

Understanding and Supporting Individuals with Prenatal Alcohol Exposure and Their Families

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Disclosure to Audience

No one involved in the planning or presentation of this activity has any relevant financial relationships with a commercial interest to disclose

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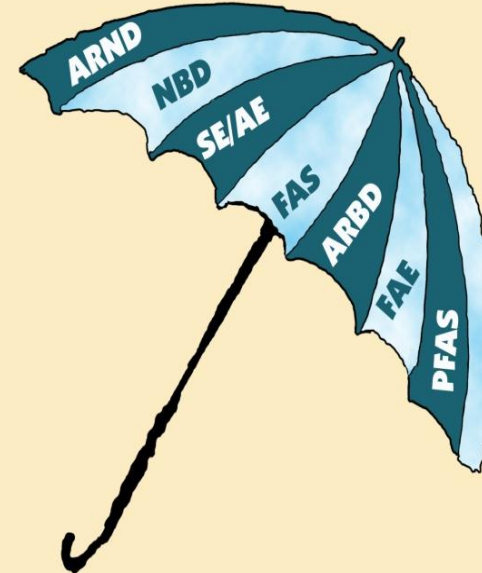
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What are FASDs?

- ❖ FASD is an umbrella term, not a diagnostic category
- ❖ Includes FAS *and* less global effects of alcohol upon a fetus
- ❖ FAS is the only medical diagnosis

Fetal alcohol spectrum disorders



Lifespan Concerns

Of people aged 6-51 with FASD:

- ❖ 94% had mental health problems
- ❖ 83% adults experienced dependent living
- ❖ 79% adults have unemployment problems
- ❖ 60% have legal trouble
- ❖ 50% confinement (i.e., incarceration, treatment)
- ❖ 49% repeated inappropriate sexual behavior
- ❖ 61% dropped out of school
- ❖ 35% struggle with addiction

Streissguth et al., 2004

CNS Dysfunction

- ❖ Cognitive deficits
 - ❖ E.g., learning disabilities, memory problems
- ❖ Executive functioning deficits
 - ❖ E.g., poor concentration and planning skills
- ❖ Motor functioning deficits
 - ❖ E.g., clumsiness, balance problems, tremors
- ❖ Attention and hyperactivity
 - ❖ E.g., overactivity, difficulty completing tasks, trouble with transitions
- ❖ Social skill deficits
 - ❖ E.g., lack of stranger fear, immaturity

CNS Dysfunction

- ❖ Structural abnormality
 - ❖ Small head circumference
 - ❖ Clinically significant brain abnormalities
- ❖ Neurological damage
 - ❖ Seizure or motor control
- ❖ Functional damage
 - ❖ Significant developmental delay
 - ❖ Global cognitive deficits (low IQ level)
 - ❖ Below 16th percentile in 3+ domains

Raising a Child with Special Health Care Needs - The Ideal

- Early diagnosis – obvious impairment or subtle difference
- Awareness and understanding by family, extended family and friends, health care and service providers
- Access to Early Intervention/school supports
- DD eligibility w/ access to respite, home mod, day habilitation, funding for therapies
- Consistent support through transition points
- Meaningful and positive connections in the community
- Consistent, aware, supportive employment

Family Experiences

Infants, Toddlers, & Preschoolers

- ❖ Common issues related to FASDs
 - ❖ Sensory
 - ❖ Motor
 - ❖ Physical
- ❖ Require close monitoring and evaluation

Image by www.childcareaware.org



School-Age Children

- ❖ Common issues related to FASDs
 - ❖ Attention
 - ❖ Cognitive
 - ❖ Visual-spatial
 - ❖ Social skills



Adolescents and Teens

❖ Common issues related to FASDs

- ❖ Mood disorders
- ❖ Substance abuse
- ❖ Social skills

❖ “Hidden Disability”



Adults



- ❖ Presented disability vs. actual disability
- ❖ Difficulty with abstract thinking
- ❖ High risk for victimization
- ❖ Benefit from case management and ongoing support

Executive Functioning & Sensory Processing

Sensory processing is the cornerstone for the development of executive function skills or the skills of “thinking”.

Without the ability to process sensory information effectively, it would be difficult if not impossible to develop executive functioning skills.

Executive Function Skills

- ❖ Planning: Goal directed
- ❖ Organization: Sequential steps to task completion
- ❖ Time Management: Transition from task to task
- ❖ Working Memory: Relationship between past present and future experiences
- ❖ Metacognition: Problem solving, reflection and application, flexibility

(Dawson and Guare)

Sensory Processing Delays in FASDs

- ❖ Delays in sensory processing negatively impact the development of executive functioning skills

- ❖ Types of sensory processing
 - ❖ Auditory Processing
 - ❖ Vestibular Processing
 - ❖ Inattention and Distractibility
 - ❖ Regulation and Modulation
 - ❖ Sensory Seeking/Avoiding
 - ❖ Emotional Reactivity

(Dunn)

General Cognitive Considerations

- ❖ Expect individuals with FASD to have difficulty learning from mistakes or experiences
- ❖ They need support, repetition and patience in maintaining employment, accessing curriculum, keeping appointments, and negotiating legal matters
- ❖ When there is little recognition of the diagnosis, services are poorly reimbursed, and community supports are lacking, and actions often lead to incarceration.
- ❖ With adequate services, structured environments, and understanding, many individuals are able to live productive and successful lives.

Intervention Approaches that are not helpful

- ❖ Sarcasm
- ❖ Chaos
- ❖ Abstract concepts
- ❖ Covering up FASD and its symptoms
- ❖ Time-out
- ❖ Taking things away

- ❖ Threats
- ❖ Physical punishments
- ❖ Logical consequences
- ❖ Point systems
- ❖ Asking “Why?”

Helpful Intervention Strategies

- ❖ Calm environment
- ❖ Routine
- ❖ Limited choices
- ❖ Understanding behaviors
- ❖ Adjusting expectations

- ❖ Keeping it positive
- ❖ Trying differently
- ❖ Stepping back
- ❖ Identifying strengths
- ❖ Educating others –
increasing
understanding of FASD

Intervention Basics - Environment

Observe the individual's level of functioning and how the environment in which they are immersed is impacting them.

- ❖ What is school like for them?
- ❖ How is the home set up?
- ❖ Is their world working to facilitate life for them or is it putting up barriers?

(from *Families Moving Forward*, Heather Carmichael Olson, 2009

<http://depts.washington.edu/fmffasd/>)

Intervention Basics – Structure/Routine

- ❖ Provide consistent supervision
- ❖ Carefully structure tasks at home, school, job, etc.
- ❖ Use a visual structure (picture schedules, tasks, creating an environment that is less stimulating and external ways to stay organized).

Intervention Basics – Instructions

- ❖ Provide explicit instructions of all steps
- ❖ Break tasks down into small pieces
- ❖ Use picture schedules on walls or in a binder, checklists of task steps laminated and on a ring to keep in a pocket
- ❖ Do the task with the person rather than telling them what to do
- ❖ Check for understanding and consistent performance over time

Making Accommodations

- ❖ Observe and modify the environment
- ❖ Use clear, concrete language
- ❖ Watch for triggers
- ❖ Watch for antecedent behavior—what came before
- ❖ Educate others – share what works for this individual

(from *Families Moving Forward*, Heather Carmichael Olson, 2009)

<http://depts.washington.edu/fmffasd/>

Keys to working with individuals with an FASD



- ❖ **Structure**
- ❖ **Consistency**
- ❖ **Variety**
- ❖ **Brevity**
- ❖ **Persistence**
- ❖ **Repetition**

Resources

Alcohol-Related Birth Injury (FAS/FAE) Resource Site www.arbi.org

FAS Community Resource Center www.come-over.to/FASCRC

Centers for Disease Control and Prevention (CDC)
www.cdc.gov/ncbddd/fas

FASD Center for Excellence www.fasdcenter.samhsa.gov

Arctic FASD Regional Training Center
www.uaa.alaska.edu/arcticfasdrtc

Resources

National Organization on Fetal Alcohol Syndrome (NOFAS) www.nofas.org

Circle of Hope www.nofas.org/coh/default.aspx

Fetal Alcohol Syndrome Consultation, Education and Training Services: www.fascets.org

Fetal Alcohol Syndrome: Support, Training, Advocacy, and Resources: www.fasstar.com

The Arc of the United States: www.thearc.org

Resources

Office of Fetal Alcohol Syndrome www.hss.state.ak.us/fas/

Alaska Youth and Family Network www.ayfn.org/

Stone Soup Group www.stonesoupgroup.org

FASLink Listserv (internet email list) for individuals, families and professionals:
www.acbr.com/fas/faslink.htm

Family Empowerment Network (FEN) <http://pregnancyandalcohol.org>

FAS Community Resource Center www.come-over.to/FAS/fasonline.htm

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North Star BHS – CME Activity Course Evaluation Form

Date: 02/17/2015

Starting Time: 12:00 pm

Ending Time: 1:00 pm

Topic: **Understanding and Supporting Individuals with Prenatal Alcohol Exposure**

Presenter(s): Cheri Scott, Faculty-UAA Arctic FASD Regional Training Center; Co-Founder & FASD Family Support Project Manager-Stone Soup Group

At the conclusion of this activity, participants should be able to:	Not at All	Slightly	Moderately	Mostly	Completely
Recognize the importance of working closely with families/caregivers and community supports to identify sensory and processing issues and develop effective plans addressing those issues for individuals with PAE					
Identify sensory and process impacts that may be hindering the individual's ability to progress in their plan of care					
Work closely with families/caregivers and community supports to implement strategies that will simplify the affected individual's plan of care, taking into consideration each client's specific sensory and processing needs					

Was the presentation commercially biased in any manner?

Yes ☐ No ☐

Based on this activity, what will you do differently in your practice? _____

Topics of Interest for future Seminars: _____

Printed Name of CME participant: _____ Physician Yes ☐ No ☐

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Are you on our email distribution list? Yes ☐ No ☐

If not – do you wish to be added for future CME events? Yes ☐ No ☐