Welcome to FASD training

• Please complete the following in your packet:
  • Pretest
  • Values Clarification Activity
FOUNDATIONS OF FASD

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Cheryl Rathbun LSCSW
40th Annual Governor’s Conference for the Prevention of Child Abuse and Neglect
October 4th, 2016
Saint Francis Community Services
785-825-0541

Adapted from the CDC Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice, 2009, 2015
Learning Objective

• To provide a framework to understand the historical, biomedical, and clinical significance of fetal alcohol syndrome (FAS) and other fetal alcohol spectrum disorders (FASDs).

Unless otherwise noted, content information contained in this PowerPoint presentation is referenced in the Fetal Alcohol Spectrum Disorders Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice, Centers for Disease Control and Prevention, 2009 available at [www.cdc.gov](http://www.cdc.gov)
Learning Goal A

• Describe the basic biomedical foundation of fetal alcohol spectrum disorders (FASDs):
  • Recognition of the Issues
  • Effects of Alcohol on the Developing Embryo/Fetus
  • Characteristics of FASDs
  • Intervening with Individuals affected by FASD
Learning Goal B

• Explain basic clinical implications relevant to alcohol and pregnancy:
  • Preconceptional Counseling
  • Prevention of Alcohol-Exposed Pregnancies
  • Counseling Pregnant Women who Use(d) Alcohol
  • Framework for FAS Identification, Diagnosis and Treatment/Intervention
Learning Goal C

- Provide an overview of the epidemiological, psychosocial, and cultural issues related to fetal alcohol spectrum disorders (FASDs):
  - Scope of the Issues
  - Monitoring Prenatal Alcohol Exposure
  - Prevalence of FASDs
  - Costs of FASDs
  - Psychosocial and Cultural Issues
Learning Goal D

• How stigma and bias may affect women who use alcohol and other drugs, and individuals with fetal alcohol spectrum disorders (FASD)
AN OVERVIEW OF FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

• Individuals affected by prenatal alcohol exposure can have a range of serious, lifelong problems including physical, cognitive, behavioral, and social deficits.
Terminology

- **Fetal Alcohol Spectrum Disorders (FASD):** an umbrella term describing the range of effects that can result from prenatal alcohol exposure—**but is not a diagnostic term**

- **Fetal Alcohol Syndrome (FAS):** medical diagnosis, *usually* made by a dysmorphologist, clinical geneticist, or developmental pediatrician, but other medical professionals can make this diagnosis
FASD: Relevance to Clinical Practice

High Prevalence

- Prevalence in a Midwestern city (May, 2014)
  - FAS: 6-9/1000 children
  - All FASD: 24-48/1000 children (2.4% to 4.8%)

- Increased prevalence among children in child welfare (Lange, 2013)
  - FAS: 60/1000 children (6%)
  - All FASD: 169/1000 children (16.9%)
FASD: Perspectives on Prevalence

- 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 2014)
FASD Awareness Strategies

- **Universal Prevention:** education and awareness for everyone
- **Selective Prevention:** intervention for those at risk
- **Indicated Prevention:** targeted intervention for those at greatest risk

Free awareness and education materials available from the CDC at: www.cdc.gov/ncbddd/fasd/freematerials.html
Public Health Messages

- Alcohol use during pregnancy increases risk of alcohol related birth defects
- **No amount of alcohol consumption can be considered safe during pregnancy**
- Alcohol-related birth defects are preventable
- Pregnant women who have already consumed alcohol during pregnancy should stop in order to minimize further risk
- Recognizing that nearly half of all births in the United States are unplanned, women of child-bearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure
- Health professionals should routinely inquire about alcohol consumption by women of childbearing age, inform them of the risks, and advise them not to drink during pregnancy

2005 Surgeon General's Advisory on Alcohol Use in Pregnancy (www.cdc.gov/ncbddd/fas/fasprev.htm)
Best Public Health Message

• According to the Centers for Disease Control and Prevention (CDC), the following is an ideal prevention message related to alcohol consumption by women of childbearing age:

• **Women who are pregnant or could become pregnant should not consume alcohol**
Experiential Exercise

• Value Clarification Activity
CLINICAL IMPLICATIONS

How can I identify and help children and parents with alcohol use/abuse problems leading to FASD?
Interventions to Prevent Alcohol-Exposed Pregnancies

• Provide all clients with information about alcohol, contraception, and FASDs
• Provide alcohol screening to women of childbearing age
• Provide brief alcohol intervention for women at risk
• Provide targeted alcohol treatment and promote contraception use for women at highest risk:
  • Women who have a child with an FASD
  • Women with a history of alcohol abuse and/or dependence
# Standard Drink

<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><img src="image1.png" alt="Image of 12 oz. beer" /></td>
<td><img src="image2.png" alt="Image of 8.5 oz. malt liquor" /></td>
<td><img src="image3.png" alt="Image of 5 oz. table wine" /></td>
<td><img src="image4.png" alt="Image of 3.5 oz. fortified wine" /></td>
<td><img src="image5.png" alt="Image of 2.5 oz. cordial" /></td>
<td><img src="image6.png" alt="Image of 1.5 oz. brandy" /></td>
<td><img src="image7.png" alt="Image of 1.5 oz. spirits" /></td>
</tr>
</tbody>
</table>

Risky Drinking Definitions

• Low Risk Drinking Limits
  • Men:
    • No more than 4 per day
    • No more than 14 per week
  • Women:
    • No more than 3 per day
    • No more than 7 per week

• Heavy or At-Risk Drinking
  • Drinking above low-risk levels
Binge Drinking

• “…Drinking so much within about 2 hours that blood alcohol concentration (BAC) levels reach 0.08 grams per deciliter…”

Typically…

Women (and men > 65): ≥ 4 drinks
Men: ≥ 5 drinks
Women and Alcohol

- 50% of non-pregnant women aged 18-44 years report alcohol use
- 10% of non-pregnant women aged 18-44 years report frequent or binge drinking
- An episode of “binge” drinking for women of childbearing age is defined as more than 3 drinks in about a two hour period
Alcohol and Pregnancy

- Women who binge drink are at increased risk of an unintended pregnancy and an alcohol-exposed pregnancy
- About 7.6% of pregnant women used alcohol
IMPACT OF ALCOHOL ON PREGNANCY OUTCOMES
Potential Effects

• Premature Birth
• Pre- and Postnatal Growth Retardation
• Physical Malformations
• Microcephaly
• Cognitive and Behavioral Problems
Impact of Alcohol on the Developing Embryo/Fetus

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

- 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
Critical Period

- Scientific studies have shown that prenatal alcohol exposure can affect the development of the fetus at any point during gestation.
Timing of an Exposure

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

  • 1\textsuperscript{st} Trimester Drinking: risk for major morphological abnormalities, characteristic facial features, growth retardation, and neurological effects

  • 2\textsuperscript{nd} Trimester Drinking: risk for spontaneous abortion, growth retardation, and neurological effects

  • 3\textsuperscript{rd} Trimester Drinking: risk for growth retardation and neurological effects
CRITICAL PERIODS IN HUMAN DEVELOPMENT*

<table>
<thead>
<tr>
<th>Period</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>
<td>1-2</td>
<td>3-4</td>
<td>5-7</td>
</tr>
<tr>
<td>2</td>
<td>period of dividing zygote, implantation &amp; bilaminar embryo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>C.N.S.</td>
<td>eye, heart</td>
<td>palate, ear</td>
</tr>
<tr>
<td>4</td>
<td>heart, eye</td>
<td>heart, ear</td>
<td>palate, ear</td>
</tr>
<tr>
<td>5</td>
<td>heart, eye</td>
<td>eye, heart</td>
<td>palate, ear</td>
</tr>
<tr>
<td>6</td>
<td>eye, heart, ear</td>
<td>palate, ear</td>
<td>ear</td>
</tr>
<tr>
<td>7</td>
<td>palate, ear</td>
<td>palate, ear</td>
<td>ear</td>
</tr>
<tr>
<td>8</td>
<td>palate, ear</td>
<td>palate, ear</td>
<td>ear</td>
</tr>
<tr>
<td>9</td>
<td>brain</td>
<td>brain</td>
<td>brain</td>
</tr>
<tr>
<td>16</td>
<td>brain</td>
<td>brain</td>
<td>brain</td>
</tr>
<tr>
<td>20-36</td>
<td>brain, external genitalia</td>
<td>brain, external genitalia</td>
<td>brain, external genitalia</td>
</tr>
<tr>
<td>38</td>
<td>brain, external genitalia</td>
<td>brain, external genitalia</td>
<td>brain, external genitalia</td>
</tr>
</tbody>
</table>

- Red indicates highly sensitive periods when teratogens may induce major anomalies.
Dose
(amount of an exposure)

• **Threshold Effect:** There is no known safe level of alcohol use during pregnancy

• **Dose-Response Rate:** The higher the BAC level and the longer the exposure, the greater the risk alcohol poses to developing embryo/fetus
Who Drinks During Pregnancy?

- Among pregnant women, the highest prevalence of reported alcohol use was among those who were:
  - Aged 35-44 years (18.6%)
  - College graduates (13.0%)
  - Unmarried (4.6x married)

Tan, Denny, Cheal, Sniezek & Kanny, 2015
FAS Diagnostic Criteria

• Pre- and/or Postnatal Growth Retardation
  • Height and/or weight at or below 10\textsuperscript{th} percentile

• Specific Facial Anomalies
  • Small palpebral fissures (eye openings)
  • Thin upper lip (vermillion)
  • Smooth philtrum (ridge between nose and mouth)

• Central Nervous System Impairments

* Corrected for racial norms if possible.
Discriminating Features in FAS in Young Child

- Small eye openings
  - Short palpebral fissures
- Flat, elongated philtrum
  - Area between nose and upper lip
- Short nose
- Flattened midface
- Thin upper lip

© Family Empowerment Network UW Medical School
Related Conditions

- Partial FAS (pFAS)
- Alcohol-Related Birth Defects (ARBD)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE DSM-5)
Partial FAS

- With or without confirmed prenatal alcohol exposure
- Two or more facial features
- One or more of following:
  - Pre and/or postnatal growth retardation
  - Evidence of deficient brain growth (OFC at or below 10th percentile) or structural abnormalities
  - Evidence of cognitive/behavioral abnormalities, inconsistent with developmental level that can’t be explained by genetics/family/environment alone
Alcohol Related Birth Defects

- Confirmed prenatal alcohol exposure
- Two or more facial features
- At least one associated congenital structural deficit
Alcohol-Related Neurodevelopmental Disorder

- Confirmed prenatal alcohol exposure
- At least one of the following:
  - Evidence of deficient brain growth (OFC-Occipitofrontal head circumference - at or below 10th percentile) or structural abnormalities
  - Evidence of cognitive/behavioral abnormalities, inconsistent with developmental level that can’t be explained by genetics/family/environment alone
ND-PAE: DSM-5

• Section II
  • Neurodevelopmental disorder associated with prenatal alcohol exposure (p. 86)
    • 315.8 (F88)
• Section III: Conditions for Further Study
  • Neurobehaviorial disorder associated with prenatal alcohol exposure (p. 798)
Spectrum of FASD

FAS
- FAS with confirmed maternal exposure
- FAS w/out confirmed maternal exposure

PFAS
- Partial FAS with or w/o confirmed exposure

ARBD
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)

ARND
- Neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE)

As Defined in DSM-5

Adapted from Neuroscience and Biobehavioral Reviews (2007); 31:230-238
PEDIATRICS Vol. 106 No. 2 August 2000
Differential Diagnosis

• No feature of FAS is unique to prenatal alcohol exposure

• Many genetic conditions include growth retardation and/or CNS impairments

• Many environmental factors can lead to growth deficiencies and/or CNS deficits (e.g. poor nutrition, abuse, neglect, depression, lead exposure)

• Other syndromes include constellation of facial features similar to FAS, including:
  • Williams Syndrome
  • Noonan Syndrome
  • Dubowitz Syndrome
  • Fetal Dilantin Syndrome
FAS Diagnostic Framework

Provider Contact

Child presents for office visit

Triggers emerge:
1. Developmental problems
2. Facial abnormalities associated with FAS
3. Growth delays
4. Prenatal alcohol exposure

Provider Completes initial evaluation

1. Facial malformations
2. Growth abnormalities
3. Neuro-developmental concerns
4. Prenatal alcohol exposure

Referral to Specialist

Referral Criteria Met?
Yes
FAS Diagnosis confirmed using dysmorphic and anthropometric procedures along with appropriate neuro-developmental evaluation data
Multidisciplinary intervention plan developed

No
Continue to monitor changes in child’s health over time

Diagnosis

Services

Intervention plan is communicated to frontline providers, caregivers, and child with ongoing exchange with the intervention team

Case management plan is initiated at the community level based on recommendations
Impact of FASDs

The following problems are associated with fetal alcohol spectrum disorders:

• Delayed development
• Hyperactivity
• Learning disabilities
• Behavioral problems
Impact of FASDs

- Physical Issues
  - Low birth weight and growth
  - Sleep and sucking problems as a baby
  - Vision or hearing problems
  - Problems with heart, kidneys, or bones
  - Damage to part of the brain
  - Speech and language delays
Impact of FASDs

• Behavioral and Intellectual Disabilities
  • Poor reasoning and judgement skills
  • Learning disability or low IQ (typically 79 or less)
• Hyperactivity
• Difficulty with attention
• Poor Coordination
• Difficulty in School (especially with math)
Impact of FASDs cont.

- Poor memory
- Poor ability to communicate in social situations
- Trouble keeping a job
- Trouble with the law
- Difficulty with parenting
- Struggles with independent living
Central Nervous System Impairments

- Poor Fine and Gross Motor Coordination
- Potential Range of Cognitive Disabilities:
  - Mental retardation and/or learning disabilities (I.Q. range 30-130+)
  - Developmental delays
  - Speech and language deficits
  - Memory and processing problems
  - Attention problems and hyperactivity
Impact on Cognition

- Specific Learning Disabilities
- Poor Academic Achievement
- Discrepancy Between Verbal and Nonverbal Skills
- Slowed Movements or Reaction to People and Stimuli
Impact on Executive Functioning

• Poor Organization and Planning Skills
• Concrete Thinking
• Lack of Inhibition
• Poor Judgment
Impact on Motor Functioning

- Delayed Motor Milestones
- Clumsiness
- Balance Problems
- Tremors
- Poor Dexterity
Impact on Attention and Hyperactivity

- Distractibility
- Overactivity
- Difficulty Completing Tasks
- Trouble with Transitions
Impact on Social Skills

- Lack of stranger fear
- Vulnerability to being taken advantage of
- Immaturity
- Superficial interactions
- Inappropriate choice of friends
- Poor social cognition
Physical Issues

- Low birth weight and growth
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones
- Damage to part of the brain
- Speech and language delays
Life Long Issues

- School and Social Skills Deficits
  - 1 in 20 US School Children may have FASD
  - Experienced by 60% of individual over age 12
- Difficulty living independently
- Mental health issues
- Substance use
- Trouble keeping a job
- Difficulty with parenting
- Trouble with the law
  - Experienced by 60% of individuals
Interventions for People with FASD

• Diagnostic services are part of a continuum of needed services for individuals and their families, including:
  
  • Medical (physician, PA, nurse, nurse practitioner)
  • Mental Health (psychologist, counselor)
  • Case Management (social worker, case worker)
  • Education/Special Education
  • Occupational, Physical, Speech/Language Therapy
  • Other Health and Allied Health Services
  • Family Support and Respite
Clinical Recommendations

I. Educate about FASDs

II. Conduct alcohol screening for all women of childbearing age (e.g. discuss quantity-frequency questions); OR refer women for screening

III. Conduct brief alcohol intervention for women at risk (e.g. assess drinking patterns, risks, symptoms); OR refer women for intervention

IV. Refer patients/clients for alcohol treatment, as indicated
Clinical Recommendations cont.

V. Identify individuals with possible FASDs

VI. Screen and as appropriate diagnosis individuals with FAS or other FASDs; OR refer patients/clients for FASD screening/diagnosis

VII. Manage/coordinate treatment for individuals with FASDs

VIII. As needed, refer patients/clients with FASDs (or suspected FASDs) to appropriate services
Podcast Summary

- Check out our short podcast for a summary of Competency I of the CDC Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice
  http://www.youtube.com/watch?v=ARPgT26dg24
Intervening with Individuals Affected by FASD
Addressing the Needs

- Physical
- Environment/Educational
- Counseling/Therapy
- Psychopharmacologic
- Complementary Therapies
Physical

• Safe living environment
  • Basic protective factors
• Adequate Nutrition
  • Overall Good nutrition
  • Some indication of protective properties of nutrients
    • i.e. Vitamins
• Activity/Exercise
• Adequate Sleep
Environmental & Educational Strategies

- Structure
- Predictability
- Monitored level of stimulation
- Recognized retention difficulties
- Multi-modality instruction
- Repetition
- Support
Structure

- Organized, safe physical environment
  - Home, work environment, school, recreational environment
- Well defined areas that remain constant
- Small number of people
- Excess "clutter" well hidden
  - Including cluttered walls
- Balance between “minimalist environment” and some stimulation
Predictability

- Staff, family members, professionals consistent presence
- Assigned seating
  - Remember those memory problems...
- Consistent routines
  - School, work, home & community schedules
- Alert in advance of activity change
- Consistent consequences
Monitored Level of Stimulation

- Protect from over-stimulation
  - Supervise T.V.
  - Monitor Internet use
  - Monitor cell phone, electronic devices
  - Monitor extraneous activities
- Learn and anticipate “danger signs”
- Give frequent, short breaks
- Re-direct behavior
Recognize Retention Difficulties

• Short sentences
• Teach 1 concept at a time
  • May need to break concepts into small steps
• Have individual repeat information just heard
Recognize Retention Difficulties

- Teach memory strategies for daily living skills
  - Meal time
  - Medications
  - School time
  - Sleep time
  - Work schedules
  - Appointments
- Concrete Language
Communications

- Abstract vs. Concrete
100 Adults were Surveyed…

• What word does every dog know?

• And the Top 5 answers are…
<table>
<thead>
<tr>
<th>Abstract Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAS/FAE/FDE: Educational Implication Susan Doctor, Ph.D.</strong></td>
</tr>
<tr>
<td><strong>Why</strong></td>
</tr>
<tr>
<td><strong>Wait</strong></td>
</tr>
<tr>
<td><strong>Listen</strong></td>
</tr>
<tr>
<td><strong>Watch</strong></td>
</tr>
<tr>
<td><strong>Get in line</strong></td>
</tr>
<tr>
<td><strong>Do you understand?</strong></td>
</tr>
<tr>
<td><strong>Later</strong></td>
</tr>
<tr>
<td><strong>Be responsible</strong></td>
</tr>
<tr>
<td><strong>What are you feeling?</strong></td>
</tr>
</tbody>
</table>
Concrete Language
Diane Malbin, www.fascets.org

Show me
What’s easy?
What’s hard?
What does it make you want to DO?
Is there a story
Tell me
Can you draw it?

Come with me
Now
Go to…
Let’s start here (demonstrate)
It’s time to go when…
What works?
Think about ‘Idioms’

As easy as pie
Beat around the bush
Be up and running
In the red
Keep your fingers crossed
Elvis has left the building

When pigs fly
Pull the plug
Pulling your leg
Put a sock in it
No dice
Pay the piper
Timeframes

• Modify timeframes
  • Increased time to complete objectives
    • Homework, chores, daily living activities
  • Increased time for transitions and changes
  • Increased time to process and respond to requirements
Multi-Modality Instruction

• Pictorial cues of tasks/routines
• Use of songs, music, or rhythm cues
• Use of lists
• Sign language to supplement verbal language
• Use tape recorders and earphones
• Model behavior
Repetition

Repeat

Repeat

Repeat

Repeat
Caution: What to Watch For

• Don’t Assume if an individual can repeat rules that they understand them and are capable of following them
  • Information processing
  • Expressive vs. Receptive language

• “Masking”
  • i.e., waiting for others to go first
    • Clue gathering
Caution: What to Watch for

• Idioms
• Watch for reactions to loud or unexpected noises
• Behavior may be related to (or exacerbated by) other needs
  • Sleep
  • Sensory
• Consider a ‘sensory diet’
  • i.e., 1 hour before bedtime turn off video/computer
Counseling/Therapy

• Start counseling early
  • Don’t wait for psychological or behavioral issues to present themselves

• Focus on social skills
  • Area where many people with FASD stumble—and get into trouble
  • Improvement in social skills has broad effect on other aspects of life
Counseling/Therapy, cont.

• Modify counseling to accommodate cognitive disability:
  • Decrease stimulation in environment
  • Individual vs. group counseling
  • Plan session time
    • Time of day
    • Length of session
    • Number of sessions per week
Counseling/Therapy, cont.

- Consider insight of client vs. actual behavior
  - Concrete vs. Insight-oriented counseling
- Choose practical language to help client identify issues of importance
  - Increase ‘concrete’ language
  - Specific to the individual with FASD
  - Don’t expect generalization: teach in real environments
  - May require field-trips to home, work, community
Counseling/Therapy, cont.

- AA Twelve Step Facilitation
  - Re-word to make more concrete
- Community Reinforcement Approach
- Contingency Management

**Motivational Interviewing (MI) may not be as effective in this population**
Complementary Therapies (CDC 2009)

• Biofeedback
• Relaxation therapy
• Medication
• Yoga
• Acupuncture/acupressure
• Reiki/energy healing
• Vitamin/herbal supplements
Medication (CDC 2009)

- **Stimulants**
  - Not a treatment for FAS(D) itself
  - Address over activity, inattention, impulsivity and some secondary condition

- **Antidepressants**
  - Address depressive symptoms, sleep problems
  - Secondary effects include school disruption, negativity, irritability, aggression, anit-social behavior
Medication, cont.

• Neuroleptics
  • Psychotic symptoms not associated with FASD
  • Can address aggression, anxiety, or behavior regulation

• Anti-Anxiety
  • Anxiety more common
  • Maybe basis for underlying cause in some psychiatric conditions
Stigma and FASD

3 main categories of stigma that exist within FASD

- Personal responsibility and blame toward biological mothers
  - Oversimplification, drinking culture in America
- Felt and enacted stigma experienced by children and families
  - Child is “troublemaker” or “not trying hard enough”
- Anticipated life trajectories for individuals with FASD
  - Destined for conflict with the law
Stigma and FASD

Alcohol, Pregnancy and Stigma

• Pregnant women who drink alcohol often experience:
  
  Judgmental attitudes from service providers
  Feeling of shame
  Depression
  Low self-esteem
  Fear of losing their children

(Green et al., 2014)
Stigma and FASD

Caregivers and Stigma

• When parents experience persistent chronic stress, the case is related to the perceptions that people with disabilities are stigmatized in the community, rather than the severity of their child's disability

(Green et al., 2014)
Stigma and FASD

• Individuals with FASD and Stigma
  • Stigma is a clinical risk factor
  • Delays treatment seeking
  • Worsens course and outcome of treatment
  • Reduces compliance
  • Increases the risk of relapse

• These risk factors can lead to:
  • Further disability
  • Discrimination
  • Isolations

(Green et al., 2014)
Experiential Exercise

• The Wright Family Story
• Please get into groups of 6 to 10
• Stand in a circle shoulder to shoulder
• Each person will be given an item
• A story will be read and every time you hear any word that sounds like “right” pass the object in your hands to the person on your right. Every time you hear the word “left” pass the object to the person on your left.
Exercise Questions

• How much of the story can you remember?
• What does this activity tell us about communication?
• What does this activity tell us about teamwork?
• What does this activity tell us about listening skills?
• How might a person who has been affected by prenatal substance exposure struggle?
• How might others struggle with working with someone who might have been prenatally exposed?
Tips for Providers to Reduce Stigma

• Move away from the behavior of the birth mother and onto the substance of Alcohol
  Define FASD as “The range of effects that can occur when a developing baby is exposed to alcohol” vs. FASD occurs when a pregnant women drinks alcohol” (National Organization of Fetal Alcohol Syndrome)

• Continue to educate teachers, employers, service provider and families about FASD with attention to respect, inclusivity and acceptance (Green et al., 2014)
Tips for Providers to Reduce Stigma

• Support evidence-based approaches to enable pregnant women in addressing their alcohol use

• Keep in mind that alcohol dependence is a chronic disease that should be treated as any other chronic disease

(Green et al., 2014)
Tips for Providers to Reduce Stigma

• The stigma of drinking during pregnancy prevents women from speaking openly with their health care providers or their child’s pediatrician

• Stigma can also increase relapse and higher levels of alcohol exposure

(NOOFAS)
Summary

• “Stigmatization is linked to depression, anxiety disorders, aggressive behavior and lower quality of life. Stigma marks certain individuals as less worthy than others, marginalizes them, and impedes their access to needed educational and health services.”

(American Academy of Pediatrics)
Summary

• “Negative public attitudes and social beliefs towards women who drink during pregnancy foster a cycle of fear, blame and shame that have far-reaching impacts on FASD prevention, diagnosis, and treatment across the lifespan.”

(FASD 101 Curriculum, Unpublished, 2016)
Closing

• Questions
• Complete the Post Survey
Select Websites

**Federal Government Sites**
- CDC’s Fetal Alcohol Spectrum Disorders website: [www.cdc.gov/ncbddd/fas/](http://www.cdc.gov/ncbddd/fas/)
- Substance Abuse and Mental Health Services Administration: [www.samhsa.gov/](http://www.samhsa.gov/)
- SAMHSA's FASD Center for Excellence: [www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov)

**Organizations**
- FASD Education and Outreach Projects: [www.FASDeducationl.org](http://www.FASDeducationl.org)
- Minnesota Organization on Fetal Alcohol Syndrome (MOFAS): [www.mofas.org](http://www.mofas.org)
- The Arc of the United States: [www.thearc.org](http://www.thearc.org)

**University Sites**
- Fetal Alcohol and Drug Unit of the University of Washington: [depts.washington.edu/fadu/](http://depts.washington.edu/fadu/)
- Fetal Alcohol Syndrome Diagnostic & Prevention Network, University of Washington: [depts.washington.edu/fasdpn/](http://depts.washington.edu/fasdpn/)
References

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