Seeing the Unseen
Fetal Alcohol Spectrum Disorder

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Disclosures

The presenter:

• has no financial relationships to disclose

Disclaimer

This presentation does not represent the values or beliefs of SC DSS or DAODAS

Warning – sensitive topics and cases will be discussed. The case scenarios are for education and not intended to finger point at any one individual or agency

Case Scenarios – are real, de-identified and are for educational purposes only
Today’s Agenda

- FASD Overview
- Challenges and barriers
- Ways to support families
- SC Efforts
- Call to action and next steps
Objectives

By the end of the presentations, participants will:

1. Identify symptoms of FASD
2. Discuss barriers to assessment and diagnosis of FASD
4. Identify ways to get involved with SC FASD efforts
5. Describe prevention of FASD
Impact of Covid – 19 Pandemic

• Covid-19 is exacerbating some of the most prevalent risk factors for child abuse and neglect: **Substance Use**, Domestic Violence, Financial Stress, Job Insecurities and Social Isolation
• Awareness, communication and collaboration is crucial now and, in the months, ahead in order to prevent further abuse, neglect and promote the overall health and well being of all
• It is estimated that **over 107,000 people in the US died due to overdose in 2021, 12 people every hour**
• Two thirds of the overdose deaths involved synthetic opioids  (Source: CDC)
Impact of COVID-19: National Increases in Substance Use and Overdoses

• Alcohol sales in retail stores increased by 21%
• Alcohol sales online increased by 234%
• Cocaine use increased by 10%
• Heroin use increased by 13%
• Methamphetamine use increased by 20%
• Fentanyl use increased by 32%

Binge Drinking Can Cause Injury, Disease, Death

Binge drinking is defined as

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♂ +

on an occasion, in about 2–3 hours

More Intervention Is Needed

4 in 5 adults who binge drink were not advised to reduce drinking by a healthcare provider*

Primary Care Providers Can Make a Difference**

* SCREEN all adults

* PROVIDE FEEDBACK about health risks

* WORK TOGETHER to reduce drinking if patient desires

*At most recent checkup within the past 2 years | **The US Preventive Services Task Force recommends alcohol screening for all adults and brief counseling for those who exceed recommended limits which includes binge drinking. | 2017 data from the BRFSS, 13 states and the District of Columbia, as reported in McKnight-Eilly et al., MMWR 2020 Learn more: bit.ly/MMWRA55

WWW.CDC.GOV
Current, Binge, and Heavy Alcohol Use: Among People Aged 12 or Older; 2020

Source: National Survey on Drug Use and Health, 2020
National Prevalence of Alcohol Use 2020

- **Binge Alcohol Use**
  *5 or more drinks on one occasion*
  22% of people report binge drinking
  - 12-17 (4.1%)
  - 18-25 (31.4%)
  - Adults 26 or older (22.9%)

- **Heavy Alcohol Use**
  *5 days during a month*
  6.4% of people report heavy alcohol use
  - 18-25 (8.6%)
  - Adults 26 or older (7.7%)

- **Alcohol Use Disorder**
  *inability to stop or control drinking*
  28.3 million people aged 12 years and older have an AUD.
  (only 2.1 Million report receiving treatment)

Source: National Survey on Drug Use and Health, 2020
40.1% of South Carolina Women who reported binge drinking

Binge drinking is defined as 4 or more alcoholic drinks on one occasion

Source: 2021 CDC
56.4% of South Carolina Women reported any alcohol use in the last 30 days.
DAODAS PATIENT SUBSTANCE USE PROFILES FOR ALL DISCHARGED EPISODES OCCURRING IN SFY 2021

Patient Substance Use Disorder Diagnosis Profile

<table>
<thead>
<tr>
<th>Substance</th>
<th>Discharges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>15,874</td>
</tr>
<tr>
<td>Marijuana</td>
<td>13,273</td>
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<tr>
<td>Opiates</td>
<td>6,587</td>
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<tr>
<td>Tobacco</td>
<td>9,463</td>
</tr>
<tr>
<td>Cocaine</td>
<td>4,612</td>
</tr>
<tr>
<td>Amphetamines</td>
<td>5,194</td>
</tr>
</tbody>
</table>

Total Discharges = 26,109

Source: DAODAS 12/1/2021, Clinical Information for Final Discharge Episodes in State Fiscal Year 2021
Fetal Alcohol Spectrum Disorder (FASD)

- Fetal alcohol spectrum disorders (FASD) is an umbrella term for the effects that can occur in a person whose mother drank alcohol during pregnancy
- FASD is 100% preventable and 0% curable
- Unfortunately, 90% of persons with FASD have NO facial characteristics and can exhibit a wide range of cognitive and behavioral problems.

Problem:
- Many women and men drink during childbearing years and are unaware of FAS/FASD
- Women do not often disclose alcohol use during pregnancy
- Some women do not know they are pregnant and continue to drink during critical points of development
- FAS/FASD is not easily detected at birth, and effects may not show until 18 months and up
- FASD is 30 times higher in correctional population
- Missed opportunities for early intervention, therapeutic services and family support
- Statistics show nationally 1 in 4 Foster Children have FASD, often misdiagnosed for ADHD

Prenatal Alcohol Exposure

• Leading preventable cause of birth defects and developmental disorders in the United States, according to the National Institute on Alcohol Abuse and Alcoholism

• FASD was estimated at 24 to 48 per 1000 children, or 2.4% to 4.8% (midpoint, 3.6%). (May et al. 2014)

• FASD prevalence was 71.4 per 1,000 or 7.1%. (May et al. 2021)
Impact of FASD

- Low body weight
- Poor coordination
- Hyperactive behavior
- Difficulty with attention
- Poor memory
- Difficulty in school (especially with math)
- Learning disabilities
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones
- Shorter-than-average height
- Small head size
- Abnormal facial features, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum)
- Note – not all individuals exhibit abnormal facial features

Source: CDC (2021)
https://www.cdc.gov/ncbddd/fasd/facts.html
Why is this group/work important?

A SC child with Autism/ADHD was experiencing ongoing, escalating behavioral issues in the home. Parent had safety concerns for the child as well as other siblings in the home.

Professional Advice after multiple provider visits/calls:
“Go to the nearest ER”

Solution: The mother and child in crisis went to a SC ER. The ER doctor gave mom an FASD brochure and said “(your child) probably has this, you should read this (FASD Brochure)” and the child was discharged with no resources/referrals.
“My oldest daughter. She’s in 1st grade - reading and comprehension is at a 5th grade level 😯 Math comes naturally as well. She was born with 1 facial feature - the first that is formed, upper lip. Hers is completely smooth. But I always thought because she was so smart, she had not been affected by my drinking up to 5 weeks and 3 days pregnant. The older she gets the less I can deny, she certainly has some emotional regulation and executive functioning issues. I still find it crazy that damage can be done that early - and can only imagine how many kids are affected unknowingly. I have 2 daughters with issues now, never ever would have thought FASD would be part of my life. We desperately need awareness.”
Interviews with First Responders

“We had this young kid who kept setting fires. He thought it was funny and was expressionless when we talked with him. They started as small fires and then a house was burnt down. We could always tell something was not right with him as a kid, and his parents were alcoholics. Sad you know. The kid was in and out of foster care, DJJ and is now incarcerated as someone was critically injured in that house fire. I never was trained on FASD or even thought about it as the problem”.

Fire Chief, 25 years

“We get so many calls related to substance use and overdose. It’s a true crisis. You begin to become desensitized to it and feel like it’s a hopeless cause. Yes it’s a product of the environment one is in and life circumstances, but I’ve never considered the cause FASD”.

EMS, Paramedic 15 years

“Alcoholism is a sad and debilitating disease, impacting so many lives. I can’t tell you if I’ve ever had someone with known FASD have it on their adult medical records”.–Coroner, 10 years
FASD traits in adults

- Increased behavioral problems
- Easily distractible
- Poor focus and attention
- Difficulty with memory and analyzing social situations
- Short memory span

- Slower to perform finger, hand, and foot movements
- Poor balance and coordination
- Increase rate of paranoia, passive-aggressiveness
- Increase in substance use disorders
- Higher rate of personality and psychiatric disorders

“I don’t know anything about FASD. I never thought about it before. I often pull people over for suspicion of DUI. They can’t pass the field sobriety test. They act like they are under the influence—poor balance, coordination, can’t recite the alphabet backwards. Sometimes they pass a breathalyzer but are aggressive and get arrested.” – Uniform Patrol Officer (June 2021)

Intersection of FASD and the criminal justice system

- Lack of screening and assessment for FASD in criminal justice system
- Symptoms related to FASD increase criminal risk behavior
- Deficits in cognition, executive functioning and hyperactivity increase risk of offending
- Youth with FASD “maybe disadvantaged and discriminated against within the criminal justice, due to potential difficulties engaging in police interviews, court processes or interventions”
- “…it is likely that young people with FASD will remain hidden within a system in which they are at a great risk of inadequate support, discrimination and criminalization”. (Hughes, N. et al (2016)

“Sometimes you come across a kid who just doesn’t get it…nothing gets through to them. They consistently do the same things to get in trouble and eventually they drop out of school and wind up in DJJ.” – School Resource Officer

“I never realized there was a reason behind intergenerational incarceration, it’s not only due to the external living environment, but the in utero one and exposures. We’ve missed so many kids with FASD”. Program Manager DJJ

“People with FASD have the odds stacked against them. It is a life sentence.”

25 Year Law Enforcement Officer
SC FASD Resources/Update

- 2022 SC Virtual FASD Summit SC Governor’s Proclamation
- SC FASD Brochure 2022
- SC FASD Website: Dontriskitsc.com
- SC has 10 FASD Certified Trainers through WIConnect (12/21)
- SC is has become a FASD United affiliate member 1/2023

- SC FASD Coalition – Monthly Virtual Meetings contact Michelle.Cunningham@dss.sc.gov
September 2022

Governor Henry McMaster Proclaims

September 2022 FASD Awareness Month in SC
SC “Don’t Risk It” Campaign launched September 8, 2022

SC DSS and DAODAS Joint Campaign Aims to Combat FASDs – Press Release 9/8/22
SC FASD Website

“Don’t Risk It”
https://dontriskitsc.com/
NO AMOUNT OF ALCOHOL IS SAFE DURING PREGNANCY, SO DON’T RISK IT.

What’s The Risk?
Drinking Alcohol While Pregnant Can Cause A Set Of Conditions Known As Fetal Alcohol Spectrum Disorders (FASDs).

National Center on Substance Abuse and Child Welfare

SOUTH CAROLINA

Project Liaison and Lead Agency
Michelle Cunningham – South Carolina Department of Alcohol and Other Drug Abuse Services and the South Carolina Department of Social Services

Purpose of Participation
South Carolina has received in-depth Technical Assistance and worked since December 2020 to develop Family Wellness and Support Plans. Applying to the policy academy will allow S.C. to pilot and launch FWSPs and implement internal changes to the DSS Plan of Safe Care policy in addition to enhancing data collection.

Key Partners
- South Carolina Department of Alcohol and Other Drug Abuse Services
- South Carolina Department of Social Services
- South Carolina Department of Health and Environmental Control’s Maternal and Child Health Bureau
- South Carolina Department of Health and Human Services
- South Carolina Department of Children’s Advocacy
- Medical University of South Carolina
- South Carolina Hospital Association
- University of South Carolina Institute for Families
- Community Health Workers Organization
Sponsored by the National Center on Substance Abuse and Child Welfare (NCSACW)

National experts will present on topics to include prental substance exposure and infants/children that substance affected, how to create plans of safe care, policy, legislaion and reimbursement strategies for services

There is no charge, but you must register

January Convening Registration Link:
https://events.zoom.us/ev/AjgnhZobMtP58p3W-Yj4ZlNddQFLbq9cj_TVzEbsE4P0Zv2pJsF2~AggLXsr32QYFjg8BlYLZ5l06Dg
Action items

1. Increase awareness, prevention and training:
   - FASD Brochure √
   - SC FASD Website √
   - September Summit √
   - Written testimony submitted to 2022 SC JCLCC FASD Training

2. Enhance and Expand SBIRT – √
   - DAODAS and Moms Impact √

3. Cross Systems Data Collection/Resources

4. Increase FASD Trainers and Clinicians to Diagnose Resources

Outreach
- 10/2022 SC OBGYN Society Meeting
- 1/21/23 SC CATCH Meeting
- Chrysalis Center 2/23
- Join FASD United √
- FASD Respect Act – not passed ----7

Legislator Discussions √

Continuous
Call to action

Awareness

Develop FASD track in Family Wellness Support Plan

SC Needs Clinicians to Assess and Diagnose FAS/FASD
Clinician Training to Screen and Assess for Fetal Alcohol Spectrum Disorders

• This diagnostic skills-building training is targeted to those providers in a position to diagnose FASDs (physicians, nurse practitioners, physician assistants) and those who are part of a multidisciplinary or interdisciplinary team providing care for individuals at risk for FASDs (including children and youth, individuals in substance use disorder treatment, and individuals in the social service system with undiagnosed challenges).

This training is limited to physicians, nurse practitioners and physician assistants.

• FASD Diagnostic Training - WISCONSIN CONNECT
• https://www.wisconsinconnect.org/fasd-diagnostic-training.html
Free, online trainings are available for healthcare providers who care for women at risk for an alcohol-exposed pregnancy, and for those who work with individuals living with fetal alcohol spectrum disorders (FASDs). These online trainings provide strategies to improve the delivery of care related to FASDs and their prevention.

Source: https://nccd.cdc.gov/FASD/
Thank you!

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SC FASD Coalition