FASD in Children and Adolescents: Challenges and Opportunities

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Disclosure

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Introduction
Learning Objectives

• Understand key challenges related to FASD in children and adolescents, and for their families.
• Understand opportunities related to FASD awareness, identification, and management, despite much still to be learned.

Note: Not all slides will be reviewed, but are available for your reference.
Alcohol is a teratogen. Central nervous system development potentially affected throughout entire pregnancy period.

The sole cause of FASD is women drinking alcoholic beverages during pregnancy.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996
Regarding Amount of Alcohol

- No safe amount
- Binge drinking especially hazardous:
  - Women who binge prior to pregnancy are more likely to have unwanted pregnancies.
  - Exposure to high levels of blood alcohol is especially likely to cause teratogenicity in the first trimester.

(CDC: binge drinking for women = 4 or more alcohol drinks per occasion)
Misconceptions among general public and some professionals:

- FASD occurs only if pregnant woman is an alcoholic.
- FASD occurs only in poor, African American, or Native American women.
- Alcohol use in pregnancy less dangerous than drug use.

NOFAS Curriculum for Allied Health Professionals
an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications.

Range of Neurodevelopmental Disorders Comprising “FASD”

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Alcohol Related Birth Defects (ARBD)
ARND refers to various central nervous system abnormalities linked to prenatal alcohol exposure, in the absence of facial features of FAS.

Abnormalities may include:

- Decreased head size at birth
- Structural brain abnormalities, inc. corpus callosum, hippocampus, amygdala, cortex (frontal lobes)
- Cognitive and functional impairments
- Behavioral and mental health challenges

NOFAS: http://www.nofas.org/resource/CAP.aspx
Challenges
Common Strengths in Children/Adolescents with an FASD

- Friendly and outgoing
- Verbal (but can be misleading, in terms of capability)
- Helpful
- Affectionate and lovable
- Well-intentioned
- Generous
- Determined (at first)
- Artistic
- May be intelligent, with special abilities & skills
• Public and professional awareness of FASD remains low.
• Cannot identify a condition not on the radar.
• Misinformation continues about risk factors (controlled drinking alright), prognosis (hopeless), and management (behavioral approaches based on consequences).
• Since alcohol is a brain toxin, the primary deficits (primary effects) are irreversible.
The most common form of FASD is ARND, which lacks facial features, so affected children look typical and the condition is invisible.

Each affected child has a unique profile.

Children don’t present with a chief complaint of “FASD,” but with learning, emotional, behavior, social, & legal problems.

Children with FASD are often in other systems – special education, foster care/child welfare, juvenile justice, developmental disabilities, jail, homeless.
• Many, but not all biological families lack resources and experience a range of psychosocial adversities. FASD can be multi-generational.

• Foster and adoptive families still often not informed of FASD risk in placed children, and not adequately prepared for challenges that may occur.

• FASD, recognized and unrecognized, is a major risk factor for disrupted foster care placements and disrupted adoptions.
• Co-morbidity of FASD with other psychiatric disorders is not uncommon, and may reflect a complex reality.
• The major problem is when only the comorbidities are identified and the FASD is overlooked entirely.
• The learning and functioning of the child with an FASD are counter-intuitive to most adults. This can lead to blaming and to behavioral interventions that exacerbate the condition.
Children with an FASD may be less responsive to range of interventions than children with more typical developmental capacities.

Psychotropic medications may be less effective.

Until recently, FASD was not represented on the DSM, and so could not be diagnosed by mental health professionals, “owned” by mental health, and eligible for reimbursible mental health services.
Common Deficits with an FASD – Primary Effects (1)

- ARND/FASD with variable effect on IQ (most have normal IQ), but adaptive functioning is always decreased for age.
- Learning impairments, especially mathematics and reading comprehension.
- Confounding element: Individual may speak well and give the impression of understanding.
- Communication difficulties, including limited ability to comprehend verbal and written concepts.
- Significant processing problems and memory problems.
- Limited social skills.
Common Deficits with an FASD – Primary Effects (2)

- Problems with decision-making.
- Attention problems, impulsivity, hyperactivity.
- Irritability and mood lability.
- Difficulty with cause-and-effect reasoning, so difficulty in learning from experience: poor judgment and repetition of the same mistakes over and over.
- Frequent lack of awareness of own limitations, so often not understand nature of his or her challenges.
Common Deficits with an FASD – Secondary Effects

• Disrupted attachment with primary caregivers.
• Disrupted school experience.
• At risk of physical abuse and traumatic brain injury.
• At risk of sexual victimization.
• At risk of engaging in sexually inappropriate behavior.
• At risk of victimization due to suggestibility or gullibility.
• Substance use or abuse.
• Mental health problems – ADHD, anxiety, depression, mood lability; risk of Inpatient psychiatric hospitalization or RTF.
• Difficulty maintaining employment.
• Inability to live independently.
• Legal problems including incarceration.
• Risk of suicidality or unintentional death.
Possible Co-Occurring Disorders (all ages)

- Attention Deficit/Hyperactivity Disorder
- Depression
- Bipolar Disorder
- Schizophrenia
- Substance use disorders
- Medical disorders (i.e. seizure disorder, heart abnormalities)
- Sensory integration disorder
- Reactive Attachment Disorder
- Posttraumatic Stress Disorder
- Traumatic Brain Injury
- Anxiety Disorder
- Auditory processing disorder
Opportunities: Identification of an FASD
Specific Red Flags – For High Level Suspicion

- Child diagnosed with a mental health disorder as preschooler, such as ADHD, oppositional defiance or bipolar disorder.
- Child requires “hands on” or visual learning, rather than auditory learning.
- Child easily fatigued & overwhelmed by external stimulation.
- Child with difficulty applying what has been learned, making same mistakes over and over. Not learn from experience.
- Usual explanations of challenges “don’t add up.”
• Maternal history of alcohol/substances during pregnancy
• Atypical development of child & other “red flags”
• Physical exam with some signs of an FASD (growth, head, other)
• Emerging screening test for FASD – Life History Screen (LHS) (Dubovsky). A potential pre-treatment, self-report measure, administered face-to-face by trained provider.
• Standard psychological/educational testing:
  – Variable IQ, with achievement test scores lower.
  – Low adaptive functioning.
• DSM V diagnosis for FASD – 315.8: “Neurodevelopmental disorder associated with prenatal alcohol exposure” (ND-PAE)
Opportunities: Management/Intervention
Early intervention *can* dramatically improve life skills, as well as provide the groundwork for later development. Therefore, early intervention may help to ensure more resilient individuals who can have a more productive, satisfying life.
Three Core Intervention Principles

• Support and collaborate with the family

• Collaborate with other involved professionals, and pursue a team based, system of care approach

• Help the child function more effectively
It’s not that these children won’t. But it may be that they can’t. (Malbin)

Understand the child with an FASD as having a problem, rather than being the problem.

Recognize that some children and adolescents need more support from parents and others to succeed than typical children. This can be helpful and should not be seen as “enabling” (Dubovsky).
Basic Principles for Supporting Child (1)

- Consistent routines and structure
- Limited stimulation
- Concrete language and examples – one direction at a time
- Repetition, via doing, seeing, role-playing

*Source: NOFAS FASD Interventions Dubovsky*
Basic Principles for Supporting Child (2)

- Multi-sensory learning (visual, auditory and tactile)
- Realistic expectations- acknowledge developmental deficits or cognitive impairments
- Supportive environments – build upon strengths
- Supervision – one to one; value of mentoring, modeling, and supervising

Source: NOFAS; FASD Interventions Dubovsky
• Concrete
• Consistency
• Repetition
• Routine (stable, predictable routines)
• Simplicity
• Specific (step-by-step)
• Structure
• Supervision
• No psychotropic medication addresses core deficits of an FASD or reverses pre-existing brain damage.

• Medication may act differently in the child or adolescent with an FASD – less effective.

• Overall, meds have limited role:
  – Treatment of medication-responsive, co-existing mental health disorders, especially hyperactivity and ADHD-like presentation (inattention less responsive)
  – Also, meds may enable child to benefit more from services
Appendix 1: Neurobiology of FASD
FASD and the Brain

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
Appendix 2: Common Presentations of FASD by Specific Developmental Stage
Infants

- Premature birth; medical issues are common
- Chronic ear infections
- Poor weight gain/difficulty with feeding
- Poor sleep-wake cycles/irritability/colic/hard to calm
- Atypical attachment behavior
- Impairment in self regulation
- Late milestones, delays in rolling over, crawling, walking
- Speech delays

British Columbia Ministry for Children and Families
NOFAS
• Continued motor skill delays
• Easily distracted
• Tantrums
• Disrupted sleep
• Sensory defensiveness, reactivity
• Heedless to danger, poor learning from experience or consequences
• Indiscriminate attachment – will go to anyone
• Dental problems
• Small appetites or sensitivity to food texture

British Columbia Ministry for Children and Families
NOFAS
• Impaired patterns – interest in food, sleep
• Poor motor coordination
• Flits from things, with poor attention span and distractibility
• Overly friendly, highly social, indiscriminate relationships, poor sense of boundaries
• Expressive speech – talkative and intrusive, or delay
• Comprehends danger poorly, not respond to warnings
• Prone to temper tantrums and apparent non-compliance
• Doesn’t respond well to change
• Net effect: doesn’t learn from experience or generalize

British Columbia Ministry for Children and Families; NOFAS
School Age

- Continued sleep disturbances
- Poor social skills, making and keeping friends
- Anger and aggression associated with frustration and impulsivity
- Poor self worth, low self esteem
- Developmental delays
- Poor self care
- Boundary issues
- Attention problems, possible hyperactivity
- Easily frustrated/tantrums
- Difficulty understanding cause and effect; failure to understand consequences, so judgment impaired
- Very concrete thinking
- Onset of academic problems, especially math

British Columbia Ministry for Children and Families; NOFAS
Adolescence

- Less obvious FAS facial features
- Academic plateau, increased need for abstract thinking
- Memory problems/working memory – storing and retrieving information
- Inconsistent performance day to day, unpredictable
- Impulsivity, distractibility, disorganized
- Anxiety, depression and/or mood swings
- Victimization
- Increased desire for independence
- Unrealistic expectation of others
- High risk of sexual activity and pregnancy
- May become slightly obese
- Lying, stealing or antisocial behavior
- May function better in the evening
• Memory problems

• Difficulty storing and retrieving information

• Inconsistent performance ("on" and "off") days

• Impulsivity, distractibility, disorganization

• Ability to repeat instructions, but not able to put them into action ("talk the talk but don't walk the walk")

British Columbia Ministry for Children and Families; NOFAS
• Difficulty achieving normative development: The “will” is there, but the “way” is much more challenging.

• Lack of full awareness of abilities and limitations (e.g., insight).

• Limited judgment.

• Impulsivity.

• Denial – of limitations and needs.

• Limited ability to generalize, think abstractly, learn from experience.

• Limited practical knowledge about successful community living.

• At risk to be taken advantage of.

• Ongoing tension between accepting parental support and desiring autonomy – wants to run own life, but can’t.

NOFAS; Malbin
Resources
• BEAMS: The Fasstar Trek Method: [http://www.comeover.to/FAS/BEAM.htm](http://www.comeover.to/FAS/BEAM.htm)


• SCREAMS: [http://www.come-over.to/FAS/ScreamsArticle.htm](http://www.come-over.to/FAS/ScreamsArticle.htm)


• National Screening Tool Kit - Canadian Association of Paediatric Health Centres:  [http://www.caphc.org](http://www.caphc.org)

• PA Families, Inc : [http://pafamiliesinc.com/about.php](http://pafamiliesinc.com/about.php)

• Fetal Alcohol Spectrum Disorder Support Group – Pittsburgh area contact kimjaxon1218@yahoo.com

• Stone Soup (support group): [www.stonesoupgroup.org/FASDnetwork.html](http://www.stonesoupgroup.org/FASDnetwork.html)

Assessments for Infants and Children

• **Recommended Evaluation Tools:** (Read the articles on [Early Intervention for Infants with FAS](http://come-over.to/FASCRC) first)

  - [Bayley Scales of Infant Development](http://come-over.to/FASCRC) for cognitive and motor evaluations from ages 0-2.

  - [K-ABC](http://come-over.to/FASCRC) is useful for cognitive evaluations for children ages 3-5.


  - [Vineland Adaptive Behavior Scales](http://come-over.to/FASCRC) for children of all ages is essential to measure functional abilities and life skills.

Source: FAS Community Resource Center, FAStar [http://come-over.to/FASCRC](http://come-over.to/FASCRC)