The Hidden Disability of Fetal Alcohol Spectrum Disorders (FASD) and What Individuals with an FASD Need to Succeed

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Objectives:

1. Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities

2. Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities

3. Identify and emphasize attitudes that enhance the opportunities for persons with DD to achieve their optimal potential

4. Develop strategies to promote community inclusion in meeting the needs of persons with developmental disabilities

Notes:
The Hidden Disability of FASD & What Individuals With An FASD Need to Succeed

Shelly L. Bania, Certified FASD Trainer
FASD Program Supervisor/Project Director

CARE of Southeastern Michigan
A non-profit human services agency founded in 1977.

PREVENTION
Our educational resources help people avoid negative influences.

PATHWAYS
We link people with the treatment and support that changes lives.

PURPOSE
We help people rediscover their value as human beings.

Shelly began at CARE in 2002
Shedding light on FASD since 2003
Certified FASD Trainer in March 2011
Project Director for Federal contract(s)
Screening, Referral for Diagnosis and Case Managed Treatment Plans for Youth with an FASD, and FASD Prevention

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Why address FASD?

Joshua, a three year old, was slated for a change in placement because the foster care system didn’t think his caretakers were handling his behaviors effectively and blamed poor parenting skills. CARE staff was at the placement decision meeting and requested a stay of action in order to screen for FASD.

Joshua screened at risk of a Fetal Alcohol Spectrum Disorder and within a few months was diagnosed with an FASD. His parents attended CARE’s parenting series, Triumph through the Challenges of FASD (Double ARC, Toledo) and gained parenting strategies specific to FASD. He received intervention services. He did not change foster-care placements and within a year was adopted by his foster parents.

Identifying the Hidden Disability makes a Difference.

Why address FASD?

**With Diagnosis**
- Placement Stability
- Attachment
- Treatment for trauma
- Sensory Integration Therapy
- Social Skills Training
- Participates in recreational swim and hockey
- Graduates from High School
- Works Part-time
- Member of the FASD Self-Advocates Group
- Speaks nationally and internationally by telling his story of success, offering hope, and advocating for changes that help individuals like him be successful.

**Without Diagnosis**
- Multiple placements
- No family stability
- Attachment disorder
- Explosive and aggressive behaviors
- Suspended from kindergarten
- Reactive response to just about everything
- Depression
- Low Self Esteem
- Dropped out of school
- Trouble with law
- Homeless
- On your caseload

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The Hidden Disability of FASD

What Individuals With An FASD Need to Succeed

**Key points of discussion –**
- FASD – Key facts
- Common Brain Dysfunction
- Overlapping Characteristics – Why This is So hard
- FASD Across the Ages
- Common Strengths
- Framework for Trying Differently
- Case Study
- Mapping Exercise

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Why address FASD?

**Time Warp: Two very different Joshua’s**

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Why address FASD?

90% have other mental health diagnoses
80% cannot keep a job
70% will be confined – jail or rehab
60% will have trouble finishing school
over 50% will do things sexually which could get
them into legal trouble

WHAT is a Fetal Alcohol Spectrum Disorder (FASD)

- FASD: umbrella term describing range of effects that can result from
  prenatal alcohol exposure
- Not a diagnostic term
- Individuals affected by prenatal alcohol exposure can have a
  range of serious, lifelong problems including physical,
  cognitive, behavioral, and social deficits.
  - DSM 5 – 315.8 – Neurodevelopmental Disorders/
    Other Specified Neurodevelopmental Disorder
- Alcohol causes “Diffuse Brain Damage” – Dr. Sterling Clarren
- FASD is the LEADING developmental disability and
  it is 100% preventable

“

A developing baby can’t process alcohol. Developing babies lack the ability
 to process alcohol through the liver. They absorb all of the alcohol and
 have the same blood alcohol content as the mother.

Alcohol causes more harm than heroin or cocaine during pregnancy. The
 Institute of Medicine says, “Of all the substances of abuse (including
 cocaine, heroin, and marijuana), alcohol produces by far the most serious
 neurobehavioral effects in the fetus.”

-National Organization on Fetal Alcohol Syndrome (NOFAS)”
WHAT is a Fetal Alcohol Spectrum Disorder (FASD)

The Effects of Alcohol Consumption on a Developing Baby

- Brain growth spurt
- Brain development
- Brain growth spurt
- Brain development
- Brain growth spurt
- Brain development
- Brain growth spurt
- Brain development

When you stop drinking, you have a 40% chance of having a healthy baby!

FASD – The #’s

- Alcohol used during pregnancy can result in FASD. An estimated 40,000 newborns each year are affected by Fetal Alcohol Syndrome (FAS), or have a Fetal Alcohol Spectrum Disorder (FASD), with damage ranging from major to subtle.

- 1 in 10 babies have FASD, nearly the same rate as Autism. FASD is more prevalent than Down Syndrome, Cerebral Palsy, Cystic Fibrosis, Spina Bifida, and Sudden Infant Death Syndrome (SIDS) combined.

- The incidence rate of FASD is unusually high among the U.S. foster care population. It is estimated that almost 70% of the children in foster care are affected by prenatal alcohol exposure in varying degrees.

Why we need Prevention

1 in 5 high school females are drinking at binge drink levels

1 in 8 adult women drink at binge drink levels

43% of pregnancies in Michigan (50% nationally) are unplanned.

In Michigan, 54.5% of women ages 18-45 consume alcohol

and of those 15.2% of women drink at binge drink levels.
Every day in our country
10,657 babies are born

- 1 will be born HIV positive
- 4 will be born with Spina Bifida
- 10 will be born with Down syndrome

**107 will be born with a Fetal Alcohol Spectrum Disorder**

Barbara Wybrecht, BSN, PHN, National FASD Trainer

Screening


Identifiers

**Alcohol Exposure:**
- Maternal alcohol (and/or drug) use during pregnancy
- Any occurrence of biological Mother in (TA) treatment across lifespan
- Biological sibling diagnosed with FASD

**Physical:**
- Size of head small for age
- Sleeping/eating concerns
- Smooth space between nose and lip (no vertical groove)
- Short eye opening
- Height/weight small for age
- Thin upper lip in comparison to bottom lip
Identifiers

Social/Behavioral:
- Difficulty understanding body language/facial expressions
- Acts age inappropriate
- Explosive
- Impulsive
- Boundary issue

Functioning/Learning:
- Poor reasoning and judgment
- Difficulty understanding cause and effect
- Limited focus and attention
- Learning Disability
- Below average IQ
- Speech and Language delays

Common Areas of Brain Dysfunction

- **Impulsivity** - No stop gap, “No Brakes”

- **Attention Deficits and Hyperactivity**

- **Literal thinking and poor social skills** – Think “faulty” wiring or “signal-lost” due to changes to the Corpus Callosum from the alcohol exposure.

- **Perseveration** – Stuck in a loop.

- **Memory deficits** – Can be confusing to the outside world because of times of accuracy.

- **Confabulation** – the brain is putting the various pieces of the puzzle together into a believable story – may not be true. Sounds like lying. At the core is memory deficits.
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Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Why This is So hard

Across the Lifespan – Infants and Toddlers

Across the Lifespan – School Age

Physical/Developmental
- Continues to be small (<10% of population)
- Persistent problems with toileting
- Frequent illnesses
- Developmental delays more pronounced
- Poor sleep/wake cycle

Language
- Has been considered for receptive language disorder
- Language OUTPUT is higher than comprehension
- Difficulty with word retrieval
- Excessively chatty

Sensory
- Tense out in response to over-stimulation
- High tactile needs
- No sense of personal space/boundaries
Across the Lifespan – Adolescent and Adult

Social/Secondary
- Often appear more capable than they are
- Shows little remorse for actions/blames others
- Poor comprehension of social rules can lead to frustration/lose temper easily
- Appears IDLE of social skills
- Manipulated by older negative peers
- Alcohol/Drug use
- Delinquency
- Sexual issues – (i.e. inappropriate touch) physically more mature than development

Physical/Developmental
- Dental anomalies are more pronounced
- Accident prone

Functioning
- SUPERVISION needs are similar to those of preschooler
- Forgets new learning
- Problems with sequencing/Organized
- Profits high

Behaviors
- Risk taking
- Lying and stealing behaviors may increase
- Cannot make transitions/adjust behavior for surroundings
- Low self esteem – depression

FASD Across the Lifespan

http://knowfasd.ca/

What Individuals With An FASD Need to Succeed
**FASD Across the Lifespan**

**Mindshift – Think Younger**

“**An 18 year old with an FASD**

May talk like a 20 year old

Look like an 18 year old

Read like a 16 year old

Comprehend like a 6 year old

Have the social skills of a 7 year old

Have the emotional maturity of a 6 year old”

- Barbara Wybrecht

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**Common Strengths**

- Friendly, outgoing
- Likeable
- Verbal
- Helpful
- Generous
- Caring
- Bright in some areas
- Charming
- Determined
- Have points of insight
- Good with younger children
- Not malicious
- Artistic, musical, mechanical

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**Trying Differently**

<table>
<thead>
<tr>
<th>Setting task or expectation</th>
<th>Requires the ability to...</th>
<th>What you might see</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand spoken instruction</td>
<td>Process information quickly</td>
<td>Blank stare, confusion, non-compliance</td>
</tr>
</tbody>
</table>

**What to do?**

**Accommodations:**

- Slow Down
- Build on strengths
- Use Visual Aids
Trying Differently

<table>
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<th>Setting task or expectation</th>
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<th>What you might see</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be age appropriate</td>
<td>Act one's chronological age</td>
<td>Dysmaturity</td>
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</tbody>
</table>

What to do?

Accommodations:
- Adjust your expectations
- Provide cues
- Practice / role-play

Meet individuals living with an FASD

Meet Nicholas, Sam, and Ricky

Nicholas
http://www.youtube.com/watch?v=bd3tsHOzTr0&list=PLiFZcDuldDA7k1pnjI1SHzq5p6_Ka-PwJ

Sam
http://www.youtube.com/watch?v=km6Mwcze3wg&list=PLiFZcDuldDA7k1pnjI1SHzq5p6_Ka-PwJ

Ricky
http://www.youtube.com/watch?v=2mC3mXEwCI
Mapping Exercise

<table>
<thead>
<tr>
<th>Name/Age</th>
<th>Strengths/Interests</th>
<th>Challenges</th>
<th>Wishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nicholas, 9</td>
<td>Likes Legos</td>
<td>Smaller than peers</td>
<td>Play on Baseball Team [Preferences: Graduation [Awards: College]</td>
</tr>
<tr>
<td>Sam, 25</td>
<td>Likes to Read</td>
<td>Concentration</td>
<td>Has Friends</td>
</tr>
<tr>
<td>Ricky, 34</td>
<td>Likes Basketball &amp; Baseball</td>
<td>Impulsivity, Emotions</td>
<td>[Preferences: Independence/Interdependence, Wants to drive</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td></td>
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<tr>
<td></td>
<td>Acceptance</td>
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In each group:
Discuss what services are needed — ANY and ALL — and in what system, for your assigned person to be successful.
Write it on Post-it. Report out. Place on Newsprint.

Story of Hope

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