



Examining Characteristics of Children with Fetal Alcohol Spectrum Disorders (FASD): A Retrospective Records Review

Capstone Project

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Agenda

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- Research Team
- Background
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- Research
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- Dissemination

Acknowledgements

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- No conflict of interest to disclose

Research Team

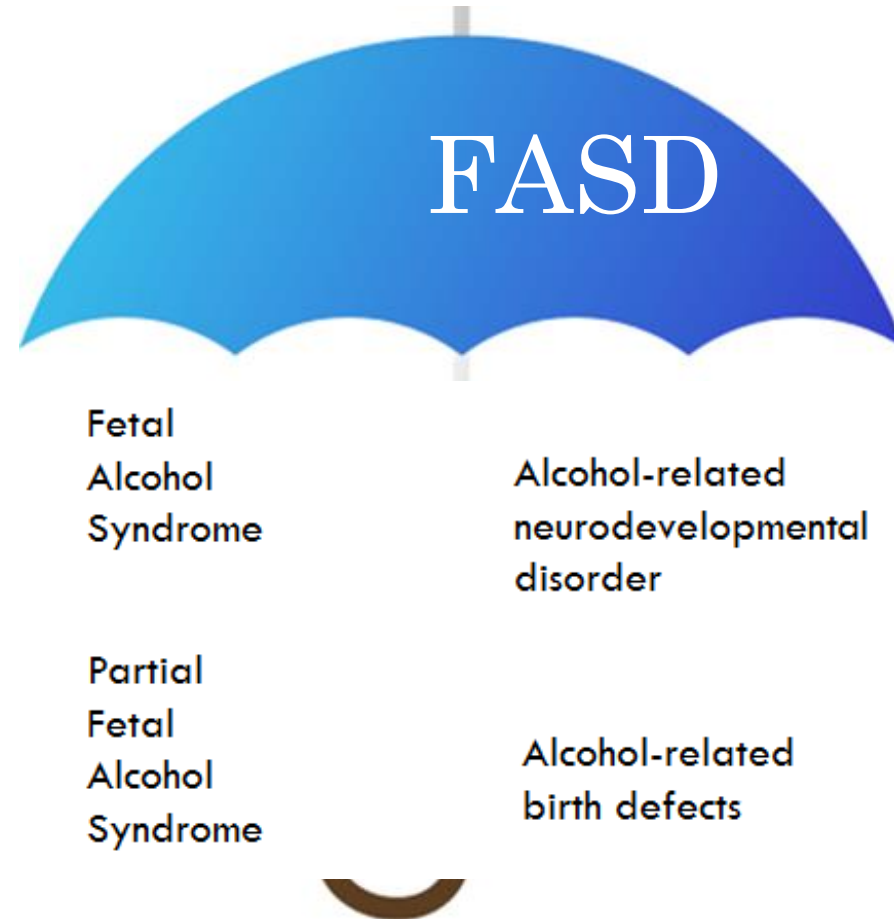
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- Research Team:
 - Dina Hill, Ph.D. (co-investigator)
 - Tiffany Otero, Ph.D. (co-investigator)
 - Cassandra Cerros, Ph.D. (co-investigator)
 - Amanda Jaeger (graduate research assistant)



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& DISABILITY

Background

Diagnosing Fetal Alcohol Spectrum Disorder (FASD)



Signs and Symptoms

- Abnormal facial features
- Small head size
- Low birth/body weight
- Poor coordination
- Emotional regulation difficulties
- Poor attention
- Learning disabilities (especially in math)
- Speech and language delays
- Low IQ
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with heart, kidneys, or bones



CDC (2019)

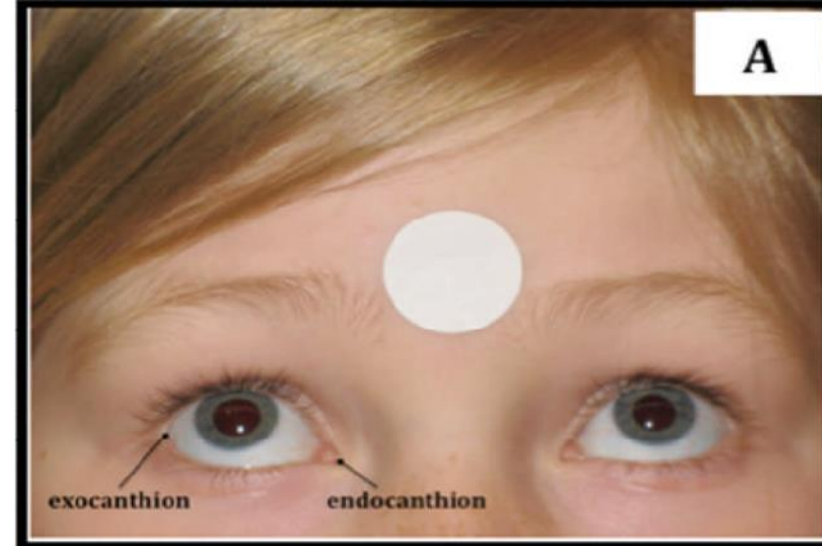
Minor Facial Anomalies



Lip-Philtrum Guide I

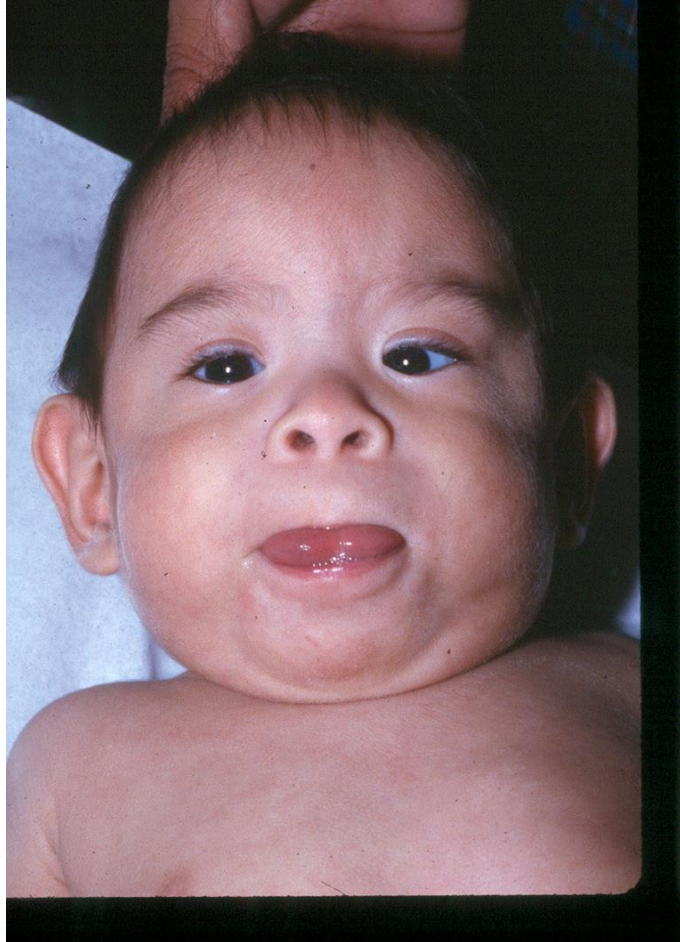
Thin vermilion border of upper lip (score of 4 or 5 on lip/philtrum guide)

Smooth philtrum (score of 4 or 5 on lip/philtrum guide)



Short palpebral fissures ($\leq 10^{\text{th}}$ %ile)

Deficient brain growth



Infant with FAS who has obvious microcephaly, short palpebral fissures, short upturned nose, long philtrum with thin upper lip. Philtrum appears smooth but need to assess when the mouth is relaxed.

What is it like to live with FASD?

- Video (beginning to 1:09)

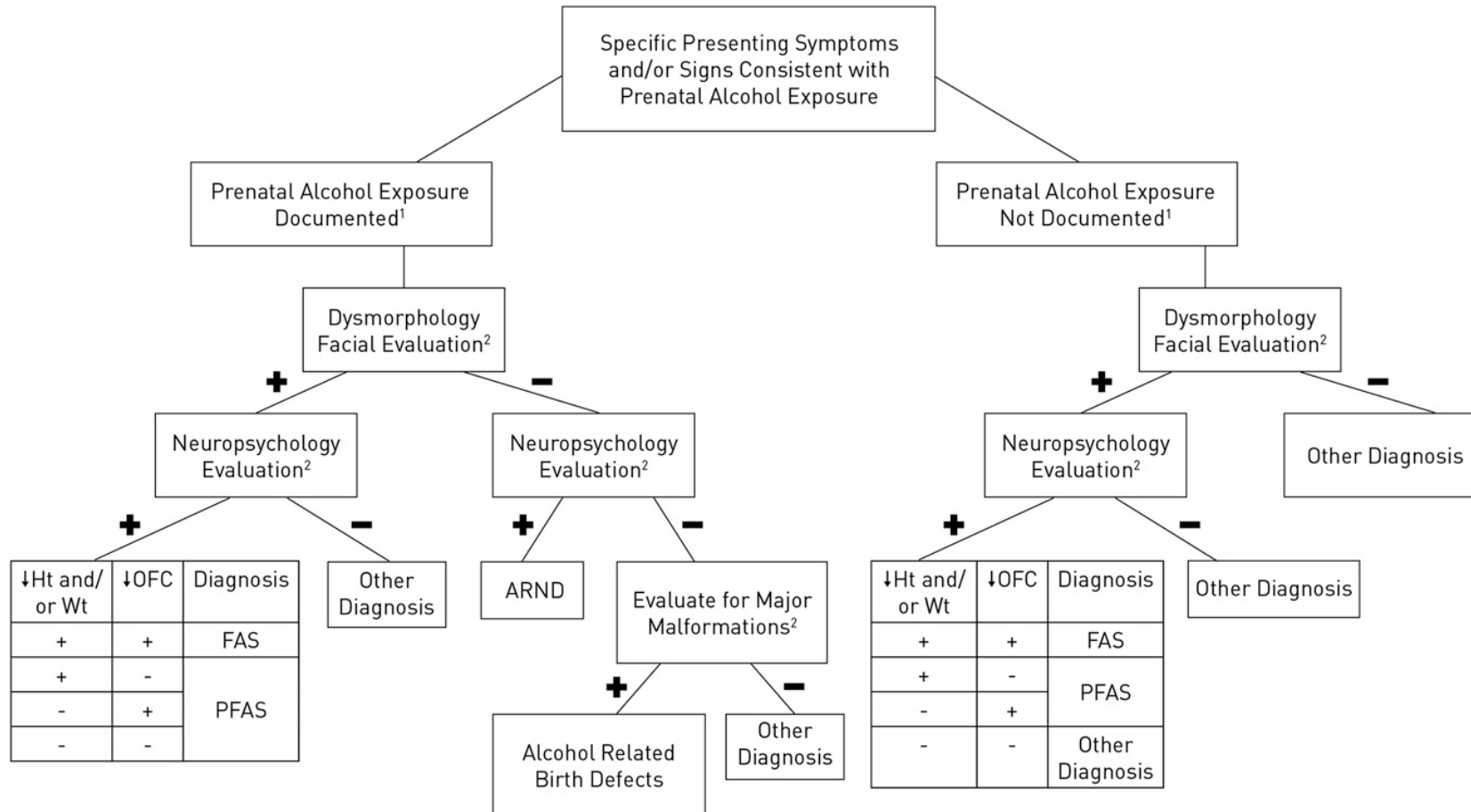


Risk Factors for FASD

- Quantity of alcohol consumed
- Pattern of exposure (binge vs. chronic)
- Developmental timing of exposure
- Genetic variation
- Maternal health status
- Socioeconomic status
- Interaction with nutritional variables
- Synergistic interactions with other drugs
- Stress level in the mother (cortisol)



Diagnosing FASD



Prevalence of FASD

- Current prevalence rates for FASD (May, 2018) suggest approximately 11.3 to 50 cases per 1000 children (1.1% to 5.0%)
- May et al. (2014): 6-9 cases of FAS in 1000 children, 24-48 cases of FASD in 1000 children
- The CDC (2002): up to 1.5 cases of FAS per 1000 births
- For comparison, according to the Autism and Developmental Disabilities Monitoring Network (CDC, 2018), the current prevalence estimates for ASD are 16.8 per 1000 (or 1 in 59). Range estimates are 13.1-29.3 per 1000 children (1.3% to 2.9%).

Complexity of Identification

- FASD is likely underdiagnosed
 - Stigma of maternal alcohol use leading to under-reporting
 - Dysmorphic features can be less noticeable in newborns
 - Neurobehavioral deficits may not be recognized until preschool age
 - Less consideration for prenatal alcohol use to be underlying factor in behavioral and learning disorders
 - Focus on measuring FAS, rather than FASD
- Symptoms overlap other conditions (e.g., ADHD)
- Type and amount of toxic exposure is difficult to obtain
 - Birth records
 - Caregiver report
 - Witness report
- Environmental factors may impact presentation
 - Access to services
 - Adverse childhood experiences



Problem Statement

- Children with a Fetal Alcohol Spectrum Disorder (FASD) present with complicated cognitive and behavioral challenges
- These challenges require intervention from a multi-disciplinary team of providers.
- Due to challenges in diagnosis and vulnerabilities of this population, many children may not be receiving the services that would improve their prognosis and overall quality of life.
- We don't know which children are accessing services (e.g., special education, mental health services, social support, etc.) and what services are providing the most benefit.
- Because of that lack of knowledge, there is limited research on intervention practices for FASD.

Goal of Project

- Conduct a retrospective chart review to examine demographic and clinical characteristics, as well as which services are being accessed and by whom.
- Primary Questions:
 - (1) What are the demographics and experiences of this population (e.g., age, ethnicity, placement, age of diagnosis)?
 - (2) What are the cognitive and behavioral challenges these children present with?
 - (3) What, if any, relationships exist between demographic characteristics, cognitive and/or behavioral challenges, and access to services?
 - (4) What, if any, relationships exist between access to services and outcomes (i.e., do children who access specific interventions show greater improvement)? By looking at a subsample of children with multiple interactions with our clinic, we can gather information about these variables and determine potential predictors of improvement.

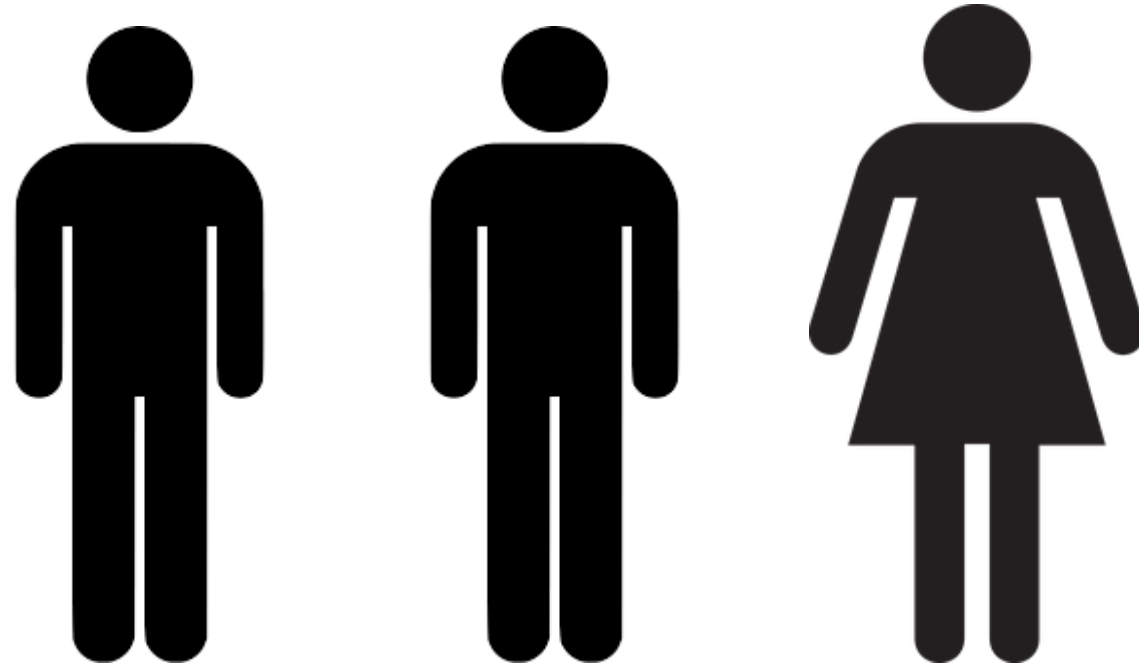
Research Project

Research

- Methods
 - Inclusion Criteria
 - Referred for concerns related to prenatal alcohol exposure
 - Seen in the clinic between August 2013 and August 2018
 - Original intent: Multiple time points
 - Revised focus: Case studies of school age children with diagnosed FASD
 - Design
 - Case Study
 - Data Collection and Reliability
 - REDCap Database tool
 - Variables: Demographics, diagnoses, medical history, educational history, results of testing.
 - Review 20% of cases, resolve discrepancies

Findings

- Case Studies of three children with known or suspected FASD.
 - 1- “John”
 - 2- “Jack”
 - 3- “Jane”



Child 1

- Pseudonym: John
- Age at initial appointment: 2 years, 9 months
- FASD Diagnosis: Alcohol Related Neurodevelopmental Disorder (ARND)
- Other diagnoses: Developmental Coordination Disorder, Speech Sound Disorder, Language Disorder
- Ethnicity: Native American (Navajo)
- Prenatal Exposures: Alcohol and Marijuana
- Medications: None
- Adverse Life Experiences: Disruption of caregiver relationship due to displacement or death.

Child 1 Test Data and Services

- Test Data

- Age 2:
 - Adaptive Behavior (Vineland-II): SS=74 (Very Low)
- Age 5 years, 5 months:
 - WPPSI-IV: GAI SS= 67 (Extremely Low); Verbal SS-71 (Very Low); Visual Spatial SS=78 (Very Low); Fluid Reasoning SS=82 (Low Average).
 - Behavior (BASC-3): Externalizing Problems T= 58 (Typical), Internalizing Problems T=76 (Clinically Significant), Behavioral Symptoms T=71 (Clinically Significant), Adaptive Skills T=26 (Clinically Significant)
 - Adaptive Behavior (ABAS-3): General Adaptive Composite SS=85 (Low Average)
 - Receptive Language SS=81 (Low Average); Expressive Language SS= 80 (Low Average)
 - Visual Motor Integration Test (VMI-6): SS=60 (Extremely Low)

- Services

- Age 2: Occupational Therapy, Speech Language Therapy, Physical Therapy
- Age 5:
 - 100% special education preschool placement
 - Eligibility: Developmental Delay
 - Speech and Language Therapy, Occupational Therapy, Physical Therapy and Adaptive PE.

Child 2

- Pseudonym: Jack
- Age at initial appointment: 4 years, 10 months
- FASD Diagnosis: Partial Fetal Alcohol Syndrome
- Other diagnoses: Cerebral palsy, Cortical visual impairment (CVI), painless limp, mild persistent asthma, recurrent croup, pes planus (flatfoot), osteopenia, mild tone differences
- Ethnicity: Hawaiian/Pacific Islander
- Prenatal Exposures: Alcohol, Tobacco, Cocaine, Heroin, Methadone, Opiates, Amphetamines, Benzodiazepines
- Medications: Methylphenidate, Risperidone, Albuterol via inhaler, and nebulizer
- Adverse Life Experiences: Disruption of caregiver relationship due to displacement or death (placed with foster family, then adopted).

Child 2 Test Data and Services

- Test Data

- Age 4 years:
 - Behavior (BASC-3): Externalizing T=69 (At-Risk), Internalizing T=44 (Typical), Behavioral Symptoms T=61 (At-Risk), Adaptive T=37 (At-Risk)
 - Cognitive (WPPSI-IV): GAI SS=74 (Very Low)
 - Visual Motor (Beery VMI-6): SS=92 (Average)

- Services

- Special Education Services
 - Eligibility: Developmental Delay
 - Speech/Language Therapy, Occupational Therapy, Physical Therapy, Orientation & Mobility, School Health
- Individual counseling

Child 3

- Pseudonym: Jane
- Age at initial appointment: 12 years, 8 months
- FASD Diagnosis: Alcohol-Related Neurodevelopmental Disorder
- Other diagnoses: Post-Traumatic Stress Disorder, Reactive Attachment Disorder of Childhood, Attention-Deficit/Hyperactivity Disorder, combined presentation
- Ethnicity: Latinx/Hispanic
- Prenatal Exposures: Alcohol, Heroin
- Medications: Montelukast, Qvar, Flonase, Allegra, Concerta, Aripiprazole
- Adverse Life Experiences: Physical abuse, physical neglect, substance misuse within household, incarcerated household member, disruption of caregiver relationship due to displacement or death

Child 3 Test Data and Services

- Test Data

- Visual Motor (Beery VMI-6) SS=70 (Very Low)
- Cognitive (WASI-II) SS=90 (Average), Verbal SS=96 (Average), Perceptual Reasoning SS= 87 (Low Average)

- Services

- Special Education Services
 - Eligibility: Emotional Disturbance
 - Social work services
 - Behavior Intervention Plan
- Individual psychotherapy
- Residential Treatment- 6 months

Product

- Training to EI providers (Fall 2018)
- Poster Presentation to funding agency (Fall 2019)
- Further develop behavioral and educational training programs for intervention



Dissemination

- Poster presented at national conference
 - NASP
 - ABPdN
 - AUCD

Manuscript preparation to begin following data collection and analysis (Summer 2020)

Selected References

- Hoyme, H.E., et. al., (2016). Updated clinical guidelines for diagnosing Fetal Alcohol Spectrum Disorders. *Pediatrics*, 138 (2), doi: 10.1542/peds.2015-4256
- May 2018, P.A., Chambers C.D., Kalberg, W.O., (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US communities. *JAMA*, 319(5), 474-482.