Occupational Therapy Roles in Identification and Treatment of Fetal Alcohol Spectrum Disorders

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Introductions
Objectives

* Awareness
  - What is it?
  - How prevalent?
  - How to recognize it?

* Relevance
  - Occupational profile?
  - Why it affects assessment/treatment?
  - Why OTs can make a difference?

* Referral
  - Why?
  - How?
  - To whom?

* Resources
  - Where can I find resources for more FASD information?
Overview

* 1. Diagnostic overview of FASD
* 2. Referral process
* 3. Occupational profile
* 4. Assessment and treatment considerations
Fetal Alcohol Spectrum Disorders: DEFINED

* FASD is an umbrella term
* NOT a diagnostic term
* Describes the spectrum of problems experienced by individuals with prenatal alcohol exposure (PAE).
* PAE can cause a range of serious physical, cognitive, behavioral, and social deficits. Neurodevelopmental problems often worsen over time, especially without intervention.
* **FASD is LIFELONG.**

FASD Regional Training Centers Curriculum Development Team, 2015
But it’s just alcohol...

“Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”

National Institute of Medicine, 1996, p. 35
FASDs are 100% Preventable

- Prenatal alcohol exposure is the leading known cause of mental retardation and developmental disabilities among babies born in North America and the Western world.
- There is no safe time or amount to drink during pregnancy
- CDC, 2016: “It is recommended that women who are pregnant or might be pregnant not drink alcohol at all. FASDs do not occur if a developing baby is not exposed to alcohol before birth.”
  http://www.cdc.gov/vitalsigns/fasd/
“Without appropriate diagnostic guidelines, affected individuals are frequently misdiagnosed and treated inappropriately (often to their considerable detriment) by mental health, educational, and criminal justice systems.”

Kable et al. 2016
Comorbidities

- 428 comorbid conditions are caused by prenatal alcohol exposure.
- Often the physician may diagnose the comorbid condition that brings the individual to seek care, rather than the FASD.
- FASD is a serious public health concern that lacks recognition, at staggering costs.

Popova et al., 2016
Common Diagnostic Comorbidities

- Hearing loss
- Visual impairment
- Seizure disorders
- Enuresis/Encopresis
- Sleep abnormalities
- Developmental Delay
- Attention deficit with hyperactivity
- Learning Disabilities
- Intellectual Disability
- Autism Spectrum Diagnoses

- Congenital limb abnormalities
- Fine or Gross Motor deficits
- Speech articulation problems
- Expressive or receptive language disorders
- Reactive Attachment Disorder
- Trauma/PTSD
- Anxiety
- Obsessive/compulsive behaviors
- Mood Disorders
- Personality Disorders
- Conduct Disorder

Popova et al., 2016
“Results suggest that the risk of adverse outcomes might be reduced by families, communities and physicians working together to assure that children with FASD are raised in long-lasting, stable, nurturing homes, and by providing the rearing families with a meaningful diagnosis for their child as early as possible in life.”

Streissguth et al. 2004
Have you met me?
Newborn with FASD Features

- Sleep difficulties
- Feeding difficulties
- Irritability
- Excessive crying
- Sensitivity to light and sound
- Seizures
- Failure to thrive
- Congenital problems with heart, kidneys, or eyes
Have you met me?
Preschooler with FASD Features

- Very talkative, intrusive
- Indiscriminately friendly
- Small for age
- Hyperactive
- Speech delay
- Fine motor delay
- Frequent temper tantrums
- May have signs of attachment disorder
Have you met me?
School-age Child with FASD Features

- Small for age
- Impulsive
- Poor attention
- Poor social skills, friendship problems
- Poor receptive language
- Specific learning disabilities
- Poor organization abilities
- Poor postural control
- Impaired abstract thinking
- Memory deficits
Have you met me?
Adolescent/Adult with FASD Features

- Poor school or job performance
- Impaired judgment
- Behavior problems, possible criminal justice encounters
- Susceptibility to victimization
- Poor peer relationships
- Difficulties with living skills
- More prone to substance abuse or mental health issues
FASD can include four medical diagnostic categories usually given by a dysmorphologist, clinical geneticist, or developmental pediatrician

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)
Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) is a new diagnosis considered to need further study by the Diagnostic Statistical Manual 5

* Intended to encompass both the neurodevelopmental and mental health symptoms associated with PAE.

Kable et al. 2016
Prevalence: 2014 *Pediatrics* Study

- Mid-western, middle-class community.
- Participants: 70.5% first graders enrolled in public and private schools
- Sample of small children (size <25th percentile) and randomly selected controls were examined.
- Mothers were interviewed for maternal risk and children were examined for physical growth, development, dysmorphology, cognition, and behavior.
- FAS: 6-9/1000 children
- All FASD: 24-48/1000 children (2.4% to 4.8%)

May et al. 2014
High Prevalence Continued

- Increased prevalence among children in child welfare
  - FAS: 60/1000 children (6%)
  - All FASD: 169/1000 children (16.9%)

Lange, 2013
FASD Prevalence in Perspective

- Down syndrome: 1.2/1000 births
- Cleft lip+/-palate: 1.2/1000 births
- Spina bifida: 1/1000 births
- Autism: 12.5-14/1000
- FAS: 6-9/1000
- All FASDs: 24-48/1000

May et al., 2014
Embryonic research has shown that craniofacial dysmorphology associated with FAS occurs with PAE in the third week of pregnancy.

Dramatic embryonic cell death was also found to occur within 24 hours.

Sulik, Johnston & Webb, 1981
Timing of Exposure

* There are multiple critical periods associated with prenatal alcohol exposure:

  * 1st Trimester Drinking: risk for major morphological abnormalities, characteristic facial features, growth retardation, and neurological effects

  * 2nd Trimester Drinking: risk for spontaneous abortion, growth retardation, and neurological effects

  * 3rd Trimester Drinking: risk for growth retardation and neurological effects
<table>
<thead>
<tr>
<th>Period of Dividing Zygote, Implantation &amp; Bilaminar Embryo</th>
<th>C.N.S.</th>
<th>Age of Embryo (in weeks)</th>
<th>Fetal Period (in weeks)</th>
<th>Full Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>5</td>
<td>heart</td>
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<td>ear</td>
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<td>15</td>
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<tr>
<td>10</td>
<td>external genitalia</td>
<td>10</td>
<td>16</td>
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</tbody>
</table>

- Indicates common site of action of teratogen.

- Central nervous system
- Heart
- Upper limbs
- Eyes
- Lower limbs
- Teeth
- Palate
- External genitalia
- Ear

*Red indicates highly sensitive periods when teratogens may induce major anomalies.*
Facts about Women and Alcohol

* 1 in 10 women drink during pregnancy.
* FAS can occur before a woman knows she is pregnant.
* Approximately half of all pregnancies in the United States are unplanned.
* There is no safe time or amount of alcohol to consume during pregnancy.

Green, McKnight-Eily, Tan, Mejia & Denny, 2016
Be aware of personal stigmatization the mother may experience and approach the issue cautiously.

- Common for mothers to deny or underreport PAE.
- Report of spouse, close relative or friend may be helpful.
- Confirmation of maternal alcohol use is required for ARND or ARBD diagnoses, but firm documentation is not always needed for FAS or PFAS diagnoses because biomarkers can be used.

- Best practice: start with broad health questions and learn about patterns of alcohol use prior to the pregnancy.

Hoyme et al. 2016
Maternal Risk of having a child with an FASD is highest When

- Maternal alcohol dependence
- Maternal depression
- Heavy alcohol use in partner or family member
- Use of other substances during pregnancy
- Drinking prevalence highest amongst White, non-Hispanic Women
- Most dramatic negative affects of PAE when mother is 30 or older
- Poor maternal nutrition also increases prenatal vulnerability
- Number of children and previous children with FAS
- Genetic predisposition
- High-risk/Binge drinking pattern

FASD Regional Training Centers Curriculum Development Team, 2015
### Standard Drinks Defined

<table>
<thead>
<tr>
<th>12 oz. of beer or cooler</th>
<th>8–9 oz. of malt liquor</th>
<th>5 oz. of table wine</th>
<th>3–4 oz. of fortified wine (such as sherry or port)</th>
<th>2–3 oz. of cordial, liqueur, or aperitif</th>
<th>1.5 oz. of brandy (a single jigger)</th>
<th>1.5 oz. of spirits (a single jigger of 80-proof gin, vodka, whiskey, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 oz.</td>
<td>8.5 oz.</td>
<td>5 oz.</td>
<td>3.5 oz.</td>
<td>2.5 oz.</td>
<td>1.5 oz.</td>
<td>1.5 oz. (shown straight and in a highball glass with ice to show level before adding mixer)</td>
</tr>
</tbody>
</table>

* 25.6% adults binge drank in Wisconsin in 2010 – highest in nation.
* The average largest number of drinks per binge is 9 in Wisconsin – also highest in the nation.

SOURCE: 2010 Behavioral Risk Factor Surveillance System Combined Landline and Cell Phone Developmental Dataset, Adults Aged 18 and Older, US

Wisconsin Women and Binge Drinking

63.3% Wisconsin women drink alcohol.
26.1% Wisconsin women binge drink – highest in US.

Prevalence Estimates of Alcohol Use and Binge Drinking Among Women 18–44 Years of Age, Behavioral Risk Factor Surveillance System (BRFSS), 2013
Impact of Alcohol on the Developing Fetus

- Alcohol readily crosses the placenta:
  - Embryo/fetus exposed to similar BAC (blood alcohol concentrations) levels as mother
  - Fetal liver/organs unable to fully metabolize alcohol

- Specific manifestations of prenatal alcohol exposure are affected by timing, dose, and other fetal/maternal factors

- Some “catch-up” in fetal growth and development may be possible if drinking stops at any time during pregnancy

FASD Regional Training Centers Curriculum Development Team, 2015
* Scientific studies of the effects of alcohol on the fetus have shown the following mechanisms:
  * Cell death and incorrect cell migration
  * Interferes with nerve formation
  * Interferes with normal synapse development
  * Affects neurotransmitter receptors
  * Regional brain development failures
  * Decrease in nervous system regeneration.
Components of FAS Diagnosis: the FASD Triad of Symptoms

1. Facial dysmorphismology
2. Small growth
3. CNS abnormalities
   * Structural – through head circumference or imaging
   * Neurological – soft signs outside of normal limits
   * Functional – performance substantially below person’s age, schooling, or circumstances
Discriminating Features in FAS in Young Child

- short nose
- flattened midface
- thin upper lip
- small eye openings
  - short palpebral fissures
- flat, elongated philtrum
  - area between nose and upper lip

Used with permission from Family Empowerment Network UW Medical School
CNS Abnormalities

* STRUCTURAL
  * Head circumference below 10th percentile
  * Clinically significant brain abnormalities evident with imaging

* NEUROLOGICAL
  * Soft neurological signs
  * Neuro problems not due to TBI or fever
Functional CNS Deficits

FAS -- Below 16th percentile in three of six domains:

- 1. cognitive or developmental deficits or discrepancies
- 2. executive functioning deficits
- 3. motor functioning delays
- 4. problems with attention or hyperactivity
- 5. social skills
- 6. other such as sensory problems, pragmatic language problems, memory deficits, etc.
Cerebral Areas Affected by Exposure

* **Brain stem** – sleep and attention regulation
* **Cerebellum** – coordinated movement, sequencing and timing, sensory processing
* **Basal ganglia** – spatial memory, automatic movement, impulse control
* **Hypothalamus** – appetite, emotions, temperature, and pain sensation
* **Hippocampus** – memory and learning
* **Corpus Callosum** – processing
* **Parietal lobes** – sensory perception, planned movement, spatial relationships, math
* **Frontal lobes** – emotional regulation, impulse control, judgment, understanding social cues, generalizing learning, and connecting actions to consequences

https://www.mofas.org/resource/areas-brain-affected-prenatal-alcohol-exposure/
Postnatal Effects of Alcohol Exposure

- Significant amount of brain maturation occurs postnatally:
  - Myelination and synapse formation continue through first year of life
  - Alcohol exposure during this time has been shown to interfere with myelination resulting in alterations in gross motor movements

- Alcohol use during lactation may be damaging to the nutritional intake of the infant:
  - Interferes with effective suckling, intake, sleep

FASD Regional Training Centers Curriculum Development Team, 2015
Risk Factors That May Trigger FASD Screening

* Symptomology of the FASD Triad
* Family history of substance abuse
* Having a sibling with an FASD
* History of being in foster/adoptive care or involvement with child protective services
* Behavior problems that are not responding to traditional methods of behavior management
* Diagnosis of ADHD with poor response to medication/therapies.

FASD Regional Training Centers Curriculum Development Team, 2015
**FASD Prescreen**

**Date:** __/__/___  
**Patient knows s/he is being assessed for FASD:** ☐ Yes ☐ No

**Name of Individual:** ____________________________  
**Date of Birth:** __/__/___

**Address:** ____________________________  
**Telephone:** ________________________

**Primary Caregiver(s):**  
☐ Self ☐ Birth Parent ☐ Adoptive Parent (at age: _) ☐ Foster Parent (at age: _) ☐ Other ____________________________

**Age of first placement outside birth family home:** ____________________________

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**Maternal Alcohol Use During Pregnancy**

○ binge drinking (≥ 4 drinks/occasion)  
  - # of occasions = __________
  
  - Frequency Per Week:  
    - None  
    - # of Days __________
    - Unknown
  
  - Quantity:  
    - None  
    - 1 drink  
    - 2-3 drinks  
    - ≥ 4 Drinks
  
  - Alcohol Use by Trimester:  
    - First  
    - Second  
    - Third  
    - Unknown

**Reported by:** ____________________________  
**Notes:** ____________________________

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**Medical Concerns**

**NUTRITION CONCERNS**

- Comments:

**BEHAVIORAL HEALTH**

- Bipolar  
- R.D.D.  
- O.C.D.  
- Anxiety  
- Depression  
- P.D.S.  
- Other:  

- Comments:

**AUDIOLGY**

- Concerns with Hearing/Hearing Aids:  

- Comments:

**IQ TEST**

- Stanford Binet  
- WISC-IV  
- WISC-VII

- Date:

---

**NEUROPSYCHOLOGY ASSESSMENT**

- Date:

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**EDUCATION HISTORY**

- Birth to Three:

- Early Childhood:

- Special Education:
  - LD  
  - CD  
  - EBD  
  - O.H.I.  
  - S.R.L.  
  - A.S.D.
  - I.P.P. Plan or #04

- Social Concerns:

- Current School:
  - Grade: ____________________________  
  - Graduated?

- Comments:

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**Notes:** ____________________________

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**Birth/Developmental**

- Term Pregnancy: Yes ☐ No ☐ Week __________

- Delivery Complications:

- Birth Weight: ☐ 0-10%  
- Birth Length: ☐ 0-10%  
- Current Weight: ☐ 0-10%  
- Current Height: ☐ 0-10%  
- O.T.C.: ☐ 0-10%

- Major Birth Defects  
  - Cleft Palate  
  - Heart Defect  
  - Hands/Arms  
  - Eyes  

- Notes:

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**Have Any of the Following Been Diagnosed?**

- Delayed Speech & Language  
- Sniffles  
- Altered Motor Skills  
- Intellectual Disability  
- Developmental Disabilities  
- FASD/ND-FAE  
- AD/HD  
- Learning Disabilities  
- A.D.D./O.H.I.  
- Other:

- Notes:
What to Bring to the Assessment


As part of a complete FASD assessment, you may be asked about or asked to provide the following:

- History of birth mom alcohol use during pregnancy if possible
- Medical history of birth family
- History of complications during pregnancy
- Birth or adoption records
- Medical records including physical growth and development
- Records from mental health, neurological and behavioral development assessments
- Results of neuropsychological tests or school assessments
- School records that document academic progress and problems, including Individual Education Plans (IEPs) if appropriate
- Social Services records if available
- Results of occupational, physical and speech/language therapy
- Records documenting any adverse childhood events
Referral for FASD Evaluation by an Occupational Therapist

- Not certain? Have questions? Contact the Wisconsin FASD Outreach Clinic and ask.
- After speaking with the family, contact the individual’s primary care provider and ask for a referral for medical FASD diagnostic evaluation.
- Contact information for diagnostic clinics around the state can be found in the Wisconsin FASD Resource Guide.

Value of an FASD Diagnosis?

- Improved understanding of the individual – shift perspectives for caregivers and system providers
- Find appropriate supports for the individual and family
- Early intervention improves outcomes
- Increased awareness of the issue will help achieve systems change and better service implementation
- Advocate for fair outcomes in criminal justice
- Prevention of secondary disabilities
COMMON SECONDARY PROBLEMS

- Disrupted school experiences
- Difficulty finding and/or maintaining employment
- Trouble with the law (both as perpetrator and victim)
- Unstable or dependent living situations
- Inappropriate/indiscriminate sexual behavior
- Naïveté with susceptibility to negative influences or scams/scapegoating
- Problems with parenting
- Mental Health Problems
- Alcohol or Drug Dependence

Streissguth, Barr, Kogan, & Bookstein, 1996
So what happens when persons with FASD are supported?
FASD IS REAL
REAL PEOPLE.
REAL LIVES.

realpeople.realmindz.com
MEET ABBY - Abby is a beautiful young lady who will be 13 soon. She is full of life! She loves to play with her animals and Legos. She also loves to talk and have fun with her friends. Abby is a blessing to her family and a joy to all who meet her! Abby has a fantastic personality and she works really hard! Abby wishes she could be taller like her friends. She doesn't like being little and wishes her brain worked better.  

LIKE

DAY 79 - Facebook RedShoesRock • www.BetterEndings.org
FASD IS REAL

MEET SKYE - Skye, is 10 years old. Presently, he participates in martial arts (black belt), equine therapy, tennis and swimming lessons, and neurobehavioral based therapy. In this picture, he is getting ready to break a board at testing. He just entered the black belt level this past June. He will test again on the black belt level to move up in the black belt categories. His best friend, Roxy, helps him feel safe and loved.

LIKE

DAY 69 - Facebook RedShoesRock • www.BetterEndings.org
FASD IS REAL
SO AM I.

MEET DETAMARA – She has accepted her FASD challenges. No longer angry and frustrated this is amazing 23 year old. She loves the quiet, simple, calm and can tell us what she needs. She says she has young people’s Alzheimers and she won’t get Alzheimers when she gets older as she already can’t remember. The only area of her memory that was intact was facial memory.

LIKE US

DAY 52 - Facebook RedShoesRock • www.BetterEndings.org
90 REAL PEOPLE. REAL LIVES.

FASD IS REAL

SO AM I.

MEET CHRISTOPHER- I am passionate about music: creating, discovering and sharing the positive benefits it has for people with developmental disabilities, especially those with an FASD diagnosis. I am fascinated with the brain, how it works and how music affects it. I found out 'why' my life was so incredibly difficult and torturous in May 2014 (one week before my 44th Bday) I learned of my having FAS. LIKE US

DAY 46 - Facebook RedShoesRock • www.BetterEndings.org
Characteristics of persons with FASD: Occupational Profile
COMMON STRENGTHS

* Very verbal
* Bright in some areas
* Have some points of insight
* Artistic, musical, or mechanical
* Friendly, cheerful, affectionate
* Likable

* Desire to be liked, social
* Helpful and willing
* Generous
* Determined
* Hard working
* Good with younger children
* *Strengths may conceal their disability!*
CLIENT FACTORS: Body Structures
Facial Characteristics

- Facial features
  - Smooth philtrum
  - Small eye openings
  - Thin upper lip
  - Epicanthal folds
  - Ptosis
  - Small upturned nose
  - Flattened nasal bridge

- Strabismus
- Maxillary hypoplasia
- Dental malocclusions
- Cleft lip/palate
- Narrow or high-arched palate
- Railroad track ears
CLIENT FACTORS: Body Structures  
Congenital Anomalies

- Small growth  
  - Microcephaly  
  - Smaller in size and weight than same-aged peers (FAS below 10th percentile)

- Heart murmur  
- Cardiac defects  
- Hypoplasia of kidneys  
- Ocular conditions (e.g. hypoplasia of optic nerves, strabismus, amblyopia, coloboma)  
- FASD may also be associated with spina bifida, webbed neck, or hydrocephalus
CLIENT FACTORS: Body Structures
Upper Extremities

- Decreased elbow pronation/supination
- Radial-ulnar fusion
- Carpal fusion
- Joint contractures
- Incomplete extension of one or more digits

- Abnormally bent or curved fifth finger
- Hockey stick crease in palm
- Other palmar crease abnormalities
- Dysplasia or absence of finger or toe nails

2005 FASD Article American Family Physician
CLIENT FACTORS: Body Functions

- Feeding difficulties
- Sleep disturbances
- Problems with motor control, strength and body posture
- Problems with sensory perception and self-awareness
- Difficulty with emotional regulation especially under stress
- Tend to be very concrete
- May have poor orientation to time
- Inconsistent levels of understanding
- Intellectual deficits
- Inconsistent ability to integrate what they know into doing
CLIENT FACTORS: Values, Beliefs, Spirituality

- Tend to want to please others
- Enjoy being helpful
- Want to be liked
- Want independence, "I can do it myself"
- Easily frustrated by "no" or "don’t"
- May feel expectations are too high; this causes anxiety
- Often believe they are bad, dumb, powerless
- May feel vulnerable and confused/lost
Complex fine motor skills (e.g. visual-motor) are more likely to be affected than basic fine motor (e.g. grip strength).

Doney et al. 2014

Problems with functional handwriting. Deficits are greater with greater task complexity.

Duval-White et al. 2013

Significant association between PAE and gross motor impairment in balance, coordination, and ball skills.

Lucas et al. 2014

Difficulty regulating isometric force.

Simmons et al. 2012

Deficits in motor skill including fine motor and balance coordination may persist into adulthood.

Connor, Sampson, Streissguth, Bookstein, & Barr, 2006
PERFORMANCE SKILLS: Social Interaction Skills

- Very concrete understanding of social interactions
- Extremely verbal but receptive language is often poor
- Poor communicators, have difficulty expressing their needs appropriately
- Confused by verbal directions
- Poor understanding of social cues
- Cannot sense or create appropriate boundaries
- Public verses private behaviors confusing
- Indiscriminately approach strangers
- Overly intrusive or too physical with others
- Very vulnerable to victimization
- May respond to situations with aggression
- Have trouble understanding how their behaviors affect others
High Verbal Skill May Lead to Inaccurate Assumptions

- Verbal expression is assumed to be an accurate indicator of cognitive understanding or emotional age
- Providers may assume that client understands them and is capable of remembering and following through behaviorally
- If client can discuss a consequence, it may be assumed that the client can anticipate or avoid it again in the future.
- Service providers and educators sometimes take insightful comments as proof that the individual is intentionally misbehaving, lazy, intentionally deceptive, deviant, unmotivated or playing games.
- Assumption is often made that the client is oriented to abstract realities and aware of “lying” or “stealing”
- IMPORTANT: Neither verbal ability nor IQ are accurate indicators of function in individuals with FASD
PERFORMANCE SKILLS: Process Skills

- Slow processing
- Impulsivity
- Poor working memory
- Difficulty with cause and effect reasoning
- Difficulty grasping the abstract
- Poor executive function
Literal Understanding

- Black and white thinking
- Communication barriers
- Results in need for “translation” across environments throughout the lifespan
Cause & Effect

- Limited understanding of consequences
- Difficulty predicting the future
- Unmotivated?
- Anxiety and trauma
What about Time?

* Meaning of numbers
* Today, tomorrow, yesterday
* Fearfulness of the future
* Treatment resistant or just confused?
Boundaries and Safety

- No perception of social cues = no boundaries
- Lack of safety
- Stealing?
- Developmentally young: me vs. you
- Frustration with “no”
Immaturity and Social Understanding Influence our Reality

- Reality or Fantasy?
- Confabulation
- Context of confusion
Judgment

- Knowing vs. doing
- Impulsivity
- Gullible or generous?
- What is money worth?
- Helping
EXECUTIVE FUNCTION

* Includes the ability to:
  * Initiate activity
  * Plan/sequence
  * Organize thoughts or materials
  * Show Judgement/Safety
  * Complete the task
  * Prioritize

* Demonstrate Working memory/recall
  * Maintain attention
  * Shift Attention
  * Self-monitor
  * Tolerate frustration
  * Self-regulate
“With Fetal Alcohol, the difference between what they know and what they can do is the disability. They know a lot, it's just hard to put thoughts into action. This happens because of deficits in their executive functioning.”

-- Jeff Noble, FASDForever.com
The presence of individual skills or pieces of knowledge does not necessarily translate to an ability to perform occupational tasks.

Self-report measures may have limited validity.

We may be more successful at identifying our client’s occupational deficits if we include *functional assessment* of executive function and adaptive behaviors.

Teaching of skills may not be sufficient to help our clients; they may also need interpersonal and environmental supports to help them carry out those skills in a functional way and to generalize across environments.
Give a man a fish, feed him for a day;
Teach a man to fish, feed him for a lifetime
Interdependence
JUST SPEED UP A BIT

YOU GOT THIS
OCCUPATIONAL PARTICIPATION: All occupations are affected

- ADLs
- IADLs
- Rest and Sleep
- Education
- Work
- Play
- Leisure
- Social participation
“Adaptive skill deficits are clearly a primary clinical concern for this population.”

Jirikowic, Kartin, & Olson, 2008
Adaptive Behavior in Children with FASD

- Study found significant discrepancies between adaptive behavior of typically developing children and children with FASD on the Scales of Independent Behavior-Revised.
  - Jirikowic, Kartin, & Olson, 2008

- Language Expression
- Eating/Meal Preparation
- Toileting
- Dressing
- Language Comprehension
- Money/Value
- Time/Punctuality
- Work Skills
- Home/Community Orientation
- Maladaptive Behaviors
Adaptive Behavior in Children: FASD vs. ADHD

- Adaptive behavior comparison between child controls and children with ADHD or FASD using the Vineland Adaptive Behavior Scales: Adaptive behavior disparities increase with age

  Crocker, Vaurio, Riley, & Mattson, 2009

- COMMUNICATION and SOCIALIZATION DOMAINS: was low for both ADHD and FASD groups in comparison to controls, but scores also decreased with age for FASD group, not ADHD

- DAILY LIVING: Both ADHD and FASD children were significantly lower than controls, with FASD children scoring significantly lower than ADHD children.
Sensory Processing, School Performance, and Adaptive Behavior

* Comparison of controls with FASD group on Sensory Profile, Bruininks-Oseretsky Test of Motor Proficiency, Quick Neurological Screening Test (2nd ed), Developmental Neuropsychological Examination – Sensorimotor and Visuospatial Processing, Scales of Independent Behavior-Revised, Wide Range Achievement Test (3rd ed), Social Skills Rating System, and Test of Nonverbal Intelligence (2nd ed.)

* Children with FASD showed significantly more problems with sensory modulation, sensory-motor performance, and more neurological soft signs.

* FASD group scored lower in academic achievement with significantly lower scores in spelling and math; they also had significantly higher problem behaviors on the SSRS.

* FASD group had significantly lower adaptive behavior and more maladaptive behaviors.

Jirikowic, Olson, & Kartin, 2008
Try Differently, Not Harder

Diane Malbin, 2002
Helpful External Supports

- Structure, structure, structure
- Supports should match emotional maturity not age
- Memory supports
- Reteaching
- Slow auditory pace
- Literal, concrete language, less is more
- Sensory supports to limit overwhelm
- Help them with physical cues (hunger, bathrooming)
- Prevention not reaction
- Anticipate transitions and provide support
- Support with time and money
- Caregivers must manage their own stress
STIGMA: Be Careful of Your Messages!

- Try harder!
- You know better!
- Lazy
- “Bad” kid
- Parenting failure
- Treatment failure
- Unmotivated
**SHAPING BEHAVIORS: Limitations of Shame and Punitive Approaches**

- Unable to connect their behaviors with consequences
- May not remember their behaviors
- Processing limitations and impulsivity means they may not be able to stop their behaviors in the future
- Poor generalization
- Poor receptive language means they may not understand punitive words/messages
- Cannot create different outcomes
Traditional Consequences May Not Work

Malbin, 2002

- Time out
- Extra work or chores
- Ignoring
- Shaming
- Sticker charts
- Contracts
- Grounding
- Suspension
- Incarceration
Thank You!

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REFERENCES

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