

FETAL ALCOHOL SPECTRUM DISORDERS IMPLICATIONS FOR EDUCATORS AND SCHOOLS

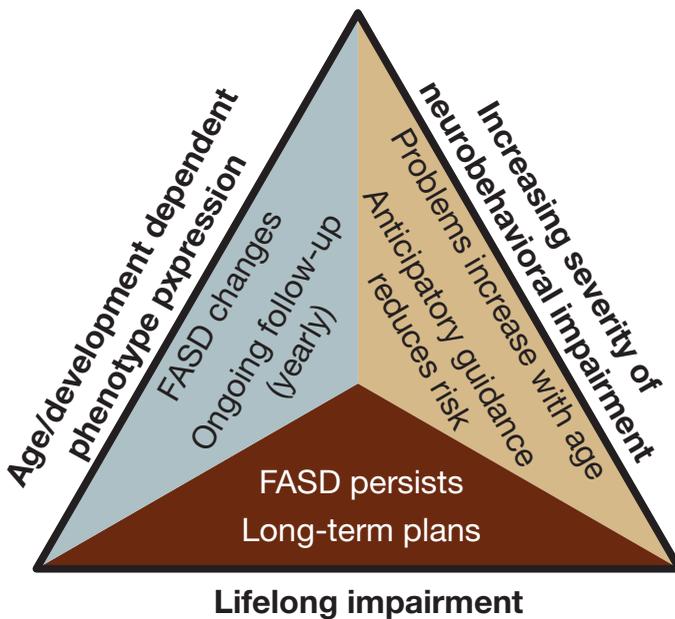
Alcohol and tobacco
cause more fetal damage
than all other drugs
combined (by a huge margin)

**FASD is behind the face:
It's:**

- ADHD
- Depression
- Cognitive Impairment
- Intellectual Disability
- Learning Disabilities
- Substance Abuse
- Judgment Deficits



The Developmental Triad



Risk Factors Ahead

- | | |
|--------|----------------------|
| Exit 1 | Abuse/Neglect |
| Exit 2 | Foster Care |
| Exit 3 | Impairments |
| Exit 4 | School Problems |
| Exit 5 | Behavior Impairments |
| Exit 6 | Dependent Living |

Larry Burd, Ph.D.

larry.burd@UND.edu

www.online-clinic.com

Prenatal Alcohol Exposure (PAE)

Some alcohol use occurs in about 40-50% of pregnancies. Prenatal alcohol exposure is a common cause of premature birth, low birth weight, birth defects, learning disabilities, heart defects, and lifelong problems with independent living.



The prevalence of drinking during pregnancy is high. When taking a history remember that drug use does not exclude alcohol use. It increases risk.

Screening for PAE

When was your last drink?

Before	Pregnancy	
	Pre-awareness	Post-awareness
Unexposed	Exposed	Exposed & high risk



Screening for alcohol use begins with one question.

Weekend Drinking During Pregnancy

Total Exposure Throughout Pregnancy	
Days Exposed	80
Binge Days	80
# Standard Drinks (14 grams)	960
Hours Exposed	2,160
Total grams ethanol	13,440



Outcomes from drinking 4 beers each Friday and Saturday during the 40 weeks of pregnancy.

What PAE Forecasts		
Prenatal	Labor & Delivery	Postnatal
<ul style="list-style-type: none"> • Smoking • Drug Use • Late and Infrequent Prenatal Care • Depression • Inadequate Nutrition • Miscarriage 	<ul style="list-style-type: none"> • Stillbirth • Prematurity • Birth Defects • Hospitalizations 	<ul style="list-style-type: none"> • Neglect • Abuse • Birth Defects • Poor Nutrition • Smoking • Parental Substance Abuse • Violence • Depression • SIDS



Early detection of PAE increases opportunities for early intervention to decrease longterm severity.

Fetal Alcohol Spectrum Disorders

Drinking during pregnancy can increase risk for a wide range of adverse outcomes. One of the most concerning outcomes is fetal alcohol spectrum disorder (FASD).

FASD is a complex disorder with expression over the lifespan. The FASD phenotype is comprised of increased mortality beginning during pregnancy, increased risk of neuropsychiatric disorders and susceptibility to chronic illness. The complexity of the phenotype is increased by delayed diagnosis and accumulating effects from multiple adverse life experiences. The lack of long term anticipatory planning with an emphasis on risk reduction increases the complexity of care across the lifespan.

A few facts:

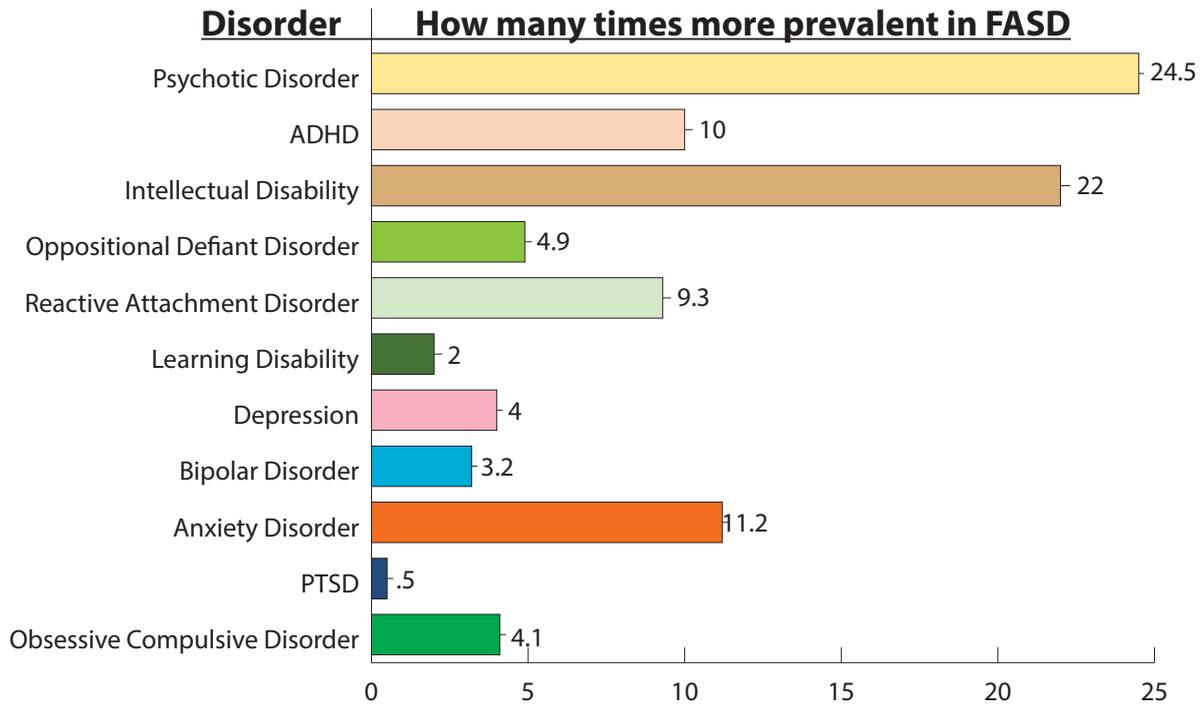
- Prevalence studies find that 1 in every 20 first grade students have FASD. It's more prevalent than autism.
- FASD is rarely diagnosed so most children with FASD are treated for something else.
- FASD is costly. The annual cost of care for each child with FASD is \$22,810.
- FASD costs more than autism or diabetes.
- FASD is often familial and is often more severe in younger siblings.

FASD persists over the lifespan

Age Same behavior, different age

- | | |
|----|--|
| 2 | Irritable, impulsive, difficult, requires lots of attention |
| 4 | Poorly organized, can't finish, easily distracted, forgets |
| 6 | Loses and forgets, comprehension deficits, social deficits |
| 8 | Can't finish, loses stuff, needs help every day, avoidant/aggressive |
| 12 | School problems, doesn't get stuff home or back to school, social deficits, extra help-helps |
| 14 | Late, social deficits, school problems, cognitive delays, behavior problems, does best at home, school problems often severe |
| 20 | Can't get things finished, avoidant, anxious, easily overwhelmed, memory is poor, why doesn't he/she change, poor choices |
| 24 | Late or missing meetings, easily overwhelmed, avoidant, social choices are poor, nods in agreement but doesn't understand, can't finish (treatment, and parenting classes after 20+ years who/what needs to change?) |

FASD and Mental Disorders



PAE and FASD are strongly associated with exposure to adverse childhood experiences (ACEs)

- | | |
|-----------------------|-------------------------|
| 1. Divorce/separation | 7. Physical abuse |
| 2. Drinking/drugs | 8. Verbal abuse |
| 3. In foster care | 9. In prison |
| 4. Neglect | 10. Mother abused |
| 5. Unloving family | 11. Sexual abuse |
| 6. Depression | 12. In residential care |

ACE score for children with and without FASD

ACE SCORE	FASD		Non-FASD		RR	p
	N	%	N	%		
None or One	10	10.2	61	58.1		
Two to Five	35	35.71	37	35.24	3.45	<.001
Six to Ten	53	54.08	7	6.67	6.27	<.001

Domains of Impairment	Impairments in FASD
Executive Functioning	Repeats mistakes. Difficulty understanding consequences, poor time management, difficulty with planning and problem solving, difficulty sequencing events. Poor organization, impulsivity, difficulty matching emotions with situation.
Sensory and Motor	Fine and gross motor impairments. Poor adaption to changes in social situations. Movement, light or background noise may make concentration or understanding difficult. Appetite regulation can be impaired (stealing food, overeating, hiding food). Vision impairments may be common.
Academic Skills	Typically, math is frequently a problem, handwriting can be poor, both reading and reading comprehension are often impaired. listening comprehension is also frequently impaired. Memory and attention deficits are also important factors.
Brain Structure	Decreased brain size, abnormal brain function and structure. Impaired ability to adapt and respond to age dependent demands.
Living & Social Skills	Difficulty with daily routines, delayed toilet training, few friends, often victimized, poor money management. May need assistance with independent living skills, self-care (e. g. showering grooming may need reminders). Measures of adaptive behavior are useful measures of daily living skills.
Focus & Attention	Attention and distractibility are common (50% have ADHD). As demands increase over activity may increase, impulsivity (may blurt out responses). Anxiety exacerbates impairments.
Cognition (Reasoning & Thinking)	Impaired rate of learning and generalization of learned skills. Concrete or literal thinking, poor abstract reasoning skills. Social rules are difficult. Often has difficulty with age appropriate humor and teasing. IQ scores may exceed measures of adaptive behavior identifying important deficits.
Communication	Expressive skills very often exceed understanding. Impairments in both reading and listening comprehension. Nonverbal communication often impaired (difficulty with nonverbal cues). Ability to follow directions and instructions is impaired.
Memory	Long and short term memory deficits, highly variable ability to recall. Sometimes shuts down due to stress. Lengthy conversations often difficult, detailed instructions are often misunderstood. Needs daily schedules and even these may be difficult to follow. Often fills in missing information, repeated questions during interviewing can then be expressed as facts.
Gullibility	Overly trusting, easily victimized, false confession can occur. Not appropriately cautious in interrogation or during probation.
Confabulation	Often related to memory deficits and desire to please. Often occurs during retelling stories or sequences of events. Memory of events and specific sequences are highly variable. People with FASD are highly suggestable.
Dementia	Early onset dementia is increased and prevalence increases across the lifespan. Often manifest as increasing difficulty with life's basic tasks and either increasing impairments or more gradual withdrawal.
What helps	Short directions (one or two steps), frequent breaks and reminders, less talk, more pictures, and low stress.
What does not	Long directions or explanations, stress, lengthy discussions, or anger.

FASD: Changes Across the Lifespan

Age	Cognitive	Motor Skills	Socialization	Behavior
Infancy	Delays in developmental Learning games Attention	Tremor Poor suckle Low tone Floppy	Interactive activities and games Attachment Reading others expressions	Sleep disturbance Regulation of behavior Irritable Temperament Impaired settling Cuddling
Toddler	Speech-language Understanding Toilet training Attention Impulsivity Memory	Tremor Fine motor Gross motor Balance Late crawling or walking	Easily Frustrated Separation problems Impaired Attachment Group participation	Difficulty in group settings Tantrums Aggression Stubborn
Child	IQ Academic deficits (math, spelling, written language) Humor Memory Recall Speech-language comprehension	Fine and gross motor Coordination Balance Handwriting Hand tremor	Requires increased supervision Difficulty sustaining friendships Group activities Games – activities with rules	ADHD Increased frustration Lack of persistence Increased risk taking Impaired independence for age Impaired executive functioning
Pre-Adolescence	IQ Academic deficits (math, spelling, written language) Planning Memory and recall Comprehension Generalization of skills and behaviors	Coordination Balance Handwriting Clumsy	Independent functioning Needs increased supervision Exploitation by others Appropriate boundaries	ADHD Impaired executive functioning Impulsive Repeats problem behavior Poor response to demands Risk taking
Adolescence/Adult	Ability to work independently Self-care Money and time management Household routines Generalization of skills and behaviors Limited benefit from treatment programs without adaption	Writing Fine motor Balance Coordination	Independent functioning Peer exploitation Increased supervision Interpersonal boundaries	Increased risk for substance abuse Depression Anxiety Repeats problem behavior Increased risk taking Impulse control Planning ahead Meeting deadlines Asking for help Organization Record keeping Peer exploitation

SCREENING AND DIAGNOSING FASD

The Neurodevelopmental Disorder Behavioral Checklist

In order to complete this checklist:

- 1) Behaviors must be impaired for the age of the person being assessed.
- 2) Interviewee needs to have known the person being assessed for at least one month.
- 3) After the reporter fills out the form, the clinician then adds other observed behaviors not already reported.

CHECK ALL THAT APPLY FOR THE APPROPRIATE AGE RANGE

BEHAVIOR	3-6 Yrs.	7 Yrs.+
Hyperactive		
Poor attention		
Impulsive		
Disorganized		
Seems unaware of consequences of actions		
No fear		
Would leave with a stranger		
Poor social skills		
Few friends		
Will talk or interact with anyone		
Easily manipulated and set up by others		
Socially inept (inappropriate speech or touching)		
Difficulty staying on topic during conversation		
Always talking		
Cocktail speech - little content		
Too loud		
Can't remember from one day to the next		
Below average IQ (<85)		
Poor school performance		
Suspended or expelled from school		
Poor sleeper		
Can't follow routine - needs reminders to get dressed, brush teeth, etc.		
Temper tantrums		
Extreme mood swings		
Requires constant supervision		
Been in trouble with the law		
Inpatient treatment for mental health, substance abuse, or in jail		
Inappropriate sexual behavior		
Poor motor skills		
Has or needs glasses		
Had foster care or was adopted		
Medication for behavior - ever		
Mother used alcohol or drugs during pregnancy (OPTIONAL)		

- 4) Calculate total score.

TOTAL CHECKED:

--	--

16

20

(Continue assessment if score is greater than or equal to above.)

Instructional Components

1) Essential Classroom Program Components

Provide short directions

an essential key for successful interventions

Make it concrete

picture guides are helpful for teaching key concepts

Work in small groups

allow more attention to topical material

Minimize anxiety, which increases impairment

especially important in treatment of substance abuse, sexual abuse or PTSD

Understand impairments

some problems cannot be treated and we need to learn how to adapt to them and minimize the effects

Address mental health concerns

need appropriate treatment

Go slowly

treatment or interventions need to last longer

Planning for transition is essential

improves generalization of learned behaviors

Think family history

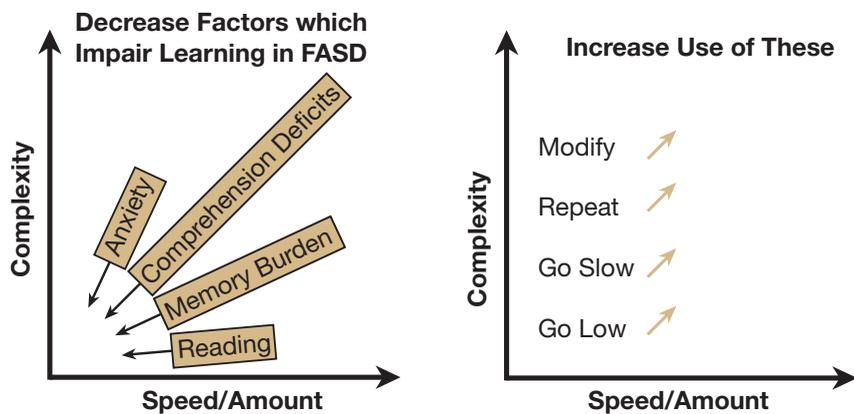
FASD is often familial

Wishing and Anger Won't Help

1) Essential factors for development of case management plans for adolescents and adults.

Notes:

2) Learning in FASD



2) Useful strategies:

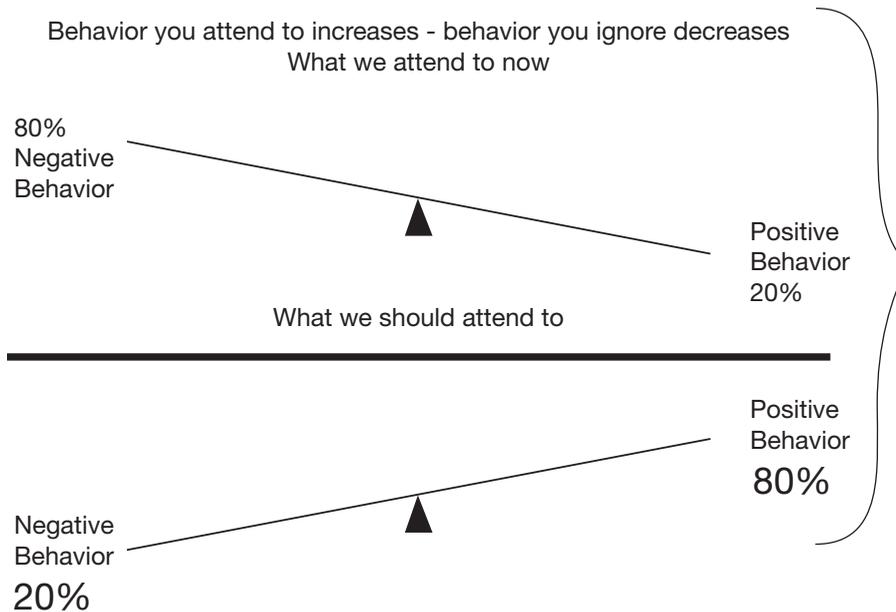
- Modify content
- Repeat important content
- Modify pace with participants' ability to learn and remember short directions
- Learn reading and listening.

3) Basic Cognitive Skills in Adolescents with FASD

<u>Characteristics</u>	<u>Grade Level</u>	<u>Percent Affected</u>	
Reading	5.0	Memory	80%
Reading comprehension	4.5	Attention (ADHD)	75%
Oral Comprehension	5.0	Executive Function Impairments	80%

3) We can improve the success rate of treatment programs by building in these treatment keys. See #4 below.

Planning for Interventions

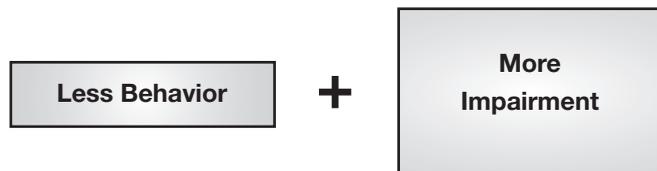


This is an essential component for effective management in schools.

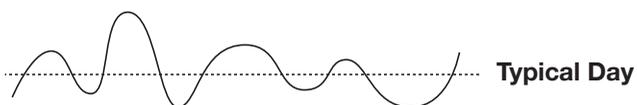
What we first see



What we want

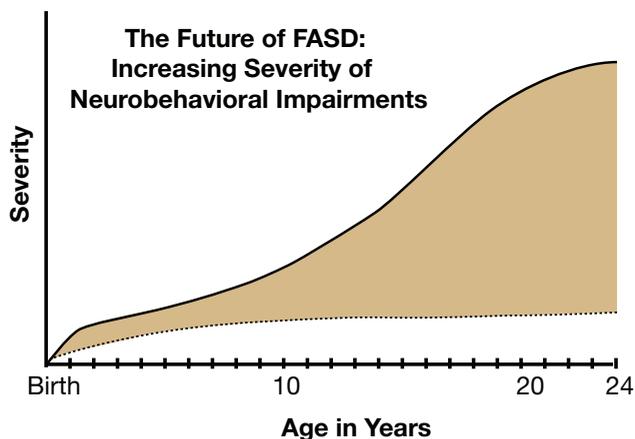


Inconsistent Performance



Most people with FASD have fewer behaviors and more impairments than we first suspect. This results in day to day performance that is HIGHLY variable.

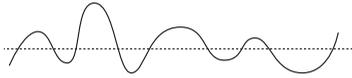
FASD Forecast



The presentation of FASD varies by age and development. Severity and complexity almost always increase with age.

FASD Intervention Sheet

Behavior looks unpredictable:

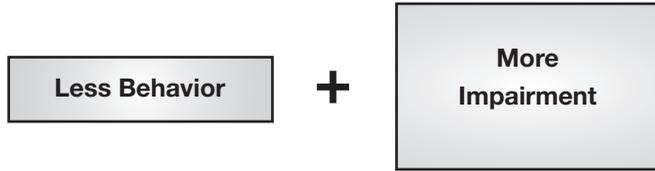


} This is due to day-to-day performance that is HIGHLY variable.

What we first see



What we should see



} Most people have fewer behaviors and more impairments than we first suspect.

Picking behaviors for intervention:

Behavior: _____ Reward: _____ How often: _____

Behavior: _____ Reward: _____ How often: _____

Behavior: _____ Reward: _____ How often: _____

Do we have optimal rewards and can we use these at home?

Policy Recommendations

Individual Education Planning and School Policy

Fetal

Alcohol

Spectrum

Disorders

Drinking and Pregnancy

In the majority of cases, drinking primarily occurs on weekends, but for women with alcohol use disorders drinking may occur on most days.

Alcohol rapidly crosses from the mother to the fetus. Increasing maternal blood alcohol can be detected in the fetus in one minute. Maternal-fetal alcohol concentrations reach equilibrium in about two hours after women quit drinking.

Variation in Blood Alcohol Concentration (BAC)

BAC varies by about 4 fold for women of the same weight consuming the same amount of alcohol.

Prevalence of Alcohol Use

- Non-pregnant women during child bearing years: 54%
- Month before pregnancy: 50%
- Pregnant women: 12% (1 in 8)
- Late pregnancy: 8.4%
- There is no known safe level of drinking during pregnancy.

Rates of Prenatal Alcohol Exposure (PAE)

- Children of women in substance abuse treatment: very high
- Children of women in prison: 80%
- Children in foster care: 70-80%
- Increased in women with other drug use
- Children in special education - 8 times higher
- Children/adolescents in residential care - 10 times more common

PAE is an important marker for increased risk of postnatal environmental adversity

PAE is associated with increased rates of adverse childhood experiences (ACEs) including parental substance abuse, smoking, neglect, abuse, malnutrition, stressful life circumstances and mortality. These risk factors often persist throughout infancy and childhood.

FASD is common but usually undiagnosed

Recent prevalence studies have found about 5% (1 of every 20) first grade children have an FASD. For most affected people the primary problem from prenatal alcohol exposure is brain damage/dysfunction. This will usually result in lifelong impairments which will change in response to age and development.

Every day in the United States
there are 500 new cases of FASD.

FASD has a high recurrence rate and younger siblings tend to be the most severely affected.

Annual cost of care for children and adults with FASD

The cost of care for a child with FASD is \$22,810 per year. US lifetime cost is \$2.5 million per person. Service systems most impacted are health care, foster care, education/special education, developmental disabilities, mental health systems, corrections systems, and substance abuse treatment. The annual cost in the US is \$3.4 billion

Outcomes

Manifestation of FASD changes over lifespan. A two-year-old is at low risk for a substance abuse disorder, but adolescents are at very high risk. A juvenile with FASD is 19 times more likely to be in the corrections system than an unaffected peer. Low rates of independent living as adults

Diagnosis matters and appropriate services improve outcomes

Actions from the Administration

System-Level Actions

- Make prenatal alcohol exposure screening a regular component of educational assessments.
- Identify community diagnostic services.
- Provide ongoing FASD training for schools and staff.

Case-Level Actions

- Screen for FASD.
- When FASD is diagnosed, screen siblings and parents.
- Ongoing evaluation of students progress and response to services and accommodations.

Prevention

Effective intervention NOW reduces risk for future problems