Fetal Alcohol Spectrum Disorders (FASD) in Youth: Become Involved

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RCPA Conference, October 11, 2017, Hershey, PA
Institute Overview:
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Faculty and Disclosures

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Goal: To educate, engage, encourage your involvement

Part 1: Presenting the Challenge
• Relevance of FASD as topic
• The reality of FASD
• Parental challenges
• Embracing FASD at the policy level

Part 2: Effective and Promising Interventions
• FASD identification, diagnosis, and early intervention
• Ongoing support for child and family
• Specific practical guidelines and medical interventions
• On the horizon – a promising future
Part 1: Presenting the Challenge
Relevance of Topic:
Why FASD? Why now?

Lyn Becker
FASD is relevant for many reasons:

• U.S. current “love affair” with alcohol and other drugs.
• 21st century focus on individual’s healthcare rights, individualized care, and quality of life.
• 1990s to present—increased attention to Developmental and Intellectual Disabilities
• Improved technology has increased researchers’ ability to identify critical information about FASD.
Why is FASD relevant?

(continued)

- Increased ability to identify persons with FASD has resulted in identifying patterns of behaviors that are highly concerning from both an individual and public health perspective.
- Increased ability to identify and more accurately calculate the costs of not addressing FASD compared to the costs of addressing FASD.
In reality, all substance (drug) use during pregnancy needs to be avoided – nicotine, marijuana, cocaine, opioids, heroin, etc.

However, “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).

In the US, 3-5 infants in 100 are likely to have FASD, a higher rate than autism and more prevalent than all the following collectively: Down Syndrome, Cerebral Palsy, SIDS, Cystic Fibrosis, and Spina Bifida.
Functional Magnetic Resonance Imaging – f MRI

- Visualize in detail specific parts of brain at work (or failing to work).
- Measures brain activity by detecting increased blood flow when brain part is working and decreased blood flow when brain part is not working. Used to map neuron activity in the brain.

Diffusion Tensor Magnetic Resonance Imaging – dt MRI

- Imaging method uses diffusion of water molecules to generate contrast in MR image. This method reveals microscopic details about tissue architecture, whether normal or abnormal, and maps white matter. (White matter - neurologic pathways that connect parts of brain for communication purposes).
Improved Technology

Extreme structural abnormalities in FAS
(12 year old male subjects)

Normal Development  Fetal Alcohol Syndrome
• **Mathematical Modeling Facial Recognition Software**: Software that identifies abnormal size, shape, and positioning of facial structures relative to other facial structures using 3-D images. Identifies small/abnormal shaped eyes, flat mid-face, higher or lower positioning of forehead, nose, oral structures. Identifies features, Fetal Alcohol Syndrome.

• **Laboratory methods of examination**: Current degree of microscopic magnification permits visualization of cellular function and molecular function such as molecular replication, transcription of genes into RNA, translation of RNA into protein, other cellular functions.

• **Alcohol and epigenetics** – Alcohol may “silence” (turn off) a gene that is supposed to be “activated” (turned on), and may “activate” (turn on) a gene that is supposed to be “silenced” (turned off).
Outcomes of persons with FASD

What we know:

• 80% of children/youth live in foster or adoptive homes (about 70% in foster and 10% in adoptive), international adoptions a higher risk.
• 60% of children/youth have a disrupted school experience such as suspension, expulsion, dropping out.
• 60% have some degree of ADD or ADHD.
• 95% have primary and/or secondary mental health/emotional disorders.
• Most adults have severe depression, about 25% attempt suicide.
Outcomes of persons with FASD

• 24% of adolescents and 46% of adults have a substance use disorder.
• As many as 50% spend time in a juvenile detention center or a correctional facility.
• 49% engage in inappropriate sexual activity.
• 80% of adults cannot maintain consistent employment.
• 80% of adults require some type of dependent living arrangement.
Outcomes of persons with FASD

- We also know this – alcohol causes damage
- When pregnant women drink alcohol – any type, amount, or time (week of gestation) – during pregnancy, significant risk of damage to fetal brain cells:
  - Physical damage – size, shape, composition
  - Functional damage – how cells carry out their specific purposes:
    - Reproduction (mitosis).
    - Pruning excess numbers of cells (apoptosis).
    - Developing into different types of brain cells (differentiation).
    - Connecting to other cells to form tissue (migration, adhesion).
    - Manner of communicating, i.e., release of neurotransmitters.
- This damage results in a variety of defects and disabilities, across a continuum from mild to severe.
What Fetal Alcohol Spectrum Disorders (FASD) Involves

Gordon R. Hodas, MD
FASD and in-utero use of alcohol:

• FASD is 100% preventable.
• The sole direct cause of FASD is women drinking alcoholic beverages during pregnancy.
• There is no safe amount during pregnancy.
• Alcohol use is toxic during all three trimesters of pregnancy.
• This includes period before pregnancy has been identified.
• Binge drinking is especially damaging.
SAMHSA’s FASD Center for Excellence Defines FASD as:

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)
- Alcohol Related Birth Defects (ARBD)

New term for FASD with neurodevelopmental impairment

- ND-PAE: Neurodevelopmental disorder associated with prenatal alcohol exposure. Diagnosable via ICD-10 (F88).
Fetal Alcohol Syndrome (FAS) – all of the following:

• Three facial abnormalities (facial features develop 4-8 weeks):
  – Smooth philtrum (groove between upper lip and nose)
  – Thin vermillion (upper lip)
  – Small cerebral palpebral fissures (eye openings)

• Growth retardation: height, weight, head circumference.

• Neurodevelopmental involvement: cognition, intelligence, attention, behavior, memory, processing, mood, attachment, motor skills, eye-hand coordination and other.

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

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

September 03, 2012 1:00 am  •  BY SCOTT FITZGERALD, The Southern
Fetal Alcohol Syndrome

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
Fetal Alcohol Syndrome

Frontal Lobes

Corpus Callosum

Hippocampus

Amygdala

Basal Ganglia

Hypothalamus

Cerebellum
ARND 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

However, physical appearance is normal – no facial features of FAS.

NOFAS: http://www.nofas.org/resource/CAP.aspx
• With a “typical” appearance and no distinguishing facial features, ARND becomes “an invisible disorder.”
• ARND is the most common form of FASD.
• Further complication: Facial features of FAS often become less evident by adolescence.
• Consequence:
  – Individuals with ARND, and even some with FAS, may be missed and not identified.
  – In contrast, mental health disorders comorbid with ARND are often identified, with the primary neurodevelopmental disorder overlooked. Missed opportunities and wrong therapies.
Risk Factors

Risk factors for alcohol use during pregnancy:

- History of trauma/adversities during childhood.
- History of placement in foster care.
- Violence and abuse during adulthood.
- History of family substance abuse, including alcohol.
- FASD by biological mother: FASD are often multi-generational.
- 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.
Particular challenges for many adopted children and those in foster care:

- In-utero exposure to alcohol and resulting ND-PAE create a major biological vulnerability.
- Exposure to other substances in utero, esp. cigarettes.
- Possible genetic predisposition to psychiatric disorders.
- Possible maternal stress during and after the pregnancy.
- Superimposed maltreatment following birth: physical or emotional neglect, physical abuse, sexual abuse.
- Limited early attachment.
Possible Co-Occurring Disorders

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

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

Goals: *Managing* primary effects of FASD, *building skills*, and *preventing, whenever possible*, secondary effects.
ND-PAE Primary Effects

- Variable IQ – most children have normal IQ.
- Decreased adaptive functioning is key.
- Hyperactivity and impulsivity.
- Difficulty with sensory regulation.
- Physical sensitivities, especially sleep.
- Problems with comprehension (oral/ written) and processing.
- Problems with short-term memory and using information.
- Problems with cause-and-effect and learning from experience.
- Irritability and mood lability.
- Academic limitations, including learning disabilities and problems with math and reading comprehension.
- Naïve and easily led: immature for chronological age.
- Often unaware of own limitations.
• Problems in school – academic, social, behavioral.
• Problems with attachment and bonding.
• At risk of childhood maltreatment – children very frustrating and “abusable.”
• Peer victimization – money, bullying, sexual abuse.
• Inadvertent, inappropriate sexual behavior. No compass.
• Alcohol and other substance abuse. Drawn to SUD.
• Psychiatric disorders, with possible Inpatient and RTF.
• Involvement in legal system.
• Problems with employment and independent living.
Causes of ND-PAE secondary effects/ poor prognosis:

• Disrupted attachments.
• Failure to identify FASD.
• Inappropriate interventions.
• Adverse Childhood Experiences (ACEs): poverty, limited social support, other adversities.
• Cumulative frustration and exhaustion.
• Blaming and punishment.
Specific deficits in information processing (Chasnoff):

- **Neurocognitive functioning:**
  - Global functioning – possible low IQ.
  - Learning – e.g. learning disabilities.
  - Memory – especially working memory (using memory to solve problems); also “Swiss cheese memory.”

- **Adaptive functioning:**
  - Communication – deficits in understanding others.
    (nuances and/or main point; in communicating feelings.
  - Social cues – difficulty in reading social cues.
  - Abstract thinking and reasoning – very concrete thinking.
Deficits (continued)

- **Self-regulation, includes:**
  - Attention – great difficulty with attention.
  - Arousal – variable: hyper-aroused, at times shut down.
  - Self-control – very difficult: impulsivity.
  - Mood regulation – unable to self-soothe: mood lability.

- **Additional considerations and implications:**
  - Deficits reflect timing of alcohol exposure, plus amount and pattern of maternal alcohol use.
  - Idiosyncratic factors for child also influence deficits.
  - Communication and learning very difficult for child.
Parent Perspective

Dianna Brocious
Adoptive parent of children with FASD

“I have met the enemy and he is winning. His names are Exhaustion and Frustration and there is no cure.”
Looking Back

- We knew nothing...or next thing to it, and in most places that still is the situation.
- It was not stages, ages or situational. It is brain damage. Even then no matter how damaged children are, they still grow up and experience stages, ages and situations.
- It is what it is, and that alone would have given our family peace. It would not have changed the drive to change it. Just to name the monster is a release.
Embracing FASD at the Policy Level

Shannon Fagan, Director
OMHSAS Bureau of Children’s Behavioral Health Services
FASD Task Force

- The Pennsylvania Department of Drug and Alcohol Programs formed the FASD Task Force in 2006.
- Task Force representation includes family members of persons with FASD along with various representatives of nonprofit organizations and governmental agencies.
- Published *The Pennsylvania Fetal Alcohol Spectrum Disorders Action Plan* in 2008 to address the scope of the problem and outline goals of the Task Force.
- Updated goals and priorities developed in 2016.
Significance of FASD

- Awareness is key
- Providing appropriate treatment and support
- Adapting service array as needed
- Supporting youth and families
- Training for providers
• In October 2016, the FASD Task Force requested that the Department of Human Services assume responsibility for the Task Force.
  – Services required by individuals with an FASD are administered by the Department of Human Services
  – Focus on provision of services in addition to prevention efforts
• Transition from DDAP to DHS began in January 2017.
  – OMHSAS will serve as the lead
  – First meeting held in June 2017
  – Quarterly meetings scheduled
Part 2: Effective and Promising Interventions
FASD Identification, Diagnosis, and Early Intervention

Shannon Fagan
Barriers to FASD Identification

- ARND is “invisible” and missed.
- Facial features of FAS less evident in adolescence and adulthood.
- Presentations highly variable. Every child different.
- Children with an FASD often speak well – but their comprehension and language processing are poor.
- FASD symptoms may overlap with trauma symptoms.
- FASD behaviors often similar to many psychiatric disorders (may mimic and/or co-occur with nearly every MH disorder).
Warning Signs/ Red Flags

- Child, diagnosed with MH disorder as preschooler (ADHD, ODD, BPD), who does not respond to Rx over time.
- Child with unexplained, undiagnosed behaviors/mental health issues, which do not appear to make sense.
- Child with difficulty applying what has been learned, making same mistakes over and over.
- Repeated poor judgment, limited self-control, self-regulation.
- Child requires “hands on” or visual learning, not respond well to auditory approach.
- Child easily overwhelmed, exhausted by external stimulation.
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 and trauma screens helpful.
  - Standard tests – IQ, achievement tests, adaptive functioning
Typical findings on psychological testing with FASD:

- Overall IQ usually normal.
- Verbal IQ: significantly higher than performance IQ.
- Overall IQ: higher than achievement scores (WRAT).
- Overall IQ: higher than adaptive behavior scores (15 points, Vineland).
Mental health diagnosis of FASD now possible:

- DSM-V identified FASD as “condition in need of further study”: “Neurodevelopmental disorder associated with prenatal alcohol exposure” (ND-PAE).

- Components of ND-PAE diagnosis: “more than minimal exposure to alcohol during gestation”; onset in childhood; plus impairments in a) neuro-cognitive functioning; b) impaired self-regulation; c) adaptive functioning.

- The good news: FASD can now be diagnosed: Use F88 on ICD-10: “Other specified neurodevelopmental disorder: ND-PAE.”
Early Intervention

- Early identification and diagnosis are important for every childhood disorder.
  - Diagnosis provides clarity, some relief of uncertainty.
- Supportive services and Intervention
  - Builds on neuroplasticity of brain, even though damaged.
  - Use of promising practices and clinical common sense.
  - Can help prevent development of secondary FASD effects.
Early Intervention (EI) and FASD:

• Birth to Three (0-3)
  – Most likely eligible, even if delays are not visible
  • “Diagnosis with a high probability of leading to developmental delays.”
  – Eligible for “At Risk Tracking” – periodic screening for delays and to determine need for future services.

• Three to Five (3-5)
  – No “At Risk Tracking” available.
  – Most likely eligible, as delays more apparent at this age.
Role of the EI Professional

- Provides supports and services to caregivers, so that they can help the child grow and develop.
- Embeds supports and services within current learning opportunities in the child’s typical routines.
- Builds on existing supports and services in the family, community, and early education resources.
- Provides coordinated, flexible, Early Intervention supports and services.
- Provides supports and services focused on the family and child’s transition between and among early education programs.
Ways to Collaborate with EI

• Make Referrals where necessary
• Participate in IFSP/IEP process
  – Coordinate goals/strategies where applicable
• Regular communication regarding progress of child/family
• Referrals for EI at CONNECT: 1-800-692-7288
Ongoing Support for Child and Family

Dianna Brocious
Support for Child & Family

Personal reflections of Dianna Brocious

• Respite, relaxation and rest.

• To educate everyone who daily comes in contact with your family what this is and what it does.

• How do you explain that sometimes you must divorce someone emotionally to truly love them without falling apart?
• It’s not that these children won’t, but rather 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 and others to succeed – not “enabling” (Dubovsky).
• Parents can serve as “external brain” for the child.
• Importance of “goodness of fit”: As adults understand child differently, relationships improve and everyone benefits.
Avoid Blaming Parents

• Parents with adoptive or foster parents typically doing the best they can – child’s limitations not due to them.
• Chasnoff: Attachment is a dyadic process, requires responsiveness and reciprocity by the child. Parent cannot achieve attachment by themselves.
• Many children with attachment difficulties, multiple reasons.
• Parents need information and support.
• Parents need to be listened to and understood.
• Parents need know where to obtain helpful services and schools
• Parents need ongoing support from pediatric medical home.
Empowering the Family

- Listen to and validate the family, who are dealing with loss and uncertainty.
- Convene a child and family team and use of system of care approach, with cohesive, collaborating team.
- Help family identify and mobilize natural supports.
- Help family access attachment therapy, also trauma treatment for child, when indicated.
- Help family access respite and other services, as needed.
- Help family to support, mentor and supervise child.
- Highlight, and help family highlight, success and genuine effort.
- Promote wellness, for child and for entire family.
Empowering the Child

- Measure each action in terms of potential for increasing attachment with child. Aim for *collaboration* with child.
- 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, and concrete prompts, to promote learning.
- Help child develop coping skills, increase awareness of feelings, and capacity to express self and ask for help.
- Address sensory needs, when prominent.
- Above helps child with self-regulation and executive functioning.
Specific Practical Guidelines and Medical Interventions

Dr. Gordan Hodas
**Interventions**

- Most interventions are practice-based, not research-based.
- Intuitive, developmentally-focused, and based on presenting clinical picture of children with ND-PAE.
- A limited research base does not diminish the relevance or significance of available interventions.
- Interventions involve the child, family, and larger system.
- They incorporate core principles of trauma-informed care.
Interventions

- Recognize and promote child’s strengths.
- Friendly and outgoing (though hard to sustain friendships)
- Verbal (can be misleading, since receptive language and processing are weak).
- Helpful and well-intentioned.
- Affectionate and lovable.
- Generous (but generosity along with naïveté makes them vulnerable to being taken advantage of).
- Determined (need to preserve this, by helping child with frustration).
- Special abilities/skills.
Interventions

- Developmental perspective/competence
- Recognize child’s limitations and deficits – such awareness is fully consistent with a strengths-based approach.
- While individual skills vary, in general the functional age of a youth with an FASD is about 50% of the chronological age.
- Make expectations and care plans congruent with child’s developmental capabilities. Be prepared to modify goals.
- Avoid approaches unlikely to work – use of points, levels, rewards and punishment, reliance on cognitive treatments.
- Importance of remaining patient and positive.
- Recognize need for lifelong support – modeling, mentoring, monitoring.
TI approach to child, family, team – core TI principles:

- **Safety** – physical & emotional, the sine qua non (Fallot & Harris)
- **Trustworthiness** – honesty, transparency, consistency (Fallot & Harris).
- **Choice** – opportunities for participation & daily decision-making (voice and choice) (Fallot & Harris).
- **Collaboration** – working together and sharing power (Fallot & Harris).
- **Empowerment** – prioritizing competency, skill-building, validation, strengths-based responses (Fallot & Harris).
- **Cultural, gender, linguistic, (and developmental) competence** – part of any effective system of care or intervention (SAMHSA).
Core parental interventions:

• Key interventions: promoting safety and attachment.
• Education of selves, and developmentally appropriate information for child re ND-PA, its impact on functioning.
• At least one unconditionally available parent (Chasnoff).
• Use of structure and predictability.
• Playful and joyful approach (Chasnoff, Dan Hughes).
• Teaching indirectly all the time, & “checking in.” Partnership.
• Bedtime rituals, including lying down, reading, games, nurturing touch.
  – Young children: Don’t make child cry self to sleep.
• Use of elements in “Eight Magic Keys.”
Dan Dubovsky: Strategies for families, child with FASD:

- Comprehensive identification of strengths and supports.
- Reduce stimuli in environment (visuals & sounds) – esp. room.
- Use softer lighting and colors, avoiding fluorescent lights.
- Use consistent routines, schedules, calendar – visual.
- Check for true understanding by child.
- Repetition, without impatience, is key.
- Prepare child for deviations and for transitions.
- Benefit of role-playing and modeling of desired behaviors.
- Simplicity – limit number of goals and plans.
- Break things down to one step at a time.
Dubovskv: Strategies (continued)

• Whenever saying, “you can’t,” also add, “but you can…”
• Consequences, when needed, are immediate, related to what occurred, and completed preferably within same day.
• Don’t use child’s preferred activities as reward, or remove these in response to a negative behavior.
• Don’t assume that lack of follow through is due to lack of motivation.
• Don’t assume generalization of skills to other situations, or that child will necessarily learn from experience,
• Goal is inter-dependence, not necessarily independence.
Interventions

Dubovsky: Strategies (continued)

• Identify co-occurring MH disorders, & treat, as needed.
• Learn signs of child getting stressed or anxious, and identify 1 or 2 things that help child calm down.
• Create or identify a potential “chill out” space.
• Person-first language – A child with FASD, not “FASD-child.”
• Use literal language – no metaphors or idioms.
• When rule is broken, help child understand & remember it.
• Wellness: art or movement therapy; animal-assisted therapy, family & cultural rituals, exercise, balanced nutrition.
• Assist with key tasks: forms/applications, managing money.
Interventions

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 and sweet, limited stimulation
– **Specific** – step-by-step instructions and information
– **Structure** – clarity and guidance provides glue
– **Supervision** – active monitoring promotes functioning
Use of Accommodations

- Consistent routines and structure
- Limited stimulation
- Concrete language and examples (being literal)
- One direction at a time
- Help with poorly developed sense of 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
Child empowerment through parental encouragement and small successes:

- This is where developmental competence comes in, helps family develop realistic expectations.
- “Goodness of fit” does not require similar capacities by parents and child. It is awareness of capability and limitations.
- Validation for effort and positive interventions, not solely successful outcomes.
- Appreciating incremental progress.
Child empowerment through self-expression (constructive use of words):

- 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.”
Mental health treatment for ND-PAE (Chasnoff):

- Benefit of dyadic or family approach.
- Familiarity with ND-PAE, and expertise in attachment therapy.
- Treatment model seeks to enhance parent-child interactions and attachment:
  - Educates and supports parents, decreasing stress.
  - Helps child develop improved skills and coping, including sensory processing and self-regulation.
  - Dyadic therapy promotes parent-child attunement, relationships.
  - Outcomes = improved child behavior, cognitive functioning, school readiness, mental health functioning, and fewer secondary effects.
Role of psychotropic medication:

• 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.
• Responses vary by individual, and often by age.
• However, meds helpful for ADHD and other medication-responsive MH disorders.
• In addition, meds may enable child to benefit more from services, and be more “present.”
Outcomes

Protective factors for child:

- Absence of violence, and presence of safety
- Loving, nurturing, stable family home environment.
- At least one adult committed and available to child.
- Early diagnosis and early intervention
- Use of special education
- Use of social services (this can include treatment services for child and family, and respite for the family)

www.cdc.gov/ncbdd/fasd/treatments.html#BehaviorandEducationTherapy
Overview of core determinants:

- Severity of in-utero alcohol exposure.
- Presence or absence of identified protective factors (e.g., EI, safety, supportive family, supportive team, etc.).
- Nature and severity of secondary effects.
- Longitudinal support over time, according to need.
- The individual child, adolescent, developing adult.
Additional elements

- Key elements:
  - Ongoing family support & encouragement.
  - Creation of sense of inter-dependence.
  - Avoidance of tough love and cut-offs.
- Another key element: Being able to tolerate uncertainty.
- Stability of young person more likely at or after age 30.
- Full independence unlikely, but satisfying life possible.
- Role of mentoring, modeling, monitoring.
On the Horizon: What the Future May Offer

Lyn Becker
Pre-conception care (PCC):

- Stop drinking prior to trying to conceive and when discontinuing birth control. (CDC)
- Modify personal risk factors – diabetes, smoking, other drug use – take vitamins & folic acid, reduce stress levels.
- Get in optimal condition before becoming pregnant; exercise.
- Improved, more consistent screening of pregnant women for use of alcohol, nicotine, other drugs.
- Example: CHOICES program.
Nutrition

- Vitamin and micronutrient deficiencies in pregnant women can contribute to abnormal fetal development, also increase damaging effects of alcohol on fetus.
- Zinc, iron, calcium supplements very important.
- Vitamins A, B6, C, D, E, and choline also important.
- Choline supplements under study, to help prevent or mitigate damage from alcohol.
Use of Breathalyzer:

• Connect to cloud-based alcohol monitoring system.
• Face of the person breathing into the mouthpiece is visible to the monitor.
• Outcomes can change woman’s intake of alcohol during pregnancy.
Use of biomarker to identify alcohol exposure in fetus – Ukraine Study:

- Moderate to high levels of alcohol exposure identified in 2\textsuperscript{nd} and 3\textsuperscript{rd} trimesters through blood sample from mothers; elevated number of small RNA molecules (microRNAs).
- When these infants were born, they demonstrated neurological and physical signs of FASD.
- This biomarker could be used to alert physician to need for Early Intervention referral after birth.
Common medications to reverse alcohol damage
(2017, Northwestern University School of Medicine)

- Two commonly used medications found to reverse alcohol-induced brain damage in mice pups:
  - Metformin – used for diabetes.
  - Thyroxine – hormone that regulates metabolism and growth and development.

- This advance opens the door for identifying medications/chemicals that can treat or nullify the brain damage caused by alcohol in FASD. (More money for research from pharm companies).
Research in developing other drugs

- Current work on designing drugs that block alcohol’s neurotoxic effects on fetal brain cells, at the molecular level.
- Neuroprotective peptides have demonstrated efficacy in mice research for improving performance in behavior and tasks, and reversing alcohol-induced changes in hippocampus and cortex.
- These neuroprotective peptides are currently being used to treat several neurodegenerative diseases.
Prevention of FASD

Technology: Increased use of computer delivered & web-based programs

- Improves function in numerous damaged areas of the brain.
- Improves math skills, spacial functions, improved memory, cause and effect, reasoning, sequencing, planning, and problem solving, self-regulation, and more.
- Can decrease depression, anxiety, stress.
- Now more commonly used for children; need for youth and adult level programs.
Technology & advancing research:

- Money allocated to research
  - US- federal/state/foundations/special interest groups.
  - Globally.

- In future, more definitive diagnostic capabilities – early identification and intervention is needed, to capitalize on the neuron plasticity present in infancy and early childhood.
Improved education and Training:

- Physician education programs in medical school, residency, and thereafter.
- Professionals who work in healthcare and human services.
- Direct service providers in healthcare, human services, law enforcement/corrections, youth athletics, youth community recreation programs, faith-based organizations, childcare facilities, etc.
Expansion of types of therapies for children:

- Includes art, play, music, animal-assisted and other therapies.
- Social skills programs for children and adolescents.
- Educational and support groups for parents.
- Neurocognitive rehabilitation, especially for foster and adopted children.
- Example: Alert Program for self-regulation.
Role of Men in FASD:

- Men contribute to birth defects in four ways (currently known):
  - Male partner’s influence on pregnant woman’s drinking habits.
  - Health of sperm (quality affected by age, use of drugs).
  - Genetic contribution (DNA), plus epigenetics.
  - Male partner’s impact on the pregnant woman’s level of stress – abusive or protective, responsible provider, emotionally stable.
Reflection & Action

• Should we pursue prevention, diagnosis, and intervention for FASD?
• Is the time now?
• What are you going to do?
Contact Information

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- Shannon Fagan: shafagan@pa.gov
- Diana Brocious: pasocdianna@gmail.com
- Lyn Becker: clyn.becker@gmail.com
FASD Resources

- NOFAS (National Organization on Fetal Alcohol Syndrome) Roundup& website. Google “NOFAS Roundup.”
## FASD Resources (continued)

- Malbin, D (2002): Trying Differently Rather Than Harder: Fetal Alcohol Spectrum Disorders. FASCETS.org/resources, to order.
- National Screening Tool Kit - Canadian Association of Pediatric Health Centres: [http://www.caphc.org](http://www.caphc.org)
FASD Resources (continued)


• Minnesota Organization on Fetal Alcohol Syndrome (MOFAS. Multiple information brochures. [www.mofas.org/support-and-resources/resources/brochures/]

• Developmental Skills Timeline (for FASD). [www.mofas.org/2014/05/developmental-skills-timeline/]

• Living with FASD: Sasha’s Story. 2014. Centers for Disease Control. [www.cdc.gov/features/living-with-fasd/index.html]

Trauma Informed Care (TIC) Resources:

- 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


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