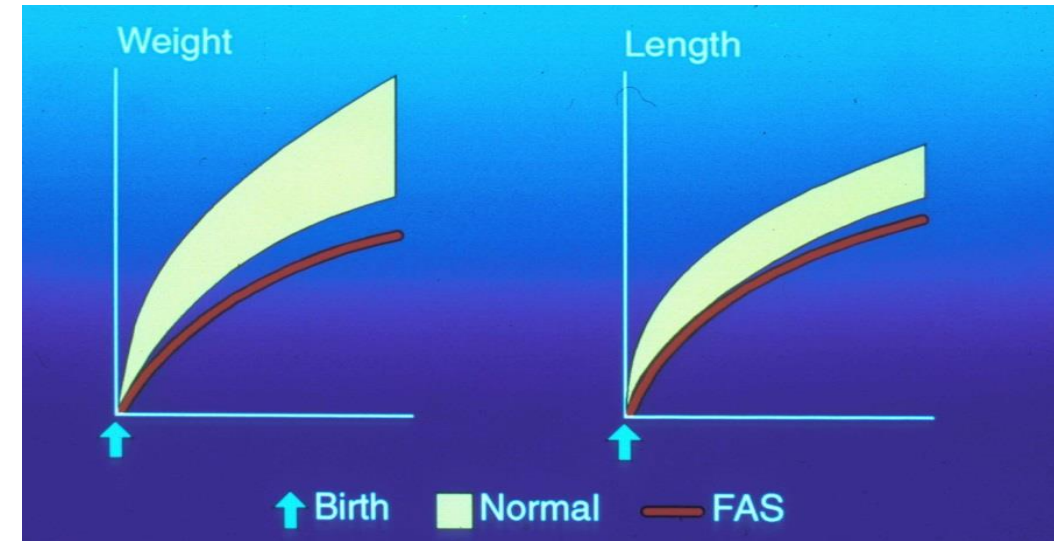


FAS is a diagnosis based on these specific findings:

- Growth deficits
- Central Nervous System / Neurobehavioral Disorders
- Specific facial abnormalities



Growth Deficits



Microcephaly



Central Nervous System / Neurobehavioral Symptoms

Structural

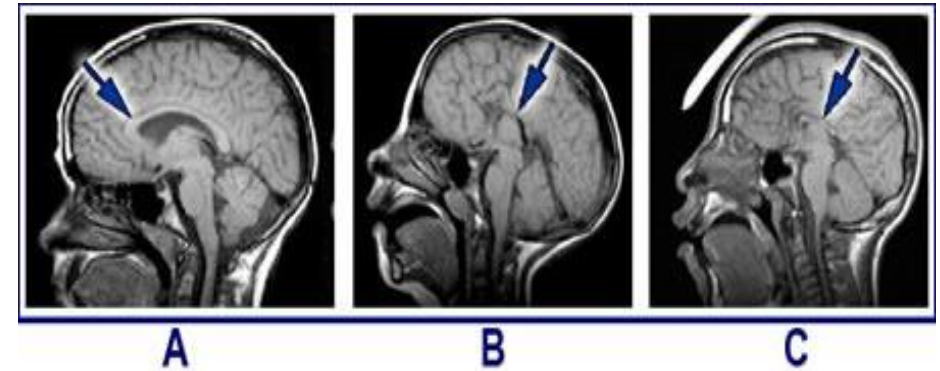
- Small head circumference
- Clinically significant brain abnormalities observable via brain imaging

Neurologic Problems

- Poor coordination
- Visual motor difficulties
- Poor motor control

Functional Deficits

- Cognitive or developmental
- Executive function
- Attention deficits or hyperactivity
- Motor functioning delay
- Other (sensory, memory, not understanding cause and effect)



- A. MRI of 14-year-old with normal corpus callosum
B. 12-year-old with FAS and a thin corpus callosum
C. 14-year-old with FAS and agenesis (absence) of the corpus callosum

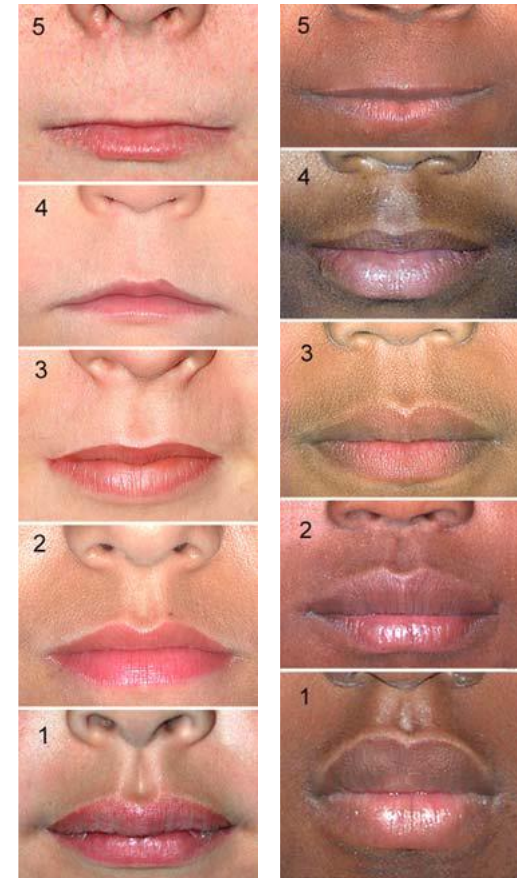
Three Cardinal Facial Features

Must have 2 of 3 for diagnosis:

Palpebral fissure length
 $\leq 10^{\text{th}}$ percentile

Smooth Philtrum
4 or 5 on Lipometer scale

Thin Vermilion Border
4 or 5 on Vermilion Lipometer scale



Lip-Philtrum Guide 1

Lip-Philtrum Guide 2

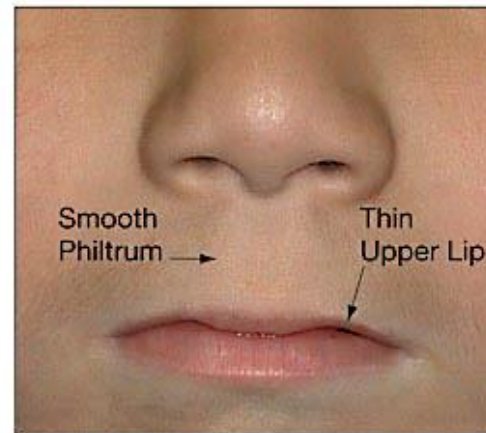
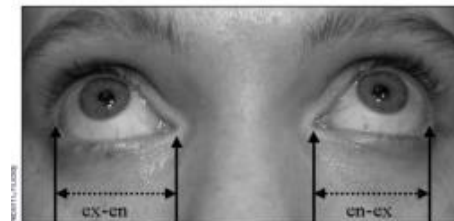


Photo: Susan Astley

ND-PAE

- Global IQ (≤ 70 on a standard IQ test)
- Executive functioning
- Learning
- Memory
- Visual spatial reasoning

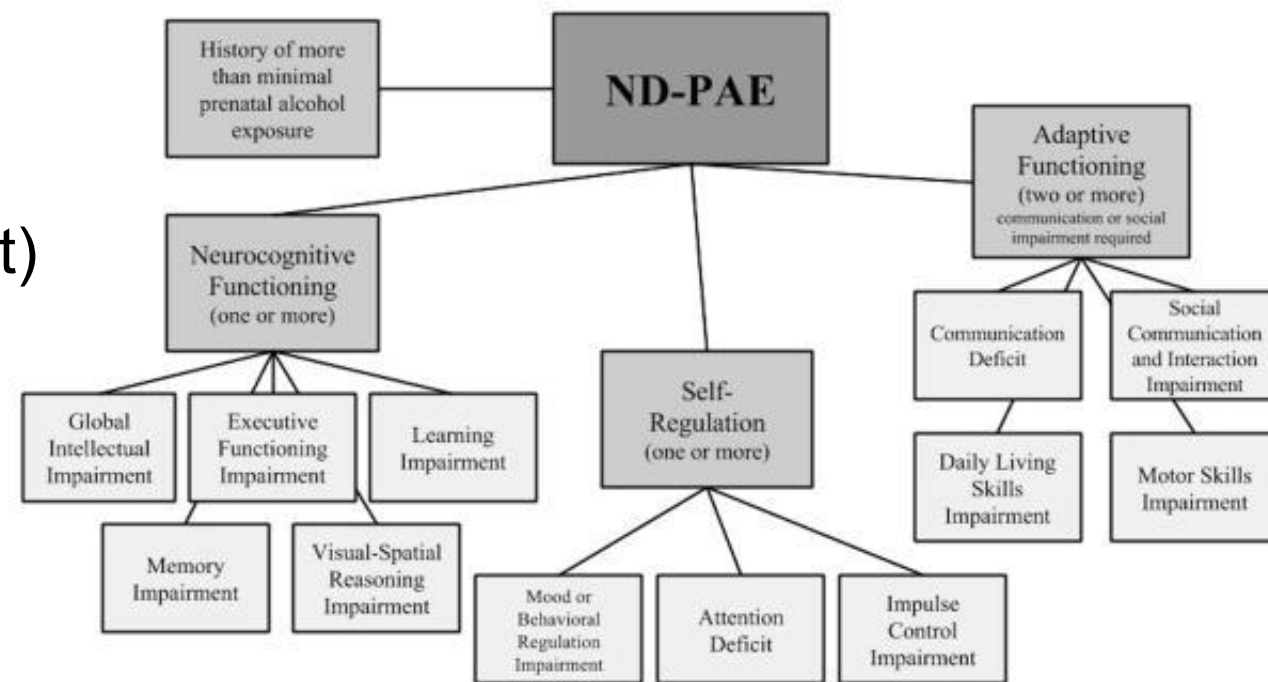


Figure from DSM5, Doyle & Mattson 2015

Common issues experienced

- Sensory: overstimulation, stress reactivity
- Social skills: easily influenced by others, misinterpret social cues
- Communication: abstract speech and idioms
- Information processing: slower processing, attention shifting, planning, organizing, extrapolating, abstract reasoning (time, money, math, etc.)
- Memory: short and long term memory impairment



Why is FASD mostly undiagnosed or misdiagnosed?

More than 85% of cases are misdiagnosed or undiagnosed

- Health care personnel often unaware of FASD or how to identify
- Diagnostic criteria is evolving and exists in different forms; no national consensus; require multidisciplinary teams
- Most children do not have facial dysmorphology
- Lack of relevant biomarkers
- Providers feel uncomfortable asking mothers about alcohol consumption
- Mothers may be reluctant to report perinatal alcohol exposure
- Absence of exposure information for adopted or foster children

Children with FASD most often DO NOT have an FASD diagnosis

Other diagnoses they may have:

- Attention-deficit/hyperactivity disorder (ADHD)
- Pervasive developmental disorders (PDD)
- Oppositional defiant disorder (ODD)
- Conduct disorder (CD)
- Autism (ASD)

May have concurrent or secondary conditions:

- Depression
- ADHD
- Post Traumatic Stress Disorder (PTSD)



Change makers Myles Himmelreich, CJ
Lutke, Emily Travis

Prevalence

Prevalence estimates vary by community, and depending upon research methods and diagnostic criteria

- Recent active ascertainment FASD estimates
 - **U.S. National** study
 - Conservative: 1.1 - 5.0%
 - Weighted: 3.1 - 9.9%
 - **Reservation-based** study
 - Conservative: 4.1%
- Meta-analysis of **global** FASD estimates
 - FASD 2.3% (0.1-11.3%)
- Meta-analysis of various **international subpopulation** FASD estimates
 - Children in care: FAS 5.2 – 14.2%; FASD 25.2 – 31.2%
 - Correctional: 14.7%
 - Special education: FAS 2.9%; FASD 8.4%
 - Aboriginal: FAS 0.2 – 6.1%; FASD 0.4 – 4.4%



Photo by Heidi Estrada

Treatment, Management, and Support

Goal: *Wrap-around culturally congruent care for the individual, caregiver, family, and community*

Appropriate Care

- Medical care including medications
- Behavioral interventions
 - Examples: MILE, Good Buddies, GoFAR
- Caregiver support
 - Examples: Families Moving Forward, FASD United, Healthy Native Nation Family Support, Triple P within Bigiswun Kids
- Community based services
 - Childcare/respice
 - Advocates
 - Local access to all above

Limited options exist
Few validated within Native
communities



Safe by Tiffany Wolfe

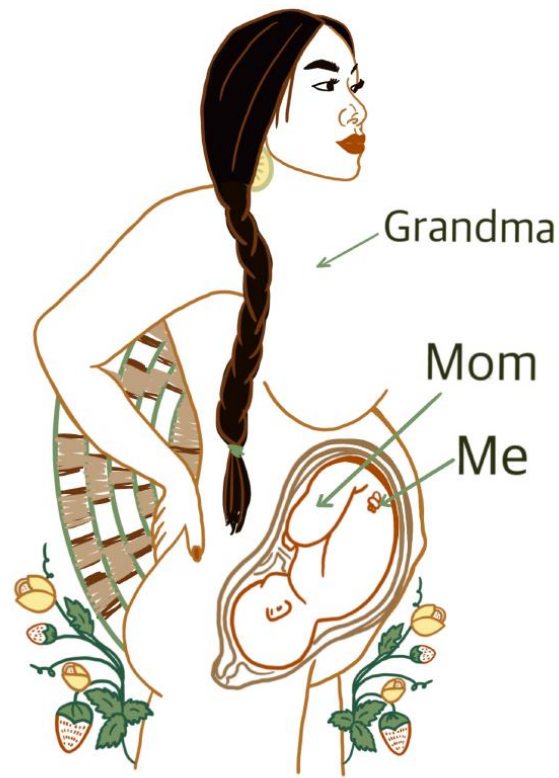
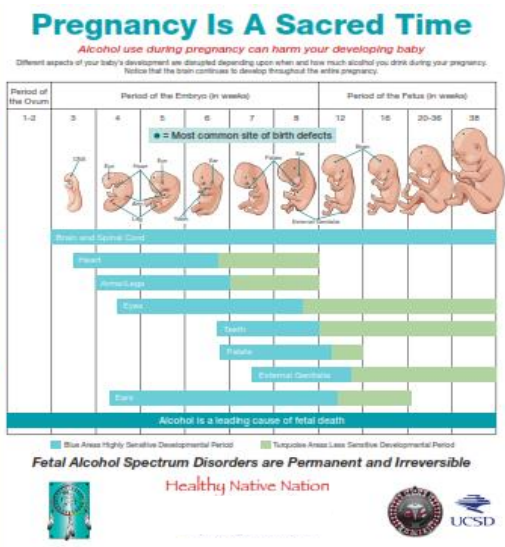
Recommendations

- National strategic plan for Native communities
 - Funding for novel, as opposed to recycled, programs
 - Funding and support for Tribal/ Community IRBs
 - Ombudsman for interactions with government agencies
 - Adoption of FASD as qualifying diagnosis for services
 - Address stigma and lack of awareness of FASD
- Local
 - Professional training and education
 - Local diagnosis
 - Local services
 - Expanded pediatric mental health services with timely access – for caregivers too
 - Local support including trained cadre of advocates and certified special needs childcare providers, advocates, resource center, facilitating access to existing resources



Artist: Shane Ward

Thank you! Questions?



Three Generations by Tiffany Wolfe



Posuun Loovig (Her Heart is Good) by Anthony Hurtado