

Wednesday, 10:00 – 11:30, D6

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
 SOUTHEASTERN MICHIGAN

Life Happens. We can Help.

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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**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

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.

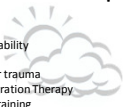

Identifying the Hidden Disability makes a Difference.



Why address FASD?

Time Warp: Two very different Joshua's

<p>With Diagnosis</p> <ul style="list-style-type: none"> <input type="checkbox"/> Placement Stability <input type="checkbox"/> Attachment <input type="checkbox"/> Treatment for trauma <input type="checkbox"/> Sensory Integration Therapy <input type="checkbox"/> Social Skills Training <input type="checkbox"/> Participates in recreational swim and hockey <input type="checkbox"/> Graduates from High School <input type="checkbox"/> Attends College, with supports and modifications <input type="checkbox"/> Certificate in Culinary Arts <input type="checkbox"/> Works Part-time <input type="checkbox"/> Member of the FASD Self-Advocates Group <input type="checkbox"/> Speaks nationally and internationally telling his story of success, offering hope, and advocating for system change that helps individuals like him be successful. 	<p>Without Diagnosis</p> <ul style="list-style-type: none"> <input type="checkbox"/> Multiple placements <input type="checkbox"/> No family stability <input type="checkbox"/> Attachment disorder <input type="checkbox"/> Explosive and aggressive behaviors <input type="checkbox"/> Suspended from kindergarten <input type="checkbox"/> Reactive response to just about everything <input type="checkbox"/> Think stress response – "Fight. Flight. Freeze." <input type="checkbox"/> Depression <input type="checkbox"/> Low Self Esteem <input type="checkbox"/> Drops out of school <input type="checkbox"/> Trouble with law <input type="checkbox"/> Homeless <input type="checkbox"/> On your caseload
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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







WHAT is a Fetal Alcohol Spectrum Disorder (FASD)

- “
- 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) ”

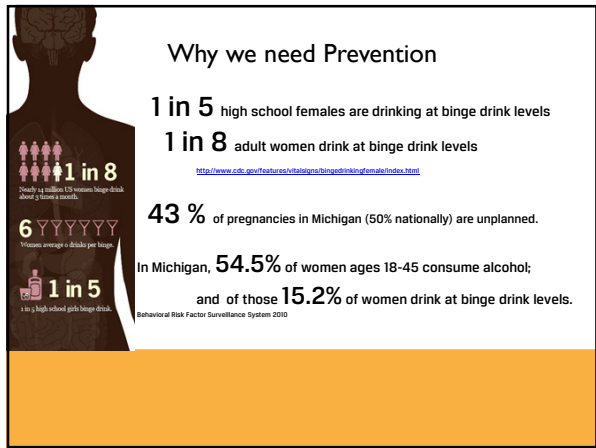
WHAT is a Fetal Alcohol Spectrum Disorder (FASD)

The Effects of Alcohol Consumption on a Developing Baby

Months 1, 2, & 3	Months 4, 5, & 6	Months 7, 8, & 9	Birth – 18 months
<ul style="list-style-type: none"> The main organs develop (heart, lungs, kidneys, etc.) The basic structure of brain is laid down 	<ul style="list-style-type: none"> Body grows rapidly Movement increases 	<ul style="list-style-type: none"> The brain grows very rapidly and organizes itself so it can work properly The lungs mature 	<ul style="list-style-type: none"> The brain continues to grow rapidly as the baby learns new things every minute 
<p>Thinking alcohol during the first 3 months can result in problems such as heart defects and facial changes.</p>	<p>Thinking alcohol during the second 3 months can slow a baby's overall growth and change the way cells in the brain develop.</p>	<p>Thinking alcohol during the last 3 months can greatly reduce brain growth and limit overall brain development.</p>	<p>A mother who drinks alcohol while breastfeeding will pass some of that alcohol along to her baby. Babies drink less milk when there is alcohol in it.</p>
<p>Stopping drinking during the first 3 months can help prevent organ damage and changes to the way the face looks.</p>	<p>Stopping drinking now can improve a baby's birth weight and growth and prevent the most severe effects on the brain.</p>	<p>Stopping drinking now can prevent the most severe effects on the brain (such as the IQ) and prepare the mother to handle the challenges of raising a child.</p>	<p>Stopping now means that a baby will get the nutrition that he or she needs, and a mother can be a better parent, more prepared to deal with the ups and downs of raising children.</p>

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

Source: The Health and Recovery, 2006



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
<http://www.cdc.gov/features/challenges/binge-drinking/sample/index.html>
- 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.

Behavioral Risk Factor Surveillance System 2010

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 100 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.
- (NOFAS – FASD: What the Foster Care System Should Know)

**Every day in our country
10,657 babies are born**

“ I 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

Michigan Department of Community Health
Fetal Alcohol Spectrum Disorders Program
FETAL ALCOHOL SYNDROME (FAS) PRE-SCREEN

FASD is a birth defect caused by alcohol use during pregnancy. FASD is a medical diagnosis. This form is not intended to take the place of a diagnostic evaluation.

FACIAL FEATURES

Last Name		First Name		Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female	
Address				Race	
City/State/Zip code				Birthdate	
Parent/Caregiver Name/s				Home Phone	
<input type="checkbox"/> Bio <input type="checkbox"/> Foster <input type="checkbox"/> Adopted <input type="checkbox"/> Other				Work Phone/Cell	

If 2 or more of the identifiers below are provided the individual should be referred for a full FASD Diagnostic Evaluation

IDENTIFIERS	Check or explain if a concern exists
1. Height and weight mean small for age	
2. Facial features (See diagram above)	

http://www.michigan.gov/documents/mich/FASD_Prescreen_form_Feb-10_314457_7.pdf

Identifiers


Alcohol Exposure:
Maternal alcohol (and/or drug) use during pregnancy
Any occurrence of biological Mother in (SA) 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.



Common Areas of Brain Dysfunction

- **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.



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

**Overlapping Behavioral Characteristics &
Related Mental Health Diagnoses in Children**

Why This is So hard

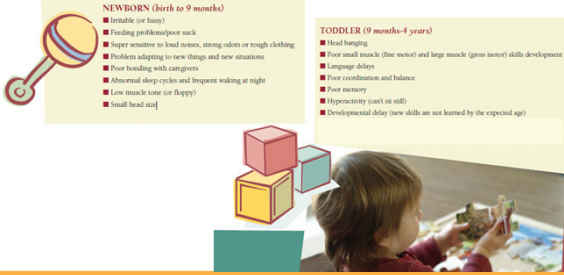
Across the Lifespan – Infants and Toddlers

NEWBORN (birth to 9 months)

- Irritable (or fussy)
- Feeding problems/poor suck
- Super sensitive to loud noises, strong odors or rough clothing
- Problems adapting to new things and new situations
- Poor bonding with caregivers
- Abnormal sleep cycles and frequent waking at night
- Low muscle tone (or floppy)
- Small head size

TODDLER (9 months-4 years)

- Head banging
- Poor small muscle (fine motor) and large muscle (gross motor) skills development
- Language delays
- Poor coordination and balance
- Poor memory
- Hyperactivity (can't sit still)
- Developmental delay (new skills are not learned by the expected age)



Fetal Alcohol Syndrome: A Parents' Guide to Caring for a Child Diagnosed with FAS
2004 by Wake Forest University Health Sciences Winston-Salem, North Carolina 27157

Across the Lifespan – School Age

EARLY SCHOOL AGE (4-12 years)

- Learning disabilities
- Trouble getting along with others
- Short attention span
- Impulsivity (acting before thinking)
- Aggressiveness
- Problems talking and listening
- Hearing problems
- Frequent temper tantrums/mood changes
- Longer time to complete tasks

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

- Tunes out in response to over-stimulation
- High tactile needs
- No sense of personal space/boundaries


Social

- Indiscriminate – people are interchangeable
- No stranger danger
- Gullible – easily talked into things
- Difficulty maintaining friendship
- Plays with younger children – often viewed as younger themselves



Fetal Alcohol Exposure: Time to Know, Time to Act, FASD Mobilization Project, Jane Hoy, <http://www.beststart.org/events/detail/FASDNOV/hoy.pdf>

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
- Apparent LACK of social skills
- Manipulated by older negative peers
- Alcohol/Drug use/abuse
- Delinquency
- Sexual issues – (i.e., inappropriate touch)– physically more mature than development

Physical/Developmental

- Dental anomalies are more pronounced
- Accident prone

Behaviors

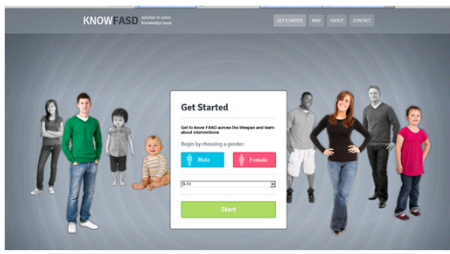
- Risk taking
- Lying and stealing behaviors may increase
- Cannot make transitions/adjust behavior for surroundings
- Low self esteem – depression

Functioning

- SUPERVISION needs are similar to those of a preschooler
- Forgets new learning
- Problems with sequencing/Disorganized
- Faulty logic

Fetal Alcohol Exposure: Time to Know, Time to Act, FASD Mobilization Project, Jane Hoy, <http://www.beststart.org/events/detail/FASDKNOW/hoy.pdf>

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

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

Dubovsky, Drexel University College of Medicine (1999)

Trying Differently

Setting task or expectation	Requires the ability to...	What you might see
Understand spoken instruction	Process information quickly	Blank stare Confusion Non-compliance

What to do?

Accommodations:

- Slow Down
- Build on Strengths
- Use Visual Aids

Demystifying FASDs - Sr. Suzzette Fisher & Sr. Mary Sartor, Double ARC

Trying Differently

Setting task or expectation	Requires the ability to...	What you might see
Be age appropriate	Act one's chronological age	Dysmaturity

What to do?

Accommodations:

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

[Demystifying FASDs](#) - Sr. Suzanne Fisher & Sr. Mary Sartor, Double ARC

Trying Differently

Setting task or expectation	Requires the ability to...	What you might see
Apologizing	Understand... <ul style="list-style-type: none"> ▪ Abstract concepts ▪ and Process the issue ▪ Cause and effect 	Defiance Insincerity Refusing to apologize

What to do?


Accommodations:

- Explain the incident in concrete language/terms
- Demonstrate HOW to apologize
- Guided practice
- Use social stories (of other persons)


[Demystifying FASDs](#) - Sr. Suzanne Fisher & Sr. Mary Sartor, Double ARC

Meet individuals living with an FASD


Meet Nicholas, Sam, and Ricky



Nicholas
<https://www.youtube.com/watch?v=3k3e4QoT20k>
<http://www.youtube.com/watch?v=3k3e4QoT20k>



Sam
<https://www.youtube.com/watch?v=6Mwca3w3jw8>
<http://www.youtube.com/watch?v=6Mwca3w3jw8>




Ricky
<http://www.youtube.com/watch?v=3mC3mX7BwC>

Mapping Exercise


Name/Age	Nicholas, 9	Sam, 25	Ricky, 34
Strengths/Interests	Intelligent Likes Legos Likes to Read Likes Baseball	Friendly Has Friends Public Speaking Likes Basketball & Baseball	Advocate Acceptance
Challenges	Smaller than peers Concentration Impulsivity Temper Following rules	Reading & Writing Easily Frustrated Gets Confused Emotional outbursts/mood swings Bipolar/Depression	Learned of FASD at 13 FASD is "Invisible" Impulsive Impaired judgment Trouble with the Law
Wishes	Play on Baseball Team [Assume: Graduate HS Attend College]	Maintain a job Friends [Assume: College]	Independence/ (Interdependence) Wants to drive

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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OF SOUTHEASTERN MICHIGAN

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