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

Northwest Psychological Fall Convention

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

Opening Statements

Sarah N. Mattson, Ph.D.
Overview of Identification and diagnosis of FASD

Professor, Department of Psychology
Director for Clinical Research, Center for Behavioral Teratology
Co-Director, Center for Clinical and Cognitive Neuroscience
San Diego State University
Fetal Alcohol Spectrum Disorders: Overview of Identification and Diagnosis

Sarah N. Mattson, Ph.D.
Professor, Department of Psychology
Director for Clinical Research, Center for Behavioral Teratology
Co-Director, Center for Clinical and Cognitive Neuroscience
San Diego State University

Acknowledgements

Funding: NIAAA

CIFASD Collaborators: Edward Riley (SDSU); Julie Kable, Claire Coles (Emory University); Jeff Wernick, Chris Boyce (University of Minnesota); Elizabeth Sowell (USC/CHLA); Ken Jones (UCSD); Tatiana Foroud, Leah Wetherill (Indiana University); Peter Hammond, Mike Sorlie (University College London); Ganz Chockalingam (Blue Resonance)

Center for Behavioral Teratology, SDSU: Eileen Moore, Matthew Hyland, Natasha Crouchman, Riley Poictorcha, Gemma Bernee, Tara Jahan, Carissa Zambrano, Chloe Shokrakweli, Kaitlin Carroll, Emily Duprey, Jill Vander Velde

Disclosures: None

Outline

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

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

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%)
**Definition of Documented Prenatal Alcohol Exposure**

Table from: Hoyme et al., 2016

**Fetal Alcohol Syndrome (FAS)**

- The effects of prenatal alcohol exposure were first described by 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)

---

<table>
<thead>
<tr>
<th>Domain</th>
<th>Feature</th>
<th>Requirement</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face</strong></td>
<td>Palpebral Fissures</td>
<td>&lt; 10th centile</td>
<td>Thin Vermillion Border</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Rank 4 or 5 on a racially normed lip/philtrum guide</td>
</tr>
<tr>
<td></td>
<td>Smooth Philtrum</td>
<td></td>
<td>Rank 4 or 5 on a racially normed lip/philtrum guide</td>
</tr>
<tr>
<td><strong>Growth</strong></td>
<td>Height and/or Weight</td>
<td>&lt; 10th centile</td>
<td>Brain Abnormalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>OFC &lt; 10th centile</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Structural brain abnormalities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Recurrent nonfebrile seizures</td>
</tr>
<tr>
<td><strong>Neurobehavioral</strong></td>
<td>Cognitive Impairment</td>
<td>Global impairment</td>
<td>IQ estimate &gt; 1.5SD below mean</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 or more neurobehavioral domain &gt; 1.5SD below mean</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Self-regulation: mood or behavioral regulation impairment, attention deficit, or impulse control</td>
</tr>
<tr>
<td><strong>Behavioral</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Fetal Alcohol Syndrome (FAS)

- A diagnosis of FAS requires all features, A–C:
  1. Short palpebral fissures (<25th percentile, or a normally measured lip-philtrum guide if available)
  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)
  4. Recurrent nonfebrile seizures (other cause of seizures have been ruled out)
  5. Structural brain anomalies
  6. Neurobehavioral impairment
    - Evidence of global impairment in at least 1 neurobehavioral domain below the mean, or
    - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
    - Evidence of behavioral deficit in at least 1 domain below the mean
  7. Evidence of developmental delay (a or b):
    a. With cognitive impairment
      - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
      - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
      - Evidence of developmental delay (a or b) below the mean, or
    b. With behavioral impairment
      - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
      - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
      - Evidence of behavioral deficit in at least 1 domain below the mean
  8. Evidence of minor facial anomalies

Partial FAS (PFAS) Without Documented PAE

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

- A characteristic pattern of minor facial anomalies, including 2 of the following:
  1. Short palpebral fissures (<25th percentile, or a normally measured lip-philtrum guide)
  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)

- Neurobehavioral impairment
  - Evidence of global impairment in at least 1 neurobehavioral domain below the mean, or
  - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
  - Evidence of behavioral deficit in at least 1 domain below the mean

- Evidence of developmental delay (a or b):
  a. With cognitive impairment
     - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
     - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
     - Evidence of developmental delay (a or b) below the mean, or
  b. With behavioral impairment
     - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
     - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
     - Evidence of behavioral deficit in at least 1 domain below the mean

- Evidence of minor facial anomalies

Partial FAS (PFAS) With Documented PAE

For children with documented prenatal alcohol exposure, a diagnosis of PFAS requires all features, A–C:

- A characteristic pattern of minor facial anomalies, including 2 of the following:
  1. Short palpebral fissures (<25th percentile, or a normally measured lip-philtrum guide)
  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)

- Neurobehavioral impairment
  - Evidence of global impairment in at least 1 neurobehavioral domain below the mean, or
  - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
  - Evidence of behavioral deficit in at least 1 domain below the mean

- Evidence of developmental delay (a or b):
  a. With cognitive impairment
     - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
     - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
     - Evidence of developmental delay (a or b) below the mean, or
  b. With behavioral impairment
     - Evidence of global impairment (perceptual motor or intellectual) below the mean, or
     - Cognitive deficit in at least 1 neurobehavioral domain below the mean, or
     - Evidence of behavioral deficit in at least 1 domain below the mean

- Evidence of minor facial anomalies

Table from: Hoyme et al., 2016
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.

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.

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 or evidence of global impairment (general intellectual ability < 70 below the mean, or performance IQ or verbal IQ or spatial IQ > 1.5 SD below the mean)
      - Evidence of behavioral deficit in at least 1 domain > 1.5 SD below the mean (mood or behavioral regulation impairment, attention deficit, or impulse control)
   b. WITH BEHAVIORAL IMPAIRMENT WITHOUT COGNITIVE IMPAIRMENT:
      - Evidence of behavioral deficit in at least 1 domain > 1.5 SD below the mean (mood or behavioral regulation impairment, attention deficit, or impulse control)
Requirements for Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Confirmed Preanatal Exposure</th>
<th>Facial Anomalies</th>
<th>Growth Deficiency</th>
<th>CNS Abnormalities</th>
<th>Neurobehavioral Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>Partial FAS with documented PAE</td>
<td>Required</td>
<td>Required</td>
<td>Not Required</td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>Partial FAS without documented PAE</td>
<td>Required</td>
<td>Required</td>
<td>1 or more required</td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>Alcohol-Related Neurodevelopmental Disorder (ARND)</td>
<td>Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Required</td>
</tr>
</tbody>
</table>

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

Hoyme et al., 2016

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.

Core Symptoms of ND-PAE

- More than Minimal Prenatal Alcohol Exposure
  - Neurocognitive Impairment (one or more):
    - Impairment in Global Intellectual Functioning
    - Impairment in Executive Functioning
    - Impairment in Learning
    - Impairment in Memory
    - Impairment in Visual-Spatial Reasoning
  - Self-Regulation Impairment (one or more):
    - Impairment in Mood or Behavioral Regulation
    - Impaired Attention
    - Impairment in Executive Control
  - Adaptive Functioning Impairment (two or more):
    - Impairment in Communication
    - Impairment in Social Interactions
    - Fine Motor Functioning
    - Fine Motor Skills
    - Impairment in Motor Skills
  - Onset of Symptoms in Childhood

DSM-5 (2013), page 799-801
Fetal Alcohol Spectrum Disorders (FASDs)

Fetal Alcohol Syndrome (FAS)
Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)
Alcohol-Related Neurodevelopmental Disorder (ARND)
Alcohol-Related Birth Defects (ARBD)
Partial Fetal Alcohol Syndrome (pFAS)

Figure from: Glass & Mattson, 2015

The Role of the Psychologist in Diagnosis of FASD
Requirements for Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Facial Anomalies</th>
<th>Growth Deficiency</th>
<th>CNS Abnormalities</th>
<th>Neurobehavioral Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS†</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
<td>Required</td>
</tr>
<tr>
<td>Partial FAS with documented PAE</td>
<td>Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Required</td>
</tr>
<tr>
<td>Partial FAS without documented PAE</td>
<td>Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Required</td>
</tr>
<tr>
<td>Early-onset Developmental Delay Syndrome (EDDS)</td>
<td>Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Required</td>
</tr>
<tr>
<td>Developmental and Behavioral Disabilities</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Not Required</td>
<td>Required</td>
</tr>
</tbody>
</table>

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

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.
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

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

New Tools to aid Identification & Diagnosis of FASD
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 39% had suspicion 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%

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 add novel measurements to the standard exam
  - Requires specialized tools and analysis and is not readily available but promising
- mHealth
  - MorpheusQ
  - FA SD-Tree
  - BRAIN-online

Clinical Translation of 3D Facial Analysis Techniques

Fully automated objective measurements of
- PFL
- Shape/philtrum length
- Upper/mid face circularity and volume
- Micrognathia
- Shape analysis - philtrum shape, midfacial hypoplasia

By: Michael Suttie, Oxford University
What Types of Tools are Being Developed?

- Telemedicine (Drs. Jones and Del Campo)
  - Allows patients in remote areas or without access to specialists to be evaluated
  - Does not address the lack of specialists

- 3D facial imaging (Drs. Suttie, Mukherjee, and Hammond)
  - Can be used to automate facial examinations and add novel measurements to the standard exam
  - Requires specialized tools and analysis and is not yet readily available for routine use

- mHealth
  - MorpheusQ
  - FAIS-Tree
  - BRAIN-online

MorpheusQ

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

Accuracy of MorpheusQ

- 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.
- PFL measurements are reliable using MorpheusQ with a SD of .47mm (range .41-.62mm) for repeated measurement (10x) of 3 people.
- PFL measurements were compared:
  - Calipers = 23.85mm
  - MorpheusQ = 23.38mm (SD = .49mm)
  - After manual correction of endo- and exocanthion landmarks, MorpheusQ = 23.67mm (SD = .20mm).

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 scores (reported or assessed; optional)
- FASD-Tree produces two outcomes:
  - Decision tree outcome (yes/no)
  - Risk score (0-6)

Patent in progress.
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).

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 set-merging.

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.
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.
What is the FASD 4-digit code?
Erika L. Stannard, PsyD, Ptarmigan Connections

Reference:

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

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.
FASD is a challenge to diagnose

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

- Alaska requires multi-disciplinary team evaluations
- Washington conducts 4-hour arena evaluations

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

[http://depts.washington.edu/fasdpn/htmls/training.htm](http://depts.washington.edu/fasdpn/htmls/training.htm)

Who conducts the evaluation?
The FASD team usually contains the following members, in addition to the all important TEAM COORDINATOR:

- Medical Provider
- Psychologist
- Speech-Language Pathologist
- Occupational Therapist
- Physical Therapist
- Parent Navigator
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

The “Short Form”

DIGIT 1: GROWTH

Table 1: Defining the 4-Digit Growth Score

Table 2: Defining the 4-Digit Growth Score

<table>
<thead>
<tr>
<th>Digit</th>
<th>Defining Score Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A, B, C</td>
</tr>
<tr>
<td>2</td>
<td>MB</td>
</tr>
<tr>
<td>3</td>
<td>None</td>
</tr>
</tbody>
</table>
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) has recommended growth standards for infants and young children under the age of two. These guidelines are based on worldwide data and are designed for use in different settings, including developing countries.

Recommendation

- Use the WHO growth charts for infants and young children of all ages.
- Use the CDC growth charts for children age 2 and older in the U.S.

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

DIGIT 2: FAS Facial Phenotype

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

Facial Feature Measurements

Caucasian and African American Norms
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.*

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
CNS Damage:

DIGIT 4: Alcohol

Structured interview to support the alcohol code:
The 4 diagnoses that fall under the umbrella of FASD:

Don’t worry, there’s a table for that too!
What to expect during a Ptarmigan Connections FASD assessment

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

When should FASD testing be completed?
- **KNOWN** alcohol exposure is the key to diagnosis.
- Usually best assessed age 6+

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
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

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.

Questions
“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

Erika L. Stannard, PsyD
Ptarmigan Connections
PtarmiganConnections.com
1505 E. Meridian Park Loop, Ste 200
Wasilla, AK 99654
907-357-4400 (office)
907-357-4410 (fax)

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

Neuropsychological assessment related to FASD

FASD
Neuropsychological Evaluation

Dr. Jacqueline Bock, PhD
Northern Psychology Resources – Soldotna, Alaska
Central Peninsula FASD Team at Frontier Community Services – Soldotna, Alaska
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.”
“Those kids get themselves into trouble – they often sound superficially competent.”

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

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
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)

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 throughout the assessment

AREAS ASSESSED

Cognitive Functioning

• Wechsler 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)
AREAS ASSESSED

Academic achievement
- Wechsler Individual Achievement Test, 5th Edition (WIAT-V)
- Woodcock Johnson Tests of Achievement, 4th Edition (WJ-IV)
- 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

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.

Attention and Executive Functioning
- Developmental Neuropsychological Assessment, 2nd Edition (NEPSY-II)
- Auditory Information Processing: Sensory Setting, Sounds
- Color Trails Test (Children and Adults)
- Test of Executive Control (TUEC)
- Test of Everyday Attention for Children (TEA-Ch)
- Stroop Color Word Test
- Delis-Kaplan Executive Functioning System (D-KEFS)
- 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)
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
- WAIS Naming Test

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)
- Rey Complex Figure Test (RCFT)
- Repeatable Battery for Neuropsychological Status (RBANS)

Visuospatial / visuomotor
- Wide Range Assessment of Visual Motor Abilities (WRAVMA)
- Bender Gestalt Test (Bender)
- Lafayette Instruments Grooved Pegboard
- Judgment of Line Orientation (JLO)
- Stir-Fry

Sensory
Sensory Profile
self or parent report / review of records
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)

PUTTING IT ALL TOGETHER

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

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
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..."

REFERENCES


Erin Johnson, PhD
Alaska Native Medical Center

Video Teleconference Assessment and Evaluations in COVID-land
FASD ASSESSMENTS VIA VTC

Erin Johnson, PhD
Alaska Native Medical Center
October 15, 2021

Telepsychology
Telemedicine
eHealth
Teleneuropsychology

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
ACTIONS

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

PSYPACT

https://psypact.site-ym.com/page/psypactmap
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

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)

Continued Issues

• Examinee internet connectivity (82.8%)
• Environmental distractions (73.2%)
• Unknown connectivity issues (58.6%)
• Examinee limited access to tech (57.3%)
• Audio clarity (55.2%)
• Lack of VTC familiarity (52.9%)
• Lack of easy admin visuoconstructional tasks (52.9%)

(From Fox-Fuller et al., 2020)
TECHNOLOGY

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

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!
TELEMED DX

Psychologist Testing
Speech-Language Pathologist
Medical Interview
Team Meeting & Parental Feedback

Well-Child, Hearing, Vision

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

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 0.93-0.99
• WJ, DKEFS, CVLT, Beery VMI, Digit Span = no significant difference in test scores

TRAININGS

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

Inter Organizational Practice Committee
• http://iopc.org/teleneuropsychology-training

National Academy of Neuropsychology

American Academy of Clinical Neuropsychology
THANK YOU

ejohnson@southcentralfoundation.com

REFERENCES


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
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)

Closing Statements
Hope Finkelstein

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