Introduction to Fetal Alcohol Spectrum Disorder (FASD) Diagnosis and Assessment: The Role of the Psychologist

Northwest Psychological Fall Convention

1

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Alaska's Department of Health and Social Services, Office of Substance Misuse and Addiction Prevention

Opening Statements

2

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Overview of identification and diagnosis of FASD

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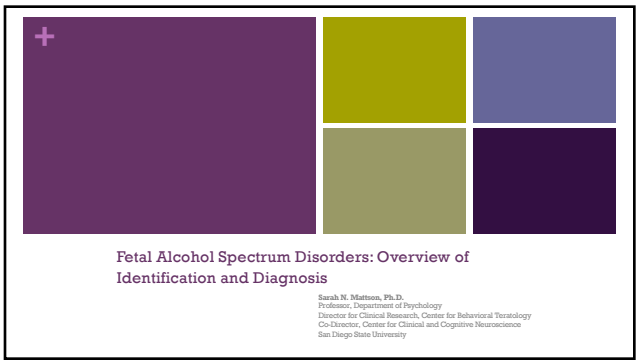
3



4

Acknowledgements

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- **CIFASD Collaborators**: Edward Riley (SDSU); Julie Kable, Claire Coles (Emory University); Jeff Wozniak, Chris Boys (University of Minnesota); Elizabeth Sowell (USC/CHLA); Ken Jones (UCSD); Tatiana Foroud, Leah Wetherill (Indiana University); Peter Hammond, Mike Suttie (University College London); Ganz Chockalingam (Blue Resonance)
- **Center for Behavioral Teratology, SDSU**: Eileen Moore, Matthew Hyland, Natasia Courchesne, Riley Felicicchia, Gemma Bernes, Tara Jahan, Carissa Zambrano, Chloe Sobolewski, Kaitlin Carroll, Emily Duprey, Jill Vander Velde
- **Disclosures**: None

5

Outline

- What is FASD?
- The role of the psychologist in diagnosis
- New tools to aid identification and diagnosis
- Summary
- Questions

6

What is FASD?

7

Fetal Alcohol Spectrum Disorder (FASD)

- FASD is a group of neurodevelopmental disorders
  - Fetal alcohol syndrome (FAS)
  - Partial fetal alcohol syndrome (PFAS)
  - Alcohol-related neurodevelopmental disorder (ARND)
  - Alcohol-related birth defects (ARBD)
- The cause of FASD is exposure to alcohol *in utero*
- Cognitive and behavioral difficulties are hallmarks of FASD

8

FASD is not Rare

- A recent epidemiologic study, CoFASP, evaluated a total of 6,639 children selected from a population of 13,146 first graders from 4 communities in the U.S.
  - Rocky Mountain, Midwestern, Southeastern, and Pacific Southwestern regions
- Average age was 6.7y; 51.9% were male, and 79.3% were white (maternal race)
- A total of 222 cases of FASD were identified
- Conservative prevalence estimates for FASD ranged from 11.3-50.0 per 1000 children **[1.1-5.0%]**

May et al., 2018

9

Definition of Documented Prenatal Alcohol Exposure

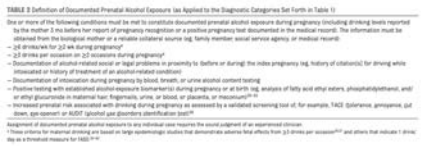
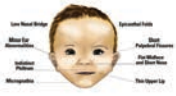


Table from: Hoyme et al., 2016

10

Fetal Alcohol Syndrome (FAS)

- The effects of prenatal alcohol exposure were first described by Lemoine (1968) and Jones & Smith (1973)
- Jones & Smith described a pattern of primarily physical features in a small group of children born to alcoholic women and coined the term, "Fetal Alcohol Syndrome"
- Diagnostic criteria were updated by the Institute of Medicine (1996) and Hoyme (2005, 2016)



Jones & Smith, 1973; Hoyme et al., 2016, Figure from Warren et al., 2011

11

Summary of Features

Domain	Feature	Requirement	Detail
Face	Palpebral Fissures	≤10th centile	
	Thin Vermilion Border	Rank 4 or 5 on a racially normed lip/philtrum guide	
	Smooth Philtrum	Rank 4 or 5 on a racially normed lip/philtrum guide	
Growth	Height and/or Weight	≤10th centile	
	Brain Abnormalities	OFC ≤10th centile	
		Structural brain abnormalities	
		Recurrent nonfebrile seizures	
Neurobehavioral Impairment	Cognitive Impairment	Global impairment	GCA or IQ estimate ≥1.5SD below mean
		1 or more neurobehavioral domain ≥1.5 SD below mean	executive functioning, specific learning impairment, memory impairment, or visual-spatial impairment
	Behavioral Impairment (without Cognitive)	1 or more behavioral domain ≥1.5 SD below mean	Self-regulation: mood or behavioral regulation impairment, attention deficit, or impulse control

12

Fetal Alcohol Syndrome (FAS)

A diagnosis of FAS requires all features, A–D:

A. A characteristic pattern of **minor facial anomalies**, including ≥2 of the following:
   1. Short palpebral fissures (≤10th centile)
   2. Thin vermillion border of the upper lip (rank 4 or 5 on a racially normed lip/philtrum guide, if available)
   3. Smooth philtrum (rank 4 or 5 on a racially normed lip/philtrum guide, if available)

B. Prenatal and/or postnatal **growth** deficiency
   1. Height and/or weight ≤10th centile (plotted on a racially or ethnically appropriate growth curve, if available)

C. Deficient **brain** growth, abnormal morphogenesis or neurophysiology, including ≥1 of the following
   1. Head circumference ≤10th percentile
   2. Structural brain anomalies
   3. Recurrent nonfebrile seizures (other cause of seizures have been ruled out)

D. **Neurobehavioral** impairment
   1. For children ≥3 y of age (a or b):
      a. WITH COGNITIVE IMPAIRMENT
      --Evidence of global impairment (general conceptual ability ≥1.5 SD below the mean, or performance IQ or verbal IQ or spatial IQ ≥1.5 SD below the mean)
      OR
      --Cognitive deficit in at least 1 neurobehavioral domain ≥1.5 SD below the mean (executive functioning, specific learning impairment, memory impairment, or visual-spatial impairment
      b. WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
      --Evidence of behavioral deficit in at least 1 domain ≥1.5 SD below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)
   2. For children <3 y of age:
      --Evidence of developmental delay ≥1.5SD below the mean

Table from: Hoyme et al., 2016

13

Partial FAS (PFAS) With Documented PAE

For children with documented prenatal alcohol exposure, a diagnosis of PFAS requires features A and B:

A. A characteristic pattern of **minor facial anomalies**, including ≥2 of the following:
   1. Short palpebral fissures (≤10th centile)
   2. Thin vermillion border of the upper lip (rank 4 or 5 on a racially normed lip/philtrum guide, if available)
   3. Smooth philtrum (rank 4 or 5 on a racially normed lip/philtrum guide, if available)

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      OR
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      b. WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
      --Evidence of behavioral deficit in at least 1 domain ≥1.5 SD below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)
   2. For children <3 y of age:
      --Evidence of developmental delay ≥1.5SD below the mean

Table from: Hoyme et al., 2016

14

Partial FAS (PFAS) Without Documented PAE

For children without documented prenatal alcohol exposure, a diagnosis of PFAS requires all features, A–C:

A. A characteristic pattern of **minor facial anomalies**, including ≥2 of the following:
   1. Short palpebral fissures (≤10th centile)
   2. Thin vermillion border of the upper lip (rank 4 or 5 on a racially normed lip/philtrum guide, if available)
   3. Smooth philtrum (rank 4 or 5 on a racially normed lip/philtrum guide, if available)

B. **Growth** deficiency or deficient brain growth, abnormal morphogenesis or abnormal neurophysiology
   1. Height and/or weight ≤10th centile (plotted on a racially or ethnically appropriate growth curve, if available), or:
   2. Deficient **brain** growth, abnormal morphogenesis or neurophysiology, including ≥1 of the following
      a. Head circumference ≤10th percentile
      b. Structural brain anomalies
      c. Recurrent nonfebrile seizures (other cause of seizures have been ruled out)

C. **Neurobehavioral** impairment
   1. For children ≥3 y of age (a or b):
      a. WITH COGNITIVE IMPAIRMENT
      --Evidence of global impairment (general conceptual ability ≥1.5 SD below the mean, or performance IQ or verbal IQ or spatial IQ ≥1.5 SD below the mean)
      OR
      --Cognitive deficit in at least 1 neurobehavioral domain ≥1.5 SD below the mean (executive functioning, specific learning impairment, memory impairment, or visual-spatial impairment
      b. WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
      --Evidence of behavioral deficit in at least 1 domain ≥1.5 SD below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)
   2. For children <3 y of age:
      --Evidence of developmental delay ≥1.5SD below the mean

Table from: Hoyme et al., 2016

15

The Diagnosis of FAS and PFAS Relies on Facial Features

- While the criteria for FAS and PFAS include cognitive and behavioral impairment, facial features are integral to the diagnosis
- The combination of facial features is relatively specific to FAS

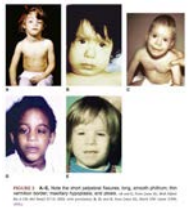


Figure from: Jones et al., 2013

16

The Diagnosis of FASD Reflects the Importance of Cognition and Behavior

- Facial features are not sufficiently sensitive
  - The majority of alcohol-exposed children are not dysmorphic
  - Children without facial dysmorphia demonstrate significant neurobehavioral deficits

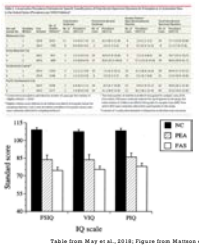


Table from May et al., 2018; Figure from Mattson et al., 1997

17

Alcohol-Related Neurodevelopmental Disorder (ARND)

Requires A and B (cannot be made definitively in children <3 y of age):

A. Documented prenatal alcohol exposure

B. Neurobehavioral impairment (a or b)
For children ≥3y of age (a or b):

a. WITH COGNITIVE IMPAIRMENT
--Evidence of global impairment Evidence of global impairment (general conceptual ability ≥1.5 SD below the mean, or performance IQ of verbal IQ or spatial IQ ≥1.5 SD below the mean)
OR
--Cognitive deficit in at least 1 neurobehavioral domain ≥1.5 SD below the mean (executive functioning, specific learning impairment, memory impairment, or visual-spatial impairment

b. WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
--Evidence of behavioral deficit in at least 1 domain ≥1.5 SD below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)

Table from: Hoyme et al., 2016

18

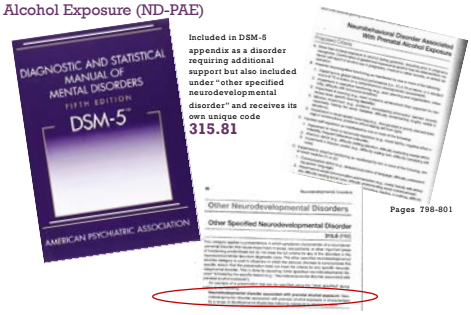
Requirements for Diagnosis

Diagnosis	Confirmed Prenatal Exposure to Alcohol	Facial Anomalies	Growth Deficiency	CNS Abnormalities	Neurobehavioral Impairment
FAS	Not Required	Required	Required	Required	Required
Partial FAS with documented PAE	Required	Required	Not Required	Not Required	Required
Partial FAS without documented PAE	Not Required	Required	1 or more required		Required
Alcohol-Related Neurodevelopmental Disorder (ARND)	Required	Not Required	Not Required	Not Required	Required

Hoyme et al., 2016

19

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)



Included in DSM-5 appendix as a disorder requiring additional support but also included under "other specified neurodevelopmental disorder" and receives its own unique code

315.81

Pages 798-801

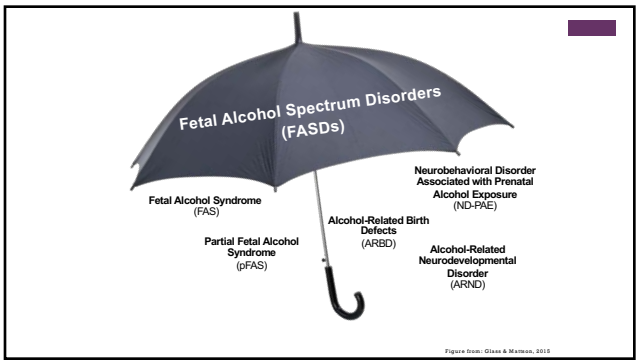
20

Core Symptoms of ND-PAE

- **More than Minimal Prenatal Alcohol Exposure**
- **Neurocognitive Impairment (one or more):**
  1. Impairment in Global Intellectual Functioning
  2. Impairment in Executive Functioning
  3. Impairment in Learning
  4. Impairment in Memory
  5. Impairment in Visual-Spatial Reasoning
- **Self-Regulation Impairment (one or more):**
  1. Impairment in Mood or Behavioral Regulation
  2. Impaired Attention
  3. Impairment in Impulse Control
- **Adaptive Functioning Impairment (two* or more):**
  1. Impairment in Communication
  2. Impairment in Social Interactions and Communication
  3. Impairment in Daily Living Skills
  4. Impairment in Motor Skills
- **Onset of Symptoms in Childhood**

DSM5 (2013), page 798-799

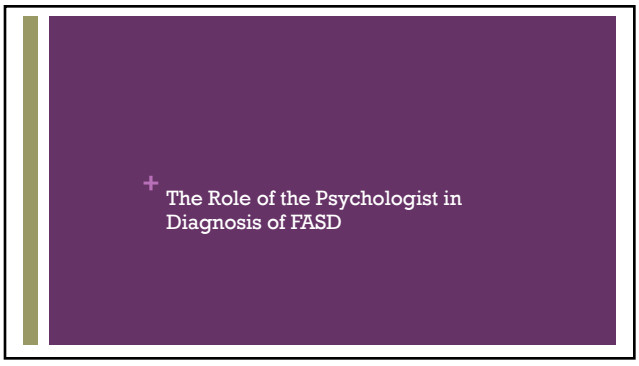
21


Fetal Alcohol Spectrum Disorders (FASDs)
Fetal Alcohol Syndrome (FAS)
Partial Fetal Alcohol Syndrome (pFAS)
Alcohol-Related Birth Defects (ARBD)
Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
Alcohol-Related Neurodevelopmental Disorder (ARND)
Figure from: Glass & Mattson, 2018

22


A Comparison Among 5 Methods for the Clinical Diagnosis of Fetal Alcohol Spectrum Disorders
Claire D. Coles, Amanda R. Galley, Jennifer G. Mulle, Julie A. Kable, Mary Ellen Lynch, and Kenneth Lyons Jones

23


The Role of the Psychologist in Diagnosis of FASD

24

Requirements for Diagnosis

Diagnosis	Confirmed Prenatal Exposure to Alcohol	Facial Anomalies	Growth Deficiency	CNS Abnormalities	Neurobehavioral Impairment
FAS [1]	Not Required	Required	Required	Required	Required
Partial FAS with documented PAE [1]	Required	Required	Not Required	Not Required	Required
Partial FAS without documented PAE [1]	Not Required	Required	1 or more required		Required
Alcohol-Related Neurodevelopmental Disorder (ARND) [1]	Required	Not Required	Not Required	Not Required	Required
Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) [2]	Required	Not Required	Not Required	Not Required	Required

[1] Hoyme et al. (2016)
[2] From the Diagnostic and Statistical Manual (American Psychiatric Association, 2013)

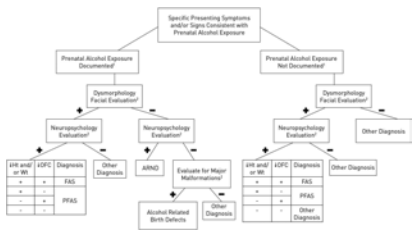
25

Neurobehavioral Impairment is Part of all FASD Diagnoses

- FASD diagnosis should be conducted by a multidisciplinary team that includes a psychologist, neuropsychologist, or other developmental clinician

26

FASD diagnostic algorithm.



H. Eugene Hoyme et al. Pediatrics 2016;138:e20154256

PEDIATRICS

27

Neurobehavior From 10,000 Feet

- Global intellectual deficits
  - Intellectual deficiency (IQ<70 plus adaptive function deficits) common but not universal
  - Average IQ in the 70s-80s
- Deficits in executive function, verbal learning, nonverbal learning/memory, language visuospatial function, motor function, and attention
- Problem behaviors including hyperactivity, impulsivity, distractibility
- Elevated rates of psychiatric disorders including ADHD, conduct disorder, oppositional defiant disorder, depressive disorders
- Academic difficulties, adaptive behavior deficits, delinquency, substance abuse, legal trouble, dependent living
- Deficits occur in alcohol-exposed individuals with and without facial dysmorphology

Barr et al., 2006; Fryer et al., 2007; Mattson et al., 1998, 2011; O'Connor et al., 2001, 2002, 2006; , Ware et al., 2012

28

Psychologists Play a Critical Role in FASD Diagnosis

- Using current practices, as many as **80%** of affected children are not identified or are misdiagnosed
- Reasons for this failure include
  - Over-reliance on physical features – the majority of those affected are not dysmorphic and physical markers of exposure are not sufficiently sensitive
  - Drinking records are often unavailable (or not requested)
  - Stigma surrounding alcohol inhibits proper assessment
- A neurobehavioral profile that is reliable, valid, sensitive, and specific, will help us accurately identify these children
  - Providing a clinically useful, effective, and efficient screening tool will further improve the clinician's ability to identify children

Mattson & Riley, 2011; Chasnoff et al., 2015

29

New Tools to aid Identification & Diagnosis of FASD

30

Why Do We Need New Tools?

- 80% of affected individuals are undiagnosed or misdiagnosed
- There are not enough specialists trained in the diagnosis of FASD
  - In 2019, there were "at most just over 2 clinical geneticists per 1 million in the population." (Maiese et al., 2019)
- General clinicians are not confident in their knowledge of FASD or the skills needed for diagnosis
  - In 2002, 49% of Toronto-area family physicians surveyed had "very little confidence" in their ability to diagnose FAS and 18% had suspicions of FAS but did not make a diagnosis (Nevin et al., 2002)
  - In 2006, over 75% of pediatricians in Western Australia suspected FAS but did not make a diagnosis (Elliott. 2006)
  - In 2018, in the CoFASP epidemiologic study, only 2 of 222 (0.90%) children with FASD were known to be previously diagnosed (May et al., 2018)
- Traditional tools (lip/philtrum tools, palpebral fissure measurements) have weak to moderate reliability and are prone to error, even in experts
  - For example, at some ages, a 1mm difference in PFL results in a change from 25th% to 10th%

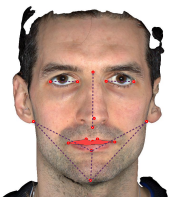
31

What Types of Tools are Being Developed?

- Telemedicine (Drs. Jones and Del Campo)
  - Allows evaluation of patients in remote areas or without access to specialists
  - Does not address the lack of specialists overall
- 3D facial imaging (Drs. Suttie, Mukherjee, and Hammond)
  - Can be used to automate facial examinations and also adds novel measurements to the standard exam
  - Requires specialized tools and analysis and not yet readily available but promising
- mHealth
  - MorpheusO
  - FASD-Tree
  - BRAIN-online

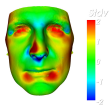
32

Clinical Translation of 3D Facial Analysis Techniques



Fully automated objective measurements of

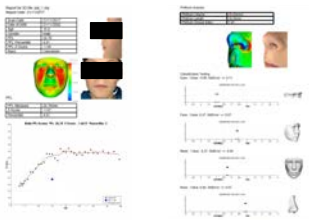
- PFL
- Nose/philtrum length
- Lip Area/Circularity and volume
- Micrognathia
- Shape analysis – philtrum shape, midfacial hypoplasia



Dr. Michael Suttie, Oxford University

33

Clinical Report



34

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- mHealth
  - MorpheusQ
  - FASD-Tree
  - BRAIN-online

35

MorpheusQ

- Lip & Philtrum Rank
- PFL measurement
- 3D Model

Patent

Dr. Edward Riley, SDSU, and Dr. Gaze Chockalingam, Blue Resonance

36

Goals of MorpheusQ Development

- To develop tools that would:
  - Empower non-dysmorphologists to screen for FAS
  - Provide more confidence
  - Improve accuracy in the diagnostic process
  - Make screening and diagnostic assistance in remote areas as accessible as in San Diego

Dr. Edward Riley, SDSU, and Dr. Gaea Chockalingam, Blue Resonance

37

Accuracy of MorpheusQ

Lip Rank

- Using MorpheusQ's lip rank tool, experts agreed 85% of the time on whether a patient had FAS with a correlation of .90
- Nonexperts agreed with the expert 78-88% of the time, , with a correlation of .82

Fig. 7. Example of scoring images with MorpheusQ. Subject on left, being matched in MorpheusQ by moving green slider bar.

Palpebral Fissure Length

- PFL measurements are reliable using MorpheusQ
  - SD of .47mm (range .41-.62mm) for repeated measurement (10x) of 3 people
- PFL measurements were compared using a mannequin
  - Calipers = 23.85mm
  - MorpheusQ = 23.38mm (SD = 0.4
  - After manual correction of endo- a landmarks, MorpheusQ = 23.67m

Dr. Edward Riley, SDSU, and Dr. Gaea Chockalingam, Blue Resonance

38

FASD-Tree

- We developed a web-based screening tool that aids in identification and diagnosis of FASD
- Only 4 measures are collected
  - Physical measurements
  - Parent report of behavior
    - CBCL
    - Vineland Adaptive Behavior Scale
  - IQ score (reported or assessed; optional)
- FASD-Tree produces two outcomes
  - Decision tree outcome (yes/no)
  - Risk score (0-5)

Patent in progress

39

FASD-Tree App

40

Accuracy of the FASD-Tree

- Both the decision tree and risk score were independently developed and validated in large samples (N>400 each) with overall accuracy rates >80%
- In a new sample, 312 children were evaluated using the FASD-tree (combining the decision tree and risk score)
- The FASD-Tree had overall accuracy of 81.3%
  - Decision tree alone was 76.9% accurate
  - Risk score alone was 84.2% accurate
- FASD-Tree outcomes relate to neuropsychological functioning (e.g., IQ and executive function)

Risk Scores Help Improve Diagnosis

41

Brief Assessment of Individual Neurobehavior (**BRAIN-online**)

- We developed a novel web-based neurobehavioral assessment designed to screen for cognitive impairment
- The test includes 7 subtests measuring fine-motor speed, reaction time, response inhibition/impulsivity, attention, problem-solving, processing speed, memory, spatial working memory, and set-shifting and
- Requires 30-45 minutes and is completed online independently by each individual using their home computer, laptop, or tablet (with connected keyboard)
- Reaction time and accuracy measures are available
- We have tested 100 youth and 300 young adults. Our research suggests that the results of BRAIN-online can distinguish between children with histories of prenatal alcohol exposure and controls

Patent in progress

42

Summary

- FASD is a complex neurodevelopmental disorder
- FASD is associated with a wide-ranging behavioral and cognitive impairment, and these effects are both sensitive and specific
- Yet, as many as 80% of affected children are not clinically identified
- New tools are under development to aid identification and diagnosis

43

Questions and Discussion

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44

Erika L. Stannard, PsyD
Ptarmigan Connections

Reporting using the 4-digit code

45

What is the FASD 4-digit code?

Erika L. Stannard, PsyD, Ptarmigan Connections

Reference:
Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition (2004). University of Washington.
Pediatric Neuropsychology: A Guide for Parents (2001). Division 40 of the American Psychological Association.

46

Our Discussion Today…

- What are the requirements for FASD evaluation in Alaska and Washington?
- Who conducts the evaluation? When should it be completed?
- How is the assessment done & what is this 4-digit code, anyway?
- Interpretation of test results & what results tell you about your patient
- Q & A

47

How does WA and AK conduct FASD Evaluations?

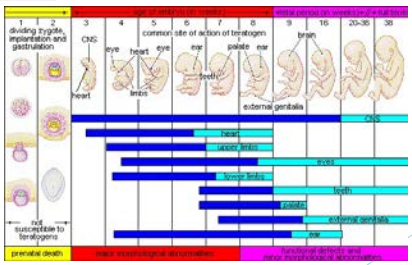
A FASD evaluation is an investigation of permanent birth defects caused by exposure to alcohol during development in the uterus.

The pattern of severity is dependent on the timing, frequency, and quantity of alcohol exposure.

Adverse childhood events confound the issue.

48

FASD is a challenge to diagnose



49

Both Alaska and Washington require team-based FASD assessments, using the University of Washington FASD 4-digit code

Alaska Department of Health and Social Services

- **Alaska** requires multi-disciplinary team evaluations

Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (FASDPN)

- **Washington** conducts 4-hour arena evaluations

FASD training:

The FASDPN at the UW offers free training for community professionals interested in learning how to recognize, refer, diagnose, treat, and prevent FASD. Information for how to enroll in the Training programs is posted on the WA FASDPN website.

http://depts.washington.edu/fasdpn/htmls/training.htm

50

Who conducts the evaluation?

The FASD team usually contains the following members, in addition to the all important **TEAM COORDINATOR.**

51

University of Washington
4-Digit Diagnostic Code

4444 = Most Severe Presentation

(multitude of codes increases accuracy and provides a spectrum for measurement)

1111 = Normal Growth

1 (complete absence) - 4 (strong presence)

- Growth Deficiency
- FAS Facial Phenotype
- CNS Abnormalities
- Prenatal Alcohol Exposure

52

The "Short Form"

53

DIGIT 1: GROWTH

Table 1: Deriving the ABC Score for Growth

Percentile Range	Circle the ABC-Scores for: Height	Weight
$\leq 3^{rd}$	C	**C**
$>3^{rd}$ and $\leq 10^{th}$	**B**	B
$>10^{th}$	A	A

Table 2: Converting the Growth ABC-Score to a 4-Digit Diagnostic Rank for Growth

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	**Moderate**	CB, **BC**, CA, AC
2	Mild	BA, BB, AB
1	None	AA

54

Which Growth Curves?

WHO Growth Standards Are Recommended for Use in the U.S. for Infants and Children 0 to 2 Years of Age

The World Health Organization (WHO) released a new international growth standard statistical distribution in 2006, which describes the growth of children ages 0 to 59 months living in environments believed to support what WHO researchers view as optimal growth of children in six countries throughout the world, including the U.S. The distribution shows how infants and young children grow under these conditions, rather than how they grow in environments that may not support optimal growth.

Recommendation

CDC recommends that health care providers:

- Use the WHO growth charts to monitor growth for infants and children ages 0 to 2 years of age in the U.S.
- Use the CDC growth charts to monitor growth for children age 2 years and older in the U.S.

Reference: https://www.cdc.gov/growthcharts/who_charts.htm

55

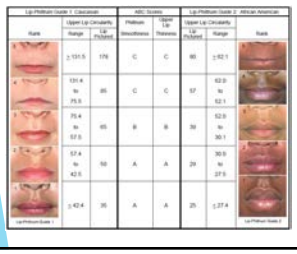
DIGIT 2: FAS Facial Phenotype

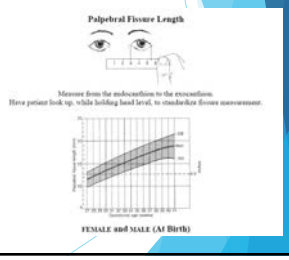
- Short palpebral fissure length
- Thin upper lip
- Smooth philtrum

56

Facial Feature Measurements

Caucasian and African American Norms





57

Typically completed with software analysis

Table 3: Deriving the ABC-Score for Facial Phenotype

5-Point Likert Rank for Philtrum & Lip	Z-score* for Palpebral Fissure Length	Circle the ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

Table 4: Converting the Facial ABC-Score to a 4-Digit Diagnostic Rank for Face

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

58

DIGIT 3: CNS Damage

BASIC PREMISE -

1. "Individuals with prenatal alcohol exposure can present with structural, neurological and/or functional CNS abnormalities;
2. that these CNS abnormalities occur along a continuum of severity; and
3. that not all functional abnormalities are due to underlying brain damage."

2 Scales in 1!

Underlying CNS Damage	Severity of Brain Dysfunction
Rank 1-4	Rank 1-3

59

CNS Functional Domains

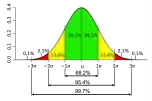
- Cognition
- Academic Achievement
- Adaptive Behavior / Social Skills
- Memory
- Executive Function
- Motor / Sensory Integration
- Language
- Attention / Hyperactivity

Ranking

1 = neurotypical → 2 = functional impairment → 3 = 3 areas > 2SD from mean

60

CNS Damage:



4 Digit Diagnostic Rank*	Probability of CNS Damage	Confirmatory Finding:
4	Definite **Structural and/or Neurological Abnormalities** *Static Encephalopathy*	• Microcephaly: OFC 2 or more SDs below the norm. *and / or* • Significant abnormalities in brain structure of presumed prenatal origin. *and / or* • Evidence of hard neurological findings likely to be of prenatal origin.
3	Probable **Significant Dysfunction** *Static Encephalopathy*	• Significant impairment in three or more domains of brain function such as, but not limited to: cognition, achievement, memory, executive function, motor, language, attention, activity level, neurological "soft" signs.
2	Possible **Mild to Moderate Delay or Dysfunction** *Neurobehavioral Disorder*	• Evidence of delay or dysfunction that suggest the possibility of CNS damage, but data to this point do not permit a Rank 3 classification.
1	Unlikely	• No current evidence of delay or dysfunction likely to reflect CNS damage.

61

DIGIT 4: Alcohol

Table 6: Criteria for Prenatal Alcohol Exposure Ranks 1 through 4

4 Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description of Alcohol Use During Pregnancy
4	High Risk	• Alcohol use during pregnancy is CONFIRMED. *and* • Exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy).
3	Some Risk	• Alcohol use during pregnancy is CONFIRMED. *and* • Level of alcohol use is less than in Rank (4) or level is unknown.
2	Unknown Risk	• Alcohol use during pregnancy is UNKNOWN.
1	No Risk	• Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

62

Structured interview to support the alcohol code:

MATERNAL ALCOHOL USE

Alcohol Consumption of the Birth Mother

Before Pregnancy	average number of drinks per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of drinking days per week:					
	Type(s) of alcohol:	wine	beer	liquor	unknown	Other (specify):
During Pregnancy	average number of drinks per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of drinking days per week:					
	Type(s) of alcohol:	wine	beer	liquor	unknown	Other (specify):

Trimester(s) in which alcohol was consumed	1st	2nd	3rd	unknown	none
Was the birth mother ever reported to have a **problem** with alcohol?	yes	suspected	no	unknown	
Was the birth mother ever **diagnosed** with alcoholism?	yes	suspected	no	unknown	
Did the birth mother ever receive **treatment** for alcohol addiction?	yes	suspected	no	unknown	
Was alcohol use during this pregnancy **positively confirmed**?	yes		no		
If yes, source of confirmation:					
Reported use of alcohol during this pregnancy is:	Reliable	Somewhat reliable	Unk. reliability		
Other information about alcohol use **during** this pregnancy					

63

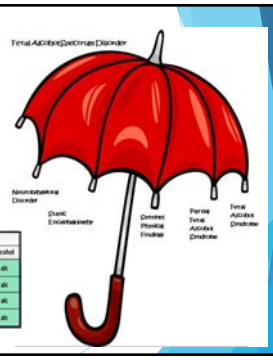
4-Digit Code

4-Digit Diagnostic Code Grid

Significant	Severe	Definite	4				4	High risk
Moderate	Moderate	Probable	3				3	Some risk
Mild	Mild	Possible	2				2	Unknown
None	None	Unlikely	1				1	No risk
Growth Deficiency	FAS Facial Features	CNS Damage		Growth	Face	CNS	Alcohol	Prenatal Alcohol

64

The 4 diagnoses that fall under the umbrella of FASD:



Four Diagnoses under the Umbrella of FASD

Diagnosis		Growth	FAS Face	Brain	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe	alc
2. PFAS	Partial FAS		face	severe	alc
3. SE/AE*	Static Encephalopathy / Alc Exposed			severe	alc
4. NDAE	Neurobehavioral Disorder / Alc Exposed			moderate	alc

65

Don't worry, there's a table for that too!

VI. 4-Digit Diagnostic Codes
Sorted Numerically

Code	Category	Diagnostic Name
1111	V	No unusual physical findings or CNS abnormalities detected (no alcohol exposure)
1112	P	No unusual physical findings or CNS abnormalities detected (alcohol exposure unk.)
1113	J	No unusual physical findings or CNS abnormalities detected (alcohol exposed)
1114	J	No unusual physical findings or CNS abnormalities detected (alcohol exposed)
1121	T	Neurobehavioral disorder (no alcohol exposure)
1122	N	Neurobehavioral disorder (alcohol exposure unknown)
1123	H	Neurobehavioral disorder (alcohol exposed)
1124	H	Neurobehavioral disorder (alcohol exposed)
1131	R	Static encephalopathy (no alcohol exposure)
1132	L	Static encephalopathy (alcohol exposure unknown)
1133	F	Static encephalopathy (alcohol exposed)
1134	F	Static encephalopathy (alcohol exposed)
1141	R	Static encephalopathy (no alcohol exposure)
1142	L	Static encephalopathy (alcohol exposure unknown)
1143	F	Static encephalopathy (alcohol exposed)
1144	F	Static encephalopathy (alcohol exposed)
1211	V	No unusual physical findings or CNS abnormalities detected (no alcohol exposure)
1212	P	No unusual physical findings or CNS abnormalities detected (alcohol exposure unk.)
1213	J	No unusual physical findings or CNS abnormalities detected (alcohol exposed)
1214	J	No unusual physical findings or CNS abnormalities detected (alcohol exposed)
1221	T	Neurobehavioral disorder (no alcohol exposure)
1222	N	Neurobehavioral disorder (alcohol exposure unknown)
1223	H	Neurobehavioral disorder (alcohol exposed)
1224	H	Neurobehavioral disorder (alcohol exposed)
1231	R	Static encephalopathy (no alcohol exposure)

66

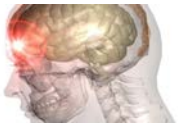
What to expect during a Ptarmigan Connections FASD assessment

Our hope for the clinic process… pre-COVID-19, anyway…

67

When should FASD testing be completed?

- KNOWN alcohol exposure is the key to diagnosis.
- Usually best assessed age 6+



68

How to talk to families about a FASD evaluation

Normalize discussions about prenatal alcohol exposure to remove the stigma of answering honestly

Document along the way

Collect records

Start referrals early

69

What will FASD test results tell me about my patient?

Testing can identify where your patient falls on the spectrum and determine the brain regions involved.

For example, difficulty reading could be due to:

- Attention problems
- Language disorder
- Auditory processing problems
- Reading Disability

70

How will FASD test results affect school decisions?

Test results can guide teachers, therapists, medical professionals, and families to better help the child achieve his or her potential.

However, a medical diagnosis is different from a special education eligibility determination. Only an IEP team can create or modify an IEP.

71

Questions

72

> "Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid." Albert Einstein

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73

Dr. Jacqueline Bock, PhD
Northern Psychology Resources
Central Peninsula FASD Team at Frontier Community Services

Neuropsychological assessment related to FASD

74

FASD

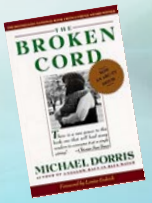
Neuropsychological Evaluation

Dr. Jacqueline Bock, PhD
Northern Psychology Resources ~ Soldotna, Alaska

Central Peninsula FASD Team at Frontier Community Services
~ Soldotna, Alaska

75

FROM THERE TO HERE….



- Public Schools
- Michael Dorris and the book, The Broken Cord
- FAS / FAE Conference
  presented by Northwest Indian College in Washington State

"*If a woman is drinking while she is pregnant – there is something else wrong*"

"*These kids get themselves into trouble – they often sound superficially competent*"

76

CENTRAL PENINSULA FASD TEAM

Frontier Community Services in Soldotna, Alaska

- Serves adults and children
- Different needs and stages in human development
  - Highlights the need for early diagnosis and intervention
  - The impact of trauma
  - Development of secondary disabilities
  - Adverse events

https://www.fcsonline.org/services_fetal.html

77

WHY NEUROPSYCHOLOGICAL ASSESSMENT?

- A critical step in the diagnostic process
- Understand the person's unique strengths and limitations
  - Daily functioning
  - Design intervention
  - Prevent or reduce the impact of secondary disabilities

78

FROM REFERRAL TO RESULTS

- Referral sources
- Interview, mental status examination, collection of collateral records, interviews with others who work with or care for the client
- Tailoring the assessment to the individual
  - Age
  - Abilities and tolerance for assessment
  - Behavior
- Flexible battery of assessment tools (tests)

79

MORE THAN A SCORE

- Report by parents, self, etc
- Collateral Information
  Medical / school / social records
- Observations and interactions during the assessment
- Individual test scores
  Item analysis
  Performance within a test
- Patterns of scores through out the assessment

80

AREAS ASSESSED

Cognitive Functioning

- Weschler Intelligence Scales for Adults, Fourth Edition
- Wechsler Preschool and Primary Scales of Intelligence, 4th Edition (WPPSI-IV)
- Wechsler Intelligence Scale for Children, 5th Edition (WISC-V)
- Stanford-Binet Scales of Intelligence, 5th Edition (SB-5)
- Leiter International Performance Scale, 3rd Edition (Leiter-3)

81

AREAS ASSESSED

Academic achievement

- Wechsler Individual Achievement Test, 5th Edition (WIAT-V)
- Woodcock Johnson Tests of Achievement, 4th Edition (WJ-4)
- KTEA-3

School readiness

- Bracken Basic Concept Scale 3rd Edition – Receptive (BBCS – 3:R)
- Bracken Basic Concept Scale – Expressive

Functional academics

- Texas Functional Living Scales

82

AREAS ASSESSED

Attention and executive functioning

Executive functioning is a set of interrelated cognitive processes that have a vital role in all aspects of adaptive functioning in daily life. The goals of executive functioning include:

(a) demonstrating purposeful, goal-directed activity
(b) displaying an active problem-solving approach
(c) exerting self-control
(d) demonstrating independence
(e) developing an independent self-management and the ability to consider outcomes

The real-life implications of executive functioning are independent of one's general intellectual ability such as the Full-Scale IQ score. Rather, executive processes mediate one's ability to use intellectual ability and skill effectively.

83

AREAS ASSESSED

Attention and Executive Functioning

- Developmental Neuropsychological Assessment, 2nd Edition (NEPSY-II)
  - Auditory Attention and Response, Animal Sorting, Statue
- Color Trails Test (Children and Adults)
- Tasks of Executive Control (TEC)
- Conners Continuous Performance Test, 3rd Edition (CPT-III)
- Test of Everyday Attention for Children (TEA-Ch)
- Stroop Color Word Test
- Delis Kaplan Executive Functioning System (D-KEFS)
  - Color-Word Interference, Design Fluency, and Tower test
- NAB Executive Functioning Battery
- Wisconsin Card Sorting Test (WCST)
- Iowa Gambling Test (IGT)

Rating Scales

- Delis Rating of Executive Functioning (D-REF)
- Behavior Inventory of Executive Functioning, Preschool Edition (BRIEF-P)
- Behavior Inventory of Executive Functioning, 2nd Edition (BRIEF-2)
- Behavior Inventory of Executive Functioning, Adult Edition (BRIEF-A)

84

AREAS ASSESSED

Language

- Peabody Picture Vocabulary Test, 5th Edition (PPVT-V)
- CELF-5 Metalinguistic
- Expressive One-Word Picture Vocabulary Test, 4th Edition (EOWPVT-4)
- Developmental Neuropsychological Assessment, 2nd Edition (NEPSY-II)
- Comprehension, verbal fluency
- Delis Kaplan Executive Functioning System (D-KEFS)
  Verbal Fluency, Proverbs, Word Context
- NAB Naming Test

85

AREAS ASSESSED

Memory and Learning

California Test of Verbal Learning, Children's Edition (CVLT-C)
Weschler Memory Scales
California Test of Verbal Learning, 3rd Edition (CVLT-3)
Child and Adolescent Memory Profile (ChAMP)
Developmental Neuropsychological Assessment, 2nd Edition (NEPSY-II)
Narrative Memory, Memory for Faces, Sentence Repetition, Memory for Designs
Rey Complex Figure Test (RCFT)
Repeatable Battery for Neuropsychological Status (RBANS)

86

AREAS ASSESSED

Visuospatial / visuomotor

- Wide Range Assessment of Visual Motor Abilities (WRAVMA)
- Bender Gestalt Test (Bender)
- Lafayette instruments Grooved Pegboard
- Judgment of Line Orientation (JLO)
- Identi-Fi

Sensory

Sensory Profile

self or parent report / review of records

87

AREAS ASSESSED

Adaptive Behavior

- Adaptive Behavior Assessment System, 3rd Edition (ABAS-III)
- Vineland Adaptive Behavior System
- Texas Functional Living Scales (TFLS)

Personality and Emotional / Behavioral

- *Observation and a thorough interview / review of records*
- Child Behavior Check List (CBCL)
- Beck (depression and anxiety) Inventories
- MMPI-2 or MMPI-A
- Personality Assessment Inventory (Adult and Adolescent)

88

PUTTING IT ALL TOGETHER

- More Than a Score Part Two
- Example using attention and executive functioning
- Analyzing the results for an accurate clinical picture

89

DIAGNOSIS AS A CHILD vs DURING ADULTHOOD

- Protective factors
- Adverse life events
- Intervention as early as possible
- Diagnoses that may assist in gaining services and educational accommodations

90

FUTURE DIRECTIONS, INTERESTS, and CONCERNS

- Greater accessibility to diagnostic teams in rural areas
- FASD in the legal system
- Trauma and adverse life events that may contribute to drinking (and other substance use) during pregnancy as well as a higher risk for people with FASD

and most of all … PREVENTION

"If a woman is drinking while she is pregnant – there is something else wrong…"

91

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92

Erin Johnson, PhD
Alaska Native Medical Center

Video Teleconference Assessment and Evaluations in COVID-land

93

Erin Johnson, PhD
Alaska Native Medical Center

October 15, 2021

FASD ASSESSMENTS VIA VTC

94

Telehealth

Telepsychology

eHealth

Telemedicine

Teleneuropsychology

95

96

GUIDELINES FOR THE PRACTICE OF TELEPSYCHOLOGY (APA, 2013)

- Guideline 1: Competency of the Psychologist
- Guideline 2: Standard of Care in the Delivery of Telepsychology Services
- Guideline 3: Informed Consent
- Guideline 4: Confidentiality of Data and Information
- Guideline 5: Security and Transmission of Data and Information
- Guideline 6: Disposal of Data and Information and Technologies
- Guideline 7: Testing and Assessment
- Guideline 8: Interjurisdictional Practice

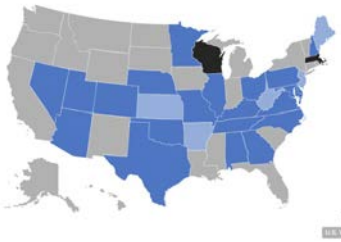
96

ACTIONS

- Emergency Courtesy Licensure
- Testing Guidance
- Expanded Reimbursement
- Free trainings

97

PSYPACT



98

99

Table 1: Telehealth Policies Before and During the COVID-19 Public Health Emergency*

	Total Number of States In 2019	Number of States As of May 2020
Services Allowed for Delivery via Telehealth		
Behavioral Health	47	51
Primary Care	36	51
Dental	19	39
Physical, Occupational, and Speech Therapy	16	49
Maternity	15	31
Long-term Services and Supports	14	41
Providers Allowed for Service Delivery via Telehealth		
Physicians	42	51
Behavioral Health Providers	41	50
Advanced Practice Providers	36	43
Dentists	15	35

Source: Changes in Medicaid Telehealth Policies Due to COVID19. MACPAC June 2020.

99

100

INTER ORGANIZATIONAL PRACTICE COMMITTEE

Guidance for Teleneuropsychology in Response to the COVID-19 Pandemic (April, 2020)

- Licensure Issues
- Reimbursement
- Informed Consent
- Interviewing and Feedback in Teleneuropsychology
- Reporting Results of TeleNP Assessment Limitations
- Telehealth and Teleneuropsychology Platforms
- Strategies for Conducting a Teleneuropsychology Episode of Care
- Test Selection
- Managing In-Person Exams When Necessary and Feasible When There is Concern About COVID-19 Exposure

100

101

VTC BENEFITS

- Increased diagnostic capacity
- Reduced wait times
- Easing travel stress
- Support team participation (teachers, Elders, probation officers)
- Comprehensive treatment plans
- Reduced costs (clinics and families)

101

- 2/3 of neuropsychologists using TeleNP by July 2020

Continued Issues

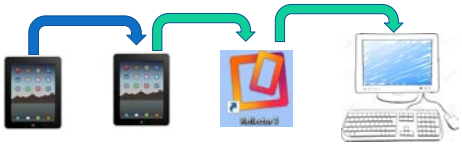
- Examinee internet connectivity (82.8%)
- Environmental distractions (78.2%)
- Unknown connectivity issues (58.6%)
- Examinee limited access to tech (57.5%)
- Audio clarity (55.2%)
- Lack of VTC familiarity (52.9%)
- Lack of easy admin visuocontructional tasks (52.9%)

(Fox-Fuller et al., 2020)

102

TECHNOLOGY

- Videoconferencing platform
- iPads/tablets
- Q-Interactive, etc.
- Screen-mirroring program
- 2 cameras
- Headphones



103

TROUBLE SHOOTING

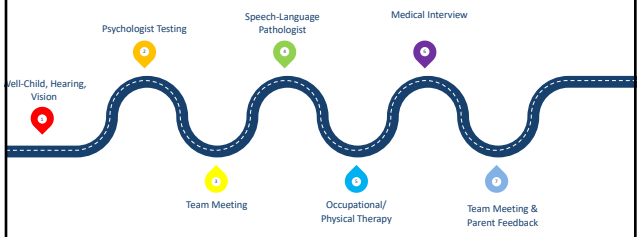
- Have back up tests
- Provide step-by-step instructions before the meeting
- Test-run equipment with a pre-visit
- Ask examinee to have quiet room and a clean space
- Ensure an adult is available
- Ask examinee to use noise-cancelling headphones
- Augment audio with telephone if needed
- Confirm examinee can see each stimulus
- Practice!

104

FASD INTERDISCIPLINARY TEAM ASSESSMENT

105

TELEMED DX



106

PSYCHOLOGY

VTC

- IQ
- Most academics
- All language
- Social cognition
- Verbal and visual memory
- Questionnaires
- Parent interviews

In-Person

- Facial analysis photos
- Non-verbal IQ
- Processing speed
- Math (age dependent)
- Spelling (age dependent)
- Computerized tests of attention
- Executive functioning

107

SPEECH-LANGUAGE PATHOLOGY

VTC

- Feeding evaluation
- Core language
- Pragmatics
- Fluency
- Apraxia

In-Person

- Lower functioning

108

OCCUPATIONAL/PHYSICAL THERAPY

VTC

- PT – All screening & range of motion
- OT – All evaluation

In-Person

109

SUCCESSES

Satisfaction

- Adults: 98% satisfaction rate for adults
  - 2/3 of older adults had no preference for in-person over VTC
- Youth: 94% of caregivers and 90% of examinees satisfaction rate

Results

- WISC-V 0.98-0.99
- CELF-4 0.92-0.99
- WJ, DKEFS, CVLT, Beery VMI, Digit Span = no significant difference in test scores

(Parikh, et al., 2013)

110

TRAININGS

American Psychological Association
- https://www.apa.org/ed/ce/telehealth

Inter Organizational Practice Committee
- https://iopc.online/teleneuropsychology-training

National Academy of Neuropsychology

American Academy of Clinical Neuropsychology

111

THANK YOU

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112

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113

Small Group Discussion
(30 mins)

Breakout Rooms:

1 Writing the Report – Moderator: Dr. Erika Stannard (Recorded)

2. Rural access to FASD – Moderator: Dr. Erin Johnson

114

Small Group Discussion
(30 mins)

Breakout Rooms:

1. Assessing adults – Moderator: Dr. Jacquelin Bock
2. Novel tools for diagnosis and assessment – Moderator: Dr Sarah Mattson (Recorded)

115

Closing Statements

Hope Finkelstein

FASD Program Manager
Alaska's Department of Health and Social Services, Office of Substance Misuse and Addiction Prevention

116