

# **Why Doesn't This Kid Do What I Ask?**

**Part 2 - Health Maintenance in Individuals with  
FASD**

**Mary DeJoseph DO  
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# Overview

- Spent morning on intervention; now consider prevention of challenging behavior
- Physical, mental, and behavioral health are interrelated
- Families and individuals with FASD may manage so many crises that preventive health care is postponed
- Mortality rates for individuals with FASD and their siblings are higher than age counterparts in one study (Burd et al 2007)
- Basic preventive and maintenance health care can assist people with FASD to self-regulate and maintain safety

# Physical And Mental Health Issues Affect Diagnosis, ADLS, And Quality Of Life

- Recommendations for clinical preventive services- safety, sleep, oral and dental care, nutrition and fitness, sexuality
- Life expectancy
- Special health risks in people with FASD- growth, nutrition, specific deficiencies, immune competence, stress management
- Recreation

# Person-First Language

- Language is a powerful tool for expressing respect- it influences attitude, belief and behavior
- Identifies the person as an individual with strengths and abilities who has an FASD
- Always speak about a person by putting the person's name or "a person/ individual with" first before including any mention of difficulties the person
- Barriers- habit, time, training

# Utilizing Person-First Language

## Non-Person first:

- He's ADHD
- She's FAS
- Those Fetal Alcohol kids
- He's autistic
- She's an FAS mom

## Person-First:

- John has ADHD
- Susan is a child with Fetal Alcohol Syndrome
- Kristy and Ann are teens with Fetal Alcohol Spectrum Disorders
- Mark has autism
- She is Conrad's mother and she has an FASD

# Health Maintenance in Individuals with FASD- Safety

- Risk factors for accidents and injury begin early, including increased risk of SIDS, home, pool, and playground safety
- Driving and pedestrian factors to consider-strengths and weaknesses
- Other safety situations- med schedules; decisions about legal and illegal substances; peer pressure and gangs; contraception

# Research On Sleep And FASD

(Stade et al 2008)

- Children with FASD have sleep onset delay, sleep duration changes, and other sleep disturbances
- One hundred caregivers of children aged 5–8 years participated in this study. Mean sleep duration was 7.4 hours and the mean sleep onset delay was 59 minutes.
- In the 7-day diary, 82 of the 100 caregivers reported other sleep problems such as night terrors (22), sleep walking (3), waking more than twice during the night (55), and day time fatigue (10).

# Health Maintenance In Individuals With FASD: Sleep

- Normal sleep and wakefulness- REM and NREM
- Sleep dysfunction may be primary and/ or secondary- consider sleep hygiene, preparation, and scheduling
- Sleep dysfunction and prenatal exposure to substances, including alcohol
- Sleep deprivation: behavioral manifestations include hyperactivity, aggressiveness, inattentiveness, impulsivity, depression, and other mood disorders

# Sleep Affects: Sensory Integration, Learning, And Behavior

- The causes of sleep difficulties in children with FASD are frequently multifactorial. Primary sleep disturbance may occur with brain dysfunction; sleep disturbances may be secondary to health problems, inadequate sleep hygiene, emotional and social issues.
- Approach on multiple fronts:
  - Sleep hygiene
  - Preparation for sleep
  - Sleep scheduling
  - Sleep hygiene for caregivers

# Sensory Integration

- Neurological process that integrates internal and external sensory input and organizes appropriate behavioral responses (play, learning, fun)
- Includes input from receptors for taste, smell, hearing, sight, touch, pain, vibration, gravity, movement, temperature. Brain is also processing autonomic information which may need behavioral responses (visceral, hunger, fatigue)
- Sensory processing may be altered in individuals with an FASD (Clinic for Alcohol and Drug Exposed Children, 2009)

# Health And Environment Impact Behavior and Ability to Self-Regulate

## Internal Factors

- Hunger/Hypoglycemia
- Dehydration
- Nutrition/Diet (MSG, food coloring, Nutrasweet)
- Frustration, anger
- Fear, anxiety
- Unrecognized symptoms of illness
- Too much independence
- Hormones
- Meds –missed or changed

## External Factors

- Clothing (elastic, labels, itchy, too much, too little)
- Wind, weather, air pressure temperature
- Noises: TV, radio, people
- Lighting (fluorescent)
- Visual distractions, “busy” environment
- Chaotic household or class
- Role models acting out with rudeness or aggression
- Being yelled at, blamed, put down

# Health Maintenance in Individuals with FASD: Oral and Dental Care

- ❖ Prenatal considerations in the development of mouth and tooth structures
- ❖ Risk factors and consequences with poor dentition- nutritional, inflammatory, immune status, irritability, self-image and self-esteem
- ❖ The challenges of dental visits and care
- ❖ Practical strategies- scheduling, sensory issues, preparation, educate hygienist and dentist, sedate when nothing else works

# Health Maintenance in Individuals with FASD: Nutrition and Fitness

- ❖ Basic recommendations and food pyramid
  - ❖ Factors in nutrition specific to FASD
  - ❖ Secondary causes of nutritional deficiencies
  - ❖ Working with a nutrition specialist
  - ❖ Additive-free diet for 1 week, then add 1 food at a time to assess affects on the child
- ❖ Read all food labels to avoid problem substances:
    - MSG (fast food burgers & other prepared foods)
    - FOOD COLORING
    - ARTIFICIAL FLAVORS
    - NUTRISWEET
    - GLUTEN-FREE (protein found in wheat, rye, oats, and barley)
    - CASEIN-FREE (protein found in milk-not lactose)

# Choline As A Therapeutic Intervention

- Choline is an essential nutrient related to B12, folate, methionine by a number of pathways
- Choline is critical in fetal brain development and function. In rodents, perinatal supplementation enhances memory and learning; it has also been found to reduce some behavioral and cognitive effects of prenatal stress and alcohol exposure in offspring.
- Choline is available from diet (eggs)
- Observation in humans is promising; studies pending

# ChooseMyPlate.gov and Super Tracker



- Movement and exercise can be very high yield for anxiety and hyperactivity challenges
- Gradually increase fitness and exercise time
- Swimming is exercise and sensory integration
- Relationship with personal trainer may be therapeutic

# **An Individual With FASD**

## ***May Have Multiple Co-occurring Issues To Cope With***

- FAS/ FASD
- DSM criteria mental illness
- Substance abuse/ dependence
- Trauma related diagnoses/ issues
- Medical issues
- Secondary issues in adolescents and adults-homelessness, joblessness

# Safety First: Suicide Risk

People with an FASD are at increased risk for suicide attempt for a number of reasons:

- Impulsivity and hyperactivity
- Inability to visualize consequences of actions
- Depression
- Substance use
- Poor communication skills
- Impaired stress management
- Chronic sleep deprivation

# Suicide Risk Among Individuals with an FASD Whitney (2010)

- ❖ Literal thinking can lead to a higher risk for suicide
  - Language used in discussing suicide and other deaths
    - “she is at peace”
    - “he is just away”
    - “he’s with God”
    - “God wanted her with him”
- ❖ Wanting to be like others and “go along with the crowd”
- ❖ Response to other suicides in the community
  - “If I kill myself, people will be upset”
  - “It will show that people care about me”
  - “It’s a way to get back at those I am angry with”
- ❖ Not truly understanding the finality of death

# Suicide Risk Among Individuals with an FASD Whitney (2010)

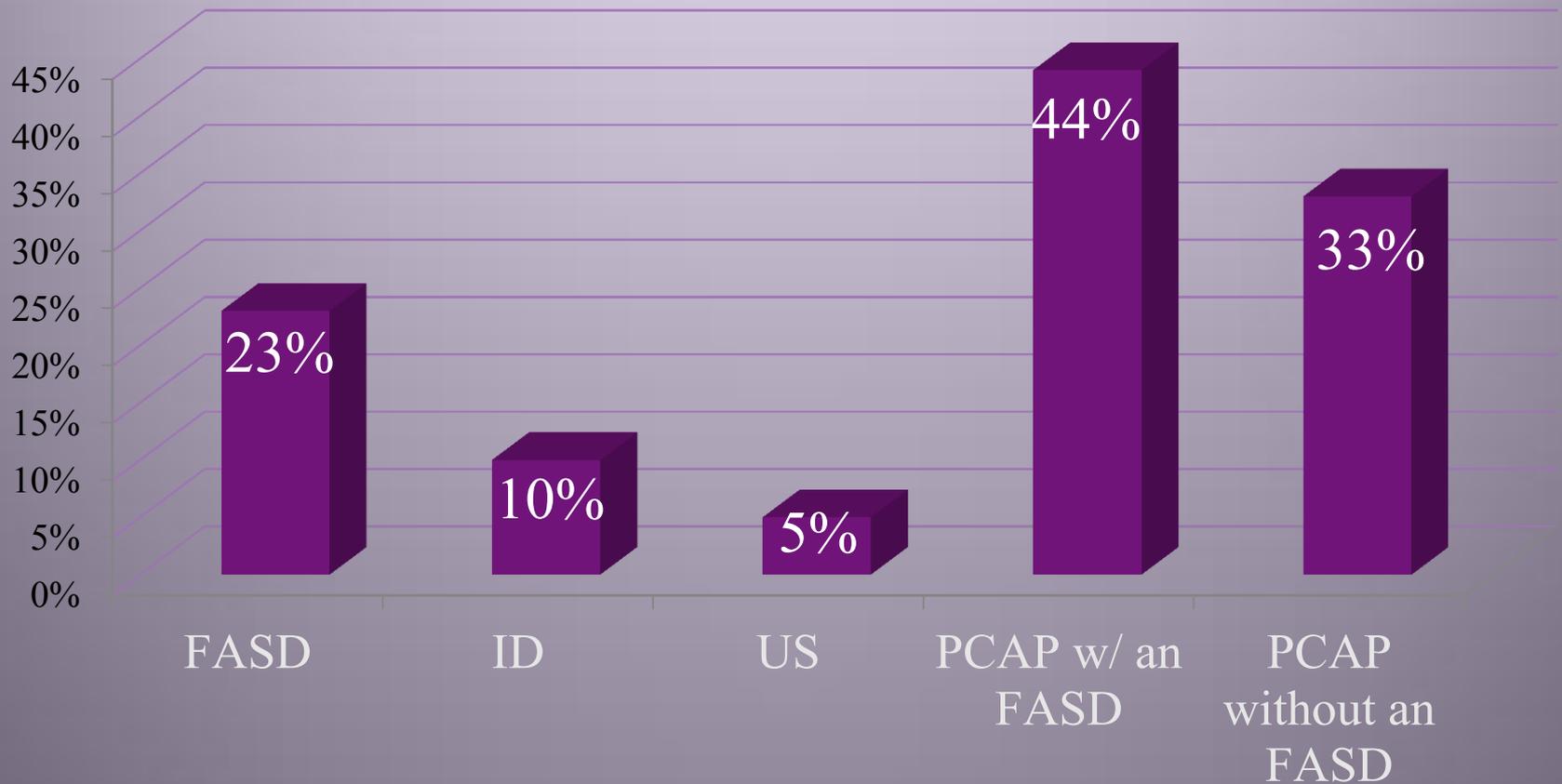
- U.S. Surgeon General's Report (1999) identified 16 suicide risk factors
- 8 of the 16 are congruent with characteristics or common life experience of someone with FASD:
  - Mental health disorders
  - Substance abuse disorders
  - Impulsivity and/or aggressive tendencies
  - History of trauma/abuse
  - Job or financial loss
  - Relational or social loss
  - Lack of social support or sense of isolation
  - Barriers to accessing medical and psychiatric care

# Suicide Risk Among Individuals with an FASD Whitney (2010)

The other 8 risk factors could apply depending on the clinical case:

- 1) Previous suicide attempt
- 2) Family history of suicide
- 3) Easy access to lethal means
- 4) Hopelessness
- 5) Some major physical illnesses
- 6) Local clusters of suicide that have a contagious influence or influence of significant people who have died by suicide
- 7) Stigma associated with help-seeking behavior
- 8) Certain cultural & religious beliefs

# Adult Suicide Attempts: FASD, Intellectual Disabilities, U.S. Population, Women in the Parent-Child Assistance Program (PCAP)



<sup>1</sup>Streissguth, Barr, Kogan, and Bookstein, 1996. Understanding the Occurrence of Secondary Disabilities in Clients with FAS & FAE. Final Report to the CDC, p. 35. <sup>2</sup>Attempt rate for adults with an Intellectual Disability in mixed clinical & community samples (Hardan and Sahl, 1999; Lunsky, 2004). <sup>3</sup>U.S lifetime rate of suicide attempts (1990-1992 National Co morbidity Study; Kessler, Borges, and Walters, 1999).

# Suicide Intervention/Prevention for Individuals with an FASD

Adapted from Huggins, et al (2008)

- Standard suicide assessment protocols need to be modified to accommodate neuropsychological deficits and communication impairments
  - › Instead of “How does the future look to you?” ask “What are you going to do tomorrow? Next week?”
  - › Seriousness of the suicidal behavioral  $\neq$  level of intent to die
  - › Obtain family/collateral input
- Be careful about words used regarding other suicides or deaths

# Suicide Intervention/Prevention

Huggins, et al (2008)

- Intervene to reduce risk
  - Address basic needs and increase stability
  - Treat depression
  - Teach distraction techniques
  - Remove lethal means
  - Increase social support
- Do not use suicide contracts (impulsivity issue)
- Monitor risk closely
- Reinforce and build reasons for living
  - Be literal
- Strengthen advocate-client relationship

# Recovery Wheel



# Resources: Recovery Initiatives And People With Co-occurring Disorders

- **Definition of recovery:** A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. (SAMHSA 2011)
- *Modify recovery activities for individuals with an FASD, but don't ignore the recovery resources that may be available for people with mental illness/ addiction.*
- Specific behavioral interventions for people with an FASD are recommended (Consensus Statement ICCFASD 2012)

# Ongoing Focus: Affected Teens And Adults

- Remember the age adjustment between chronological and behavioral age
- Relationships and birth control
- Alcohol, drugs, driving
- Intensive ongoing job support-applications, volunteering, drop-in supervision
- Money, finances, banking
- Guardianship issues
- Supported apartment

# Interventions That Families Report

- Fitness program with personal trainer; swimming (Special seals and special Olympics)
- Self-enclosed special education classes and high school
- Parent education/ advocacy training
- Social skills and supervised play
- Experiential learning ie demo fires at Annual Fire Safety Day and practicing “diner” at home
- Pets
- Music, music, music
- Involvement with ARC and community activities

# SCREAMS: Prevention Of Challenging Behaviors

- **Structure:** a regular routine with simple rules and concrete, one step instruction, paired with examples
- **Cues:** verbal, visual, or symbolic reminders can counter the memory deficits
- **Role models:** family, friends, TV shows, movies that show healthy behavior and life styles
- **Environment:** minimized chaos, low sensory stimulation, modified to meet individual needs.
- **Attitude:** understanding that behavior problems are primarily due to brain dysfunction
- **Medications:** most often the right combination of meds can increase control over behavior
- **Supervision:** 24/7 monitoring may be needed for life due to poor judgment, impulse control.

# Can Medications Prevent Problems?

- There is no one specific medication to treat FASD
- Address presenting symptom but remember that you are supporting mood and behavior, not changing primary brain damage.
- Choose medication wisely- lower side effects
- Monitor carefully and change if: negative side effects, no positive change, increase of symptoms, developing new symptoms, improvement of symptoms, lack of adherence
- Never use meds alone- always include other behavioral supports

# General Management Issues Across The Lifespan: Health Care Professionals

## Medical :

- Developmental Pediatrician
- Neurologist
- Primary Care Physician
- Immunologist
- ENT/Dentist
- GI
- Ophthalmologist
- Endocrinologist
- Psychiatrist

## Allied Health:

- Audiologist
- Speech Therapist
- Nutritionist
- Psychologist
- Social Worker
- OT/PT
- LDTC
- Alternative therapies practitioners

# Summary: Person Centered Care

- ❖ Diagnostic evaluation if prenatal alcohol is known or suspected; directed case management
- ❖ Education- caregivers and affected person
- ❖ Mental health evaluation
- ❖ Health care- preventive, specialty, allied health
- ❖ Family Support Services
- ❖ Chemical dependency evaluation
- ❖ DD and Voc rehab services

**This Concludes Part 2,  
presented by Dr. Mary DeJoseph**

**Please ask questions to the speaker.**