Fetal Alcohol Spectrum Disorders (FASD): Why Professionals, Youth, and Families All Need to Become Experts

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Disclosures

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Why we all need to become FASD experts (1)

- FASD a genuine public health problem.
- FASD frequently missed.
- “Typical” interventions make it worse.
- Punishment also makes it worse – brain damage.
- Need first to acknowledge – FASD exists.
- Then need identification and intervention.
- Providers, agencies, systems need to change.
- Youth, young adults, families need more information
- Those with FASD not to be blamed, not their fault.
Why we all need to become FASD experts (2)

- FASD-competent clinicians needed – identify & treat.
- Professionals – mental health, education, human services, physical health – need to be FASD-aware.
- FASD exists, it affects how children think, process and learn, adults need to understand their needs and communicate with them differently.
- Parents/caregivers more confident & effective with information about child’s FASD and with support.
- Youth & young adults have a choice, once informed.
- Ideally, part of routine health curricula in schools.
Goal for today

• Provide information to enlighten and inform others.
• Key issues to be addressed:
  • Parent perspective.
  • The “basics” – What is FASD, especially as it affects children/adolescents?
  • What is the FASD prevalence?”
  • What are key risk factors for an FASD?
  • How is an FASD identified?
  • What are useful interventions?
Rationale for FASD focus and not other toxins

• Focus on FASD based on consequences of alcohol use in pregnancy & lack of FASD recognition of FASD.
• All substance use during pregnancy needs to be avoided.
• Includes cigarettes (premature birth, birth defects, death, ADHD), cocaine, other drugs.
• Increasing understanding also of negative impact of maternal stress during pregnancy on fetus/child.
Parent Perspective – Dianna Brocious

• Parent and family advocate
• Adoptive parent of children with an FASD, and grandparent of child with an FASD
• Member, OMHSAS Children’s Planning Council
• Family Involvement Specialist, PA System of Care Partnership
Fetal Alcohol Spectrum Disorders (FASD)  
“The Basics”
Fetal Alcohol Spectrum Disorder (FASD) as Identified by SAMHSA’s FASD Center for Excellence

..........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.

“FASD” = alcohol-related neurodevelopmental disorders:
- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- *Alcohol Related Neurodevelopmental Disorder (ARND)
  
  Other specified neurodevelopmental Disorder:
  Neurodevelopmental disorder associated w. prenatal alcohol exposure (ND-PEA: 315.8 in DSM-V; F88 in ICD 10)
- Alcohol Related Birth Defects (ARBD)
The toxic effect of in-utero alcohol

Alcohol a teratogen. Primary effects on brain not reversible

The sole direct cause of FASD is women drinking alcoholic beverages during pregnancy. There is no safe amount during pregnancy. FASD is 100% preventable.

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

—IOM Report to Congress, 1996
Fetal Alcohol Syndrome (FAS) – All of the following

Three facial abnormalities [facial features develop 4-8 wks]:
—Smooth philtrum (groove between upper lip and nose)
—Thin vermillion (upper lip)
—Small cerebral palpebral fissures (eye openings)

Growth retardation: height, weight, head circumference

Central nervous system involvement: cognition, intelligence, attention, behavior, memory, processing, mood, attachment, motor skills, eye-hand coordination and others

NOFAS: http://www.nofas.org/resource/CAP.asp
Fetal Alcohol Syndrome (FAS)

FAS Facial Characteristics:
- small eye openings
- smooth philtrum
- thin upper lip

http://en.wikipedia.org/wiki/Fetal_alcohol_syndrome#Facial_features
Alcohol-Related Neurodevelopmental Disorder (ARND) (1)

ARND (ND-PEA) refers to various neurological abnormalities linked to prenatal alcohol exposure. These include:

- Decreased head size at birth
- Structural brain abnormalities
- Functional and cognitive impairments
- Behavioral abnormalities
- Despite the above, physical appearance is normal

NOFAS: http://www.nofas.org/resource/CAP.aspx
Children with ARND have central nervous system deficits, [and] lack the facial features of FAS. Problems may include:

- Increased activity & attention deficits
- Processing problems
- Learning disabilities
- Behavioral challenges
- Social skill impairments
- Developmental delays
- Difficulty learning from experience

NOFAS: http://www.nofas.org/resource/CAP.aspx
ARND (3)

- Due to absence of the distinct FAS facial features with ARND, children have a “typical” appearance.
- In addition, facial features of FAS are often less evident during adolescence and adulthood.
- Helps explain why FASD is often missed.
- FASD “an invisible disorder.”
- Particular concern: Conditions *comorbid* with FASD are identified and treated, but the FASD is missed.
What is the prevalence of FASD?
FASD prevalence: Recent changes in estimates

• Philip May in 2009: 1% prevalence of FASD.
• Compare with May’s 2014 observational study of 1st graders in public school in Midwest:
  Prevalence = 2.4-4.8%, with 3.6% midpoint.
• Ira Chasnoff, Chicago, assessment of children receiving MH services, in foster care or adopted:
  FASD prevalence = 28.5% here.
• Further exploration of FASD prevalence in high risk groups – Carl Bell, Chicago.
Carl Bell MD, Professor of Psychiatry and Public Health, University of Illinois at Chicago

- FASD “the largest preventable public health problem in poor African American communities.”
- Review of 1979 evaluations of 274 children in special education, Chicago’s South Side: FASD prevalence = 55% +.
- 2011 audit, 162 students in school clinics: Prevalence = 32% +.
- Youth in Cook County Detention: Prevalence = 66-75%.
What are risk factors for FASD?
Risk factors for alcohol use during pregnancy

- Parental FASD: FASD often multi-generational.
- History of trauma/adversities during childhood.
- History of placement in foster care.
- Violence and abuse during adulthood.
- History of family substance abuse, including alcohol.
- Note: FASD not limited to poor, minority families:
  - Alcohol use during pregnancy occurs among all races and ethnicities, and among middle & upper class females.
  - Alcohol use during pregnancy also occurs among high school students and college students.
Barriers to FASD identification

- FASD (ARND/ND-PEA) an invisible disability.
- Facial features of FAS less evident in adolescence & adulthood.
- Presentations highly variable. Every child different.
- Children with an FASD often speak well – but poor processing and comprehension.
- FASD symptoms overlap with many symptoms resulting from trauma.
- Behaviors of concern with an FASD may be similar to many psychiatric disorders (mimic every disorder).
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
How can FASD be identified?
Potential red flags for an FASD (ARND/ND-PEA)

- Child diagnosed with MH disorder as preschooler (ADHD, ODD, BPD), who not respond to Rx over time.
- Child with difficulty applying what has been learned, making same mistakes over and over.
- Child requires “hands on” or visual learning, not respond well to auditory approach.
- Child easily fatigued & overwhelmed by external stimulation.
- When red flags present, develop working hypothesis.
Recognize primary effects and secondary effects

Primary effects – due directly to *in utero exposure* to alcohol and its impact on in utero development of infant, including brain development. Deficits not reversible.

Secondary effects – due to the *impact of the FASD* (recognized or unrecognized) on the child and family, and from adversities faced by the child and family, not from direct effect of alcohol.

Goal: *Managing* primary effects of FASD, and *preventing*, *whenever possible*, secondary effects and minimizing their impact.
FASD primary effects (1)

- Variable IQ – most children have normal IQ.
- Decreased *adaptive functioning* is key.
- Hyperactivity and impulsivity.
- Problems with comprehension (oral and written), processing, & short-term memory.
- Problems with cause-and-effect & learning from experience.
FASD primary effects (2)

- Irritability and mood lability.
- Academic limitations, including problems with math and reading comprehension (learning disabilities).
- Naïve and easily led: immature for chronological age.
- Often, unaware of own limitations.
FASD specific secondary effects

• Childhood maltreatment – children very frustrating and “abusable.”
• Peer victimization – money, bullying, sexual abuse.
• Inadvertent, inappropriate sexual behavior.
• Problems in school – academic, social, behavioral.
• Alcohol and other substance abuse.
• Involvement in legal system.
• Psychiatric disorders, and possible Inpatient and RTF.
• Problems with employment & independent living.
Potential causes of FASD secondary effects

• FASD not identified.
• Inappropriate interventions.
• Poverty and limited social support.
• Other family adversities (inc. Adverse Childhood Experiences, ACEs).
• Disrupted attachments.
• Cumulative frustration and exhaustion.
• Blaming & punishment.
Assessment of suspected FASD

• History
  – Maternal history – alcohol/substances during pregnancy
  – Atypical development of child, specific “red flags”
  – Underperforming student, and behavioral concerns

• Physical exam
  – Possible facial features and growth deficits
  – CNS deficits

• Screening and psychological testing
  – Screening – MH & trauma screens helpful.
  – Standard tests – IQ, achievement tests, adaptive functioning
Behavioral screening for an FASD

• No validated screen at present for an FASD for children and adolescents.
• Such a screen will be very helpful, once available.
• Efforts are underway but incomplete.
Typical findings on psychological testing with ARND

• IQ usually normal (but not always).
• Verbal IQ: significantly higher than performance IQ.
• Overall IQ: higher than achievement scores (WRAT).
• Overall IQ: higher than adaptive behavior scores (15 points, Vineland).
What are helpful intervention approaches?
Important intervention principle

• FASD is not just an neurodevelopmental disorder.
• It also involves trauma – developmental trauma, due to in-utero alcohol exposure.
• In addition, trauma very likely in family, and child is at risk of additional trauma growing up.
• Therefore, interventions, while addressing specific challenges of child with an FASD and family, must also be trauma-informed.
• In absence of TI approach, intervention unlikely to be effective.
Possible adverse experiences of child with an FASD –
The ten original ACEs

• Physical neglect
• Emotional neglect
• Emotional, physical, and sexual abuse (three items)
• Parental separation or divorce
• Parental/caregiver mental illness or suicide attempt
• Parental/caregiver alcohol or drug abuse
• Parental/caregiver incarceration
• Domestic abuse against mother or stepmother
Additional adverse experiences (not in ACEs)

- **In utero exposure to toxins – alcohol most damaging, but tobacco & other substances also harmful.**
- Exposure to environmental toxins, including lead.
- Poverty.
- Unsafe neighborhoods.
- Community violence.
- Discrimination.
- Bullying victimization.
- Placement in foster care (and disrupted attachments).
What is trauma-informed care (TIC)?

• Recognition of high prevalence of trauma, and its manifold short- and long-term consequences.
• Commitment to understand how the trauma relates to the individual’s current challenges (trauma-lens).
• Use of relationships to mitigate impact of trauma, prevent re-traumatization, and promote healthy functioning.
• TIC (also known as a “trauma-informed approach”) guided by specific core principles.
TI approach to child, family, team – core TI principles

- **Safety** – physical & emotional, the sine qua non (Fallot & Harris)
- **Trustworthiness** – with honesty, transparency, and consistency (Fallot & Harris).
- **Choice** – opportunities for daily decision-making & an internal locus of control (voice and choice) (Fallot & Harris).
- **Collaboration** – working together and sharing power, as a corrective to prior abuse of power (Fallot & Harris).
- **Empowerment** – prioritizing competency, skill-building, validation, strengths-based responses (Fallot & Harris).
- **Cultural, gender, & linguistic competence** – part of any effective system of care or intervention (SAMHSA).
Recognize and promote *protective factors*

- Absence of violence
- Loving, nurturing, stable family home environment
- Early diagnosis and early intervention
- Use of special education
- Use of social services

www.cdc.gov/ncbddd/fasd/treatments.html#BehavioralEducationTherapy
Recognize and promote child’s strengths (variable)

• Friendly and outgoing
• Verbal (can be misleading)
• Helpful and well-intentioned
• Affectionate and lovable
• Generous (can be taken advantage of)
• Determined (need to preserve this, help with frustration)
• Special abilities/skills
Paradigm shift: need developmental perspective when working with an FASD

• It’s not that these children won’t. It may well be that they can’t (Malbin).
  – Not lazy or “manipulative” – they have a disability.
  – Language matters: “The child has a problem,” rather than “the child is the problem.

• Some children with an FASD need greater support from parents & others to succeed. Scaffolding approach. This is helpful, not “enabling” (Dubovsky).
Application of specific TI principles to FASD interventions
“Safety”

• No blame/no shame.
• Ensure physical and emotional safety of everyone.
• Promote attachments.
• Identify strengths.
• Ensure careful supervision of child, based on age and need.
• Limit level of sensory input to child.
• Address reality-based needs related to safety.
• Create safety net – systems, services, supports.
“Trustworthiness”

- Engagement & rapport as core activities.
- Be “family-driven” and “youth-guided.”
- Listen, ask questions, learn.
- Display empathy and be genuine.
- Ask about child and family priorities.
- Build on strengths.
- Model patience.
- Maintain TI attitude: “Doing the best he/she can.”
“Choice”

• Be “family-driven” and “youth-guided.”
• Share decision-making and power – a partnership.
• Address child and family priorities.
• Encourage openness and flexibility.
• Create interpersonal safety for choice-making.
“Collaboration”

• Be “family-driven” and “youth-guided.”
• Share decision-making and power.
• Address child and family priorities.
• Promote collective brain-storming.
• Persuade, don’t coerce or threaten.
• Educate, via reciprocal give-and-take.
• Remember, it’s their family, not yours.
“Empowerment” (1)

• Convene a child and family team and use system of care approach, whenever possible.
• Help family identify and mobilize natural supports.
• Help family access trauma treatment, when indicated.
• Help family access peer support, respite, and other services, as needed.
• Help family support, mentor, & supervise child.
• Validate success and genuine effort.
“Empowerment” (2)

• Help child gain self-awareness, without losing hope.
• Incorporate needed adaptations, given child’s FASD.
• Use child’s strengths, including visual learning, use of pictures, & concrete prompts, to promote learning.
• Help child develop coping skills, inc. self-expression.
• Ensure quality primary care, attention to child’s physical health, and collaboration with PCP.
• Maintain *team* cohesiveness and unity.
• Promote wellness, not just response to crises.
“Empowerment” through self-expression by child

• Requires ongoing sense of interpersonal safety.
• Expressing own point of view – “I’m upset” or “I’m angry.”
• Asking for help – “Please help me with...”
• No shame in saying, “I don’t understand.”
• No shame in saying, “Please slow down,” or “Please repeat that.”
“Cultural/gender/linguistic competence”

• Need to understand family culture, provide linguistic support when needed, and individualize.
• Need to understand any gender-related issues.
• Missing from SAMHSA formulation: need for *developmental competence* – awareness of child’s abilities & limitations, addressing them realistically.
Need to add *developmental competence* to SAMHSA’s identified competences

- “Cultural, gender, & linguistic competence” becomes
- “Cultural, gender, *developmental*, & linguistic competence.”
- Reason: Developmentally inappropriate interventions are not trauma-informed, strengths-based, or effective.
- Developmentally inappropriate interventions more likely to *exacerbate* child and family trauma (e.g., system-induced trauma), and increase risk of secondary effects for child.
“System-induced trauma”

- Trauma to youth and family resulting from actions of service systems, often inadvertent & unintentional.
- Failure to listen and engage.
- Disqualification of concerns.
- Shaming or blaming youth or family.
- Presuming that negative behaviors are intentional.
- Some system-induced trauma inescapable (removal of some children from homes). But interpersonally based system-induced trauma can be avoided.
Developmental competence – additional elements

• Recognizing and adapting to child’s limitations & deficits – necessary and consistent with a strengths-based approach.

• Making expectations (and care plans) congruent with child’s developmental capabilities.

• Avoiding approaches unlikely to work – points, levels, rewards & punishment, cognitive treatments.

• Persisting and remaining patient.

• Recognizing need for lifelong support – modeling, mentoring, monitoring, & attention to transitions.
Promoting competence through accommodations

- Consistent routines and structure
- Limited stimulation
- Concrete language and examples (being literal)
- One direction at a time
- Repetition, via doing, seeing, role-playing
- Multi-sensory learning (visual, auditory and tactile)
- Realistic expectations
- Supportive environments
- Supervision – one to one; mentoring, modeling, monitoring

Source: NOFAS FASD Interventions Dubovsky
The “Eight Magic Keys” – Evensen and Lutke

– **Concrete** – double meanings & idioms avoided
– **Consistency** – same words and key phrases used
– **Repetition** – information repeated, for retention
– **Routine** – things kept the same, so predictable
– **Simplicity** – messages short & sweet, limited stimulation
– **Specific** – step-by-step instructions & information
– **Structure** – clarity & guidance provides glue
– **Supervision** – active monitoring promotes functioning
Psychotropic medication and FASD

– No psychotropic medication addresses core FASD deficits or can reverse pre-existing brain damage.
– At times, medication may be less effective and result in more side effects.
– However, meds helpful for ADHD and other medication-responsive MH disorders.
– Meds may enable child to benefit more from services, be more “present.”
Summary and collective core tasks
Theme of vulnerability: Children with an FASD among the most vulnerable children in any system of care

• Initial trauma, in-utero alcohol exposure, plus:
  • Reality-based challenges, including poverty.
  • Family instability and disrupted attachments.
  • Alcohol and other substance use.
  • High risk of child maltreatment.
  • Difficulty in school, and victimization by peers.
  • Involvement of multiple child-serving systems.
  • Risk of out-of-home placements.
Summary – vulnerability continued

• Many FASD effects continue across lifespan.
• If FASD not recognized and addressed, likely outcome = increasing failure over time.
• Inappropriate interventions can make it worse.
• Without trauma-informed interventions, more failure, with system-induced trauma.
Collective core tasks (1)

• Understand and be aware of FASD, so that affected individuals can be helped, & prevention is promoted.
• Identify FASD when present, or when likely present.
• Identify maltreatment or other sources of trauma, when present or likely. As with FASD, often hidden.
• Useful assumptions:
  – When maltreatment present, think FASD also.
  – When FASD present, think family trauma.
  – When FASD present, think additional child trauma, including possible maltreatment.
Collective core tasks (2)

- Educate stakeholders to achieve common understanding, so everyone “on same page.”
- Individualize, using developmentally appropriate interventions.
- Create and maintain a cohesive, collaborative team.
- Recognize fundamental need for trust, engagement, and ongoing rapport.
- Ensure that all FASD interventions are trauma-informed.
Trauma Informed Care Resources: Key Websites

• National Child Traumatic Stress Network Center (NCTSN)  
  www.nctsnet.org

• Substance Abuse and Mental Health Services Administration (SAMHSA)  
  www.samhsma.gov/

• ACE Study  
  www.acestudy.org

• Community Connections (Fallot and Harris)  
  www.communityconnectionsdc.org

• The Anna Institute  
  www.theannainstitute.org

• National Center for Trauma Informed Care (NCTIC)  
  www.samhsa.gov/nctic
Other TIC Resources


Other TIC Resources

• Hodas, G: Multiple articles on trauma informed care in Children’s Mental Health Matters series. Go to: Parecovery.org/Resources/Children’s Mental Health Matters/Children’s Mental Health Matters by Hodas.


FASD Resources

• SAMHSA: http://www.fasdcenter.samhsa.gov/documents/FASDGuide12_01


• National Screening Tool Kit - Canadian Association of Padiatric Health Centres: http://www.caphc.org
FASD Resources

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