Fetal Alcohol Spectrum Disorders (FASD) For the Courts and Correctional Systems



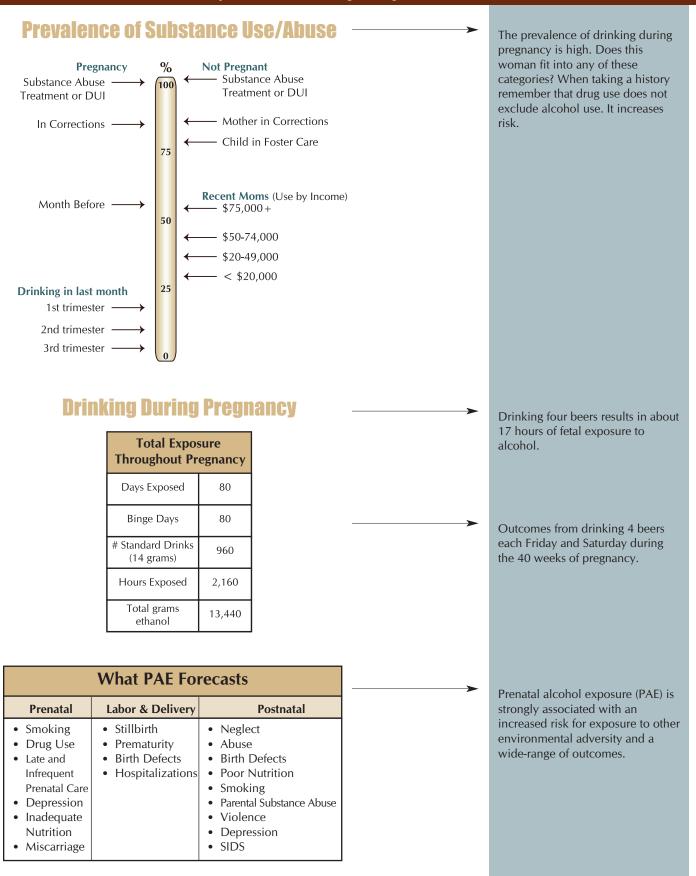
Larry Burd, Ph.D.

larry.burd@med.und.edu www.online-clinic.com

Collecting Data About Prenatal Alcohol Exposure (PAE).

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

In this section you can use the tools provided to examine alcohol use during pregnancy. It will be helpful to note that illegal drug use increases risk for alcohol use.



Screening for PAE When was your last drink? Screening for alcohol use begins with one question. **Before Pregnancy** Pre-awareness Post-awareness Unexposed **Exposed** Exposed & High Risk **Charting PAE During Pregnancy** If drinking is reported, you can provide important information on On average, how many days per week did you drink during pregnancy? frequency and quantity of alcohol (a) use. This will be important for other On an average drinking day during pregnancy, professionals who will need this how many drinks did you have? **(b)** information for diagnosis and How many days per month did you have treatment when they interact with 4 or more drinks during pregnancy? (c) the family. Complete as many of these items as you can. What is the most you had to drink on any one day during pregnancy? (d) What is a drink? Alcohol % Drink vol **Estimating Exposure Risk** If the mother or other reliable reporter is unavailable, you can **Maternal Risk Score** provide information to estimate Age over 25 years exposure risk for this fetus or baby Unmarried, divorced, widow, living with partner On TANF, WIC, Social Security or and their siblings. Score income < \$16,000 per year Check Did not graduate from high school Poor diet any one Add 5 Smokes more than 1/2 pack per day Drinks, but less than 2 days/week & Check here less than 2 drinks /drinking day Add 20 Age first drunk less than 15 years Check In treatment over three times any one Add 35 In treatment in last 12 months Previous child died Previous child with FASD, or developmental disability Children out of home (foster care or adopted) Heavy drinker (drinks 3 or more drinks/day Check for 3 or more days per week, or more than anv one 5 drinks/day on 6 or more occasions) Add 45 Uses inhalants, sniffs or illegal drugs **Risk Category Score Total** 0 None **Score** Low 20-40 Moderate 45-50 High 55-105 Very High

Did this person have prenatal alcohol exposure?

Yes. Alcohol use during pregnancy is confirmed.

Uncertain

No. We do not suspect PAE.

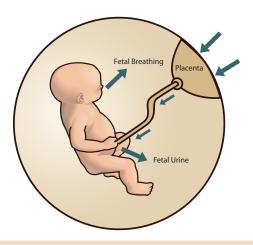
Very important information.

Drinking During Pregnancy: A common cause of birth defects developmental disability and mental disorders.

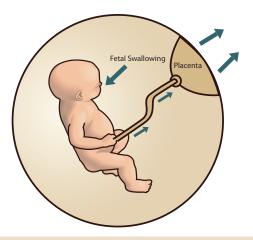
There is no safe level of alcohol use during pregnancy. It's never too late to stop drinking during pregnancy. Quitting now will protect future pregnancies.



When alcohol enters the stomach it quickly passes into her blood. In minutes alcohol crosses the placenta into the baby.



Alcohol passes from the baby into the amniotic fluid by fetal breathing movements and urination.



When amniotic fluid is swallowed, alcohol passes back across the placenta into the mom where it is eliminated.

Does this child need evaluation for FASD or followup as a child with high risk due to PAE?

Use this section to determine if the person might have a fetal alcohol spectrum disorder (FASD). Some findings are very important.

If a sibling has been diagnosed with an FASD, or if a sibling or the mother is dead, the risk for FASD is high.

Fetal Alcohol Syndrome

Low nasal bridge

Short palpebral fissures obscure the canthus (the inner corner of the eye) a normal feature in some races

Thin upper lip



Small head circumference

Epicanthic folds

Short nose

Flat midface

Indistinct philtrum (an underdeveloped groove in the center of the upper lip between the nose and the lip edge)

Fetal Alcohol Syndrome:

The facial features of a child with fetal alcohol syndrome (FAS).

Other Essential Signs Growth Impairment Height Weight

Brain Damage/Dysfunction

See chart on page 9.

FASD is not Just FAS

Most cases do NOT have

- Dysmorphic features
- Growth Impairment

Majority 80+%

- Developmental Delay
- Cognitive Impairment
- Mental Disorders
- Substance Abuse Disorders

It's important to remember that most people affected with a fetal alcohol spectrum disorder do not have the facial features of FAS.

Total Score: (Refer if score 20 or above)

FAS SCREEN FORM

NAME/ID:		DOB:// AGE:	SEX (circle one): F M
RACE (circle one):	Caucasian Hispanic Native American	African American Other	
DATE OF EXAM:			CIRCLE POINTS IF PRESENT:
HEIGHT	Inches	If < 5th percentile:	10
WEIGHT	Pounds	If < 5th percentile:	10
HEAD CIRC.	Centimeters	If < 5th percentile:	10
HEAD AND FACE	EARS STICK OUT (Protruding Auricles) SKIN FOLDS NEAR INNER EYE (Epicanthal F DROOPING OF EYELIDS (Ptosis) CROSS-EYES, ONE OR BOTH EYES (Strabisr FLAT MIDFACE/CHEEKS (Hypoplastic Maxil FLAT/LOW NOSE BETWEEN EYES (Low Nas UPTURNED NOSE GROOVE BETWEEN LIP & NOSE ABSENT OF THIN UPPER LIP CLEFT LIP OR CLEFT OF ROOF OF MOUTH	nus) la) al Bridge) DR SHALLOW (Flat Philtrum)	4 5 4 3 7 2 5 5 4 4
NECK AND BACK	SHORT, BROAD NECK CURVATURE OF THE SPINE (Scoliosis) SPINA BIFIDA (History of Neural Tube Defe	ct)	4 1 4
ARMS AND HANDS	LIMITED JOINT MOBILITY IN FINGERS & EI PERMANENTLY CURVED, SMALL FINGERS ESPECIALLY PINKIES (Clinomicrodactyly DEEP OR ACCENTUATED PALMAR CREASE SMALL NAILS/NAIL BEDS (Hypoplastic Nail) TREMULOUS, POOR FINGER AGILITY (Fine	,) ES s)	4 1 4 1 1
CHEST	SUNKEN CHEST (Pectus Excavatum) CHEST STICKS OUT (Pectus Carinatum) HISTORY OF HEART MURMUR OR ANY H	KAM OPTIONAL EART DEFECT	3 1 4
SKIN	RAISED RED BIRTHMARKS (Capillary Hema GREATER THAN NORMAL BODY HAIR, HA AND BACK (Hirsutism)		4 1
DEVELOPMENT	MILD TO MODERATE MENTAL RETARDAT SPEECH AND LANGUAGE DELAYS HEARING PROBLEMS VISION PROBLEMS ATTENTION CONCENTRATION PROBLEM HYPERACTIVITY		10 2 1 1 2 5
COMMENTS:			

For additional forms or information on FASD, contact:

Larry Burd, Ph.D. 501 N. Columbia Road, Stop 9037 Grand Forks, ND 58202-9037 701-777-3683 www.online-clinic.com larry.burd@med.und.edu

THE ARND BEHAVIORAL CHECKLIST

NAME/ID:				_ DOB://_	AGE:	SEX (circle one): F M
RACE (circle one):	Caucasian	Hispanic	Native American	African American	Other	
DATE OF EXAM:	_//_					
In audou to complet	to this shootdis	.4.				

In order to complete this checklist:

- 1) Behaviors must be impaired for the age of the person being assessed.
- 2) Interviewer needs to have known the person being assessed for at least one month.

BEHAVIOR		3-6 YEARS	7 YEARS +
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 or substance abuse, or in jail for a crime	è		
Inappropriate sexual behavior			
Poor motor skills			
Has or needs glasses			
Had foster care or was adopted			
Medication for behavior - ever			
Mother used alcohol during any pregnancy (OPTIONAL)			
Mother used alcohol in last five months of this pregnancy (OPTIONAL)			
Mother has been in treatment for alcohol use (OPTIONAL)			
For additional forms or information on ARND, contact:			
arry Burd, Ph.D.	TOTAL CHECKED:		
601 N. Columbia Road, Stop 9037		16	20

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16 20 (Continue assessment if score is greater than or equal to above)

Correction System Screening Protocol for FASD Adolescent (Anyone less than 19 years of age)

NAME/ID:	DOB:// AGE: SEX (circle one): F M
RACE (circle one): Caucasian Hispanic Native A	merican African American Other
DATE OF EXAM:/ Preferred Hand: Le	t/Right (circle one) Location Current Grade
Step 1 Weight in lbs Step 2 Height in inches	
Step 3 Review photographs Step 4	Epicanthal folds Flat nasal bridge Small palpebral fissures
Physical findings Head Circumference cm	Small palpebral fissures "Railroad track" ears Upturned Nose Spooth philtrum
<u>Check if present</u>	Thin uper lip
Thin vermillion border upper lip	
Flat philtrum	
Decreased supination	
Angulated distal palmar crease	
Clinodactyly	
Midface hypoplasia	
NEURO	BEHAVIORAL
Standard Score	Check if Present
Reading	Below average IQ
Spelling	Intellectual Deficiency
Math	Attention Deficit/ Hyperactivity disorder
Reading Comprehension	Impulsive
Adaptive Behavior	Stubborn
	Seizures
	Adaptive Behavior Scores
Graduate from high school Yes No	Communication
If no, what was the last grade completed?	Socialization
	Daily Living Skills
Ever take medication for hyperactivity as a child?	Gross/Fine Motor
	Composite
For additional forms or information on ARNID contact	<u></u>

North Dakota Fetal Alcohol Syndrome Center PO Box 9037, Grand Forks, ND 58202-9037 (701) 777-3683 www.online-clinic.com larry.burd@med.und.edu

Larry Burd, Ph.D.

Correction System Screening Protocol for FASD and Related Disorders Adult (Anyone 19 years of age or older)

NAME/ID:		DOB:/ AGE	: SEX (circle	e one): F M
RACE (circle one): Caucasian Hisp	panic Native American	African American Other		
DATE OF EXAM:// Lo	ocation	_		
Step 1 Weight in lbs			If less	s than
Step 2 Height in inches			128 lbs for men	105 lbs for women
Step 3 Review photographs Step 4			Cont	tinue
Physical findings Head Circumference c	m		If less	s than
Check if pr	-		66 inches for men	61 inches for men
Flat philtrum Decreased supination Angulated distal palmar crease Clinodactyly Midface hypoplasia				
St I		II.	Check if Prese	4
Reading Spelling Math Reading Comprehension IQ Adaptive Behavior	ard Score	Below average IQ Intellectual Deficiency Attention Deficit/ Hyperactivity disorder Impulsive Stubborn Seizures	Check II Prese	m
Craduata frama high achael Vac	NIo	Adaptive Behavi	or Scores	
Graduate from high school Yes If no, what was the last grade completed		Communication Socialization		
Ever take medication for Hyperactivity as		Daily Living Skills Gross/Fine Motor Composite		
Ear additional forms or information on ADAII) contest.			

For additional forms or information on ARND, contact:

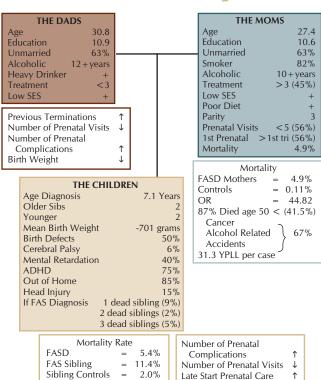
Larry Burd, Ph.D. North Dakota Fetal Alcohol Syndrome Center PO Box 9037, Grand Forks, ND 58202-9037 (701) 777-3683

email: larry.burd@med.und.edu

Age based impairments in FASD and Alcohol Related Neurodevelopmental Disorder

Age	Cognitive	Motor Skills	Socialization	Behavior
Infancy	Developmental delay 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	Frustration Threshold Separation problems 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/ Adults	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

The FASD Family



What risk factors are present for this family?

Does this person have evidence of developmental delay, birth defects, sibling with FASD, sibling death or intellectual deficits?

____ Yes, consider referral for FASD evaluation.

2____ No, but person does need monitoring as high risk for future problems.

No reason for concern

Does this person/family need management for current alcohol related problems, substance abuse for prenatal alcohol exposure or as a person with FASD?

Risk Factors Ahead

530%

13.7

Infection OR

SIDS OR

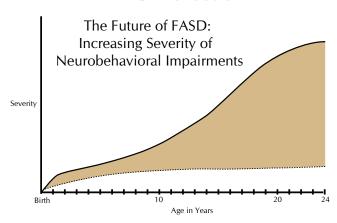
Birth Weight

Number of Malformations



These are key areas for prevention efforts for people with an FASD.

FASD Forecast



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

4 Keys to Success

1) Focus on Risk Reduction

- Abuse Neglect
- Speech and Language
- Foster Care
- ADHD
- School
- Social Development
- Self Care
- Look Ahead
- Adult Impairments

2) FASD: The Keys to Intervention

- Age & Development
- Dependent Phenotype
- Risk Reduction
- Long-term Plan
- Anticipatory Guidance
- Appreciate Impairment

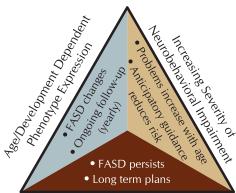
1) It is much easier to prevent or minimize problem outcomes.

2) Key components of a case management plan.

It is crucial to remember that FASD changes over time and that intervention must include plans to prevent future problems.

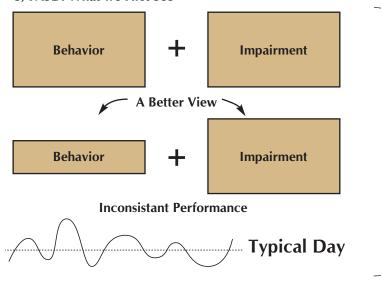
The child will require ongoing assessments to have the best outcome.

The Developmental Triad



Lifelong Impairment

3) FASD: What we First See



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

4) FASD Management Keys

- Yearly Follow-up
- Few Live Independently
- Remember the Familial and Generational Effects of FASD
- Services MATTER

4) Begin a case management plan with the understanding that this is likely a lifelong disorder requiring lifelong management.

Parents or Adults with an FASD

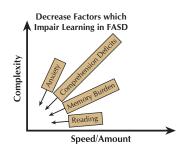
1) Does either parent have an FASD?

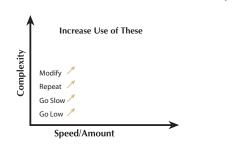
- Do they have Neurocognitive Impairment
- Useful Measures
- Intelligence Testing
- Adaptive Behavior Testing
- Selectively-More Detailed Neurocognitive Testing

2) Basic Cognitive Skills in Adolescents and Adults with FASD

Characteristics	Grade Level	Percent Affected	
Reading	5.0	Memory	80%
Reading comprehen	sion 4.5	Attention (ADHD)	75%
Oral Comprehensio	n 5.0	Executive Function	
		Impairments	80%

3) Learning in FASD





4) What should we change?

Address one problem at a time

allow participants to learn and apply solution before moving on to next topic

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 aftercare is essential

improves generalization of learned behaviors

Think family history

FASD is often familial

Wishing and Anger Won't Help

5) Success rate of Substance Abuse Programs

It is important to understand how well your intervention program works. Is the substance abuse program you use effective 5% or 40% of the time? The efficacy of the programs are important keys to participant success.

Key issues:

- 1) Adults with FASD have significant learning deficits which impact their ability to learn and remember.
- 2) We can improve the success rate of treatment programs by building in these treatment keys. See #4 below.
- 3) Useful strategies:Modify contentRepeat important content

Repeat important content
Modify pace with participants
ability to learn and remember
Short directions
Learn reading and audio content

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

5) Most programs serving this population need to make more accommodations in response to their participants' learning impairments. Otherwise the content of the programs is not easily available to the participants.

Policy Recommendations

Judicial Bench Card				
Fetal	Alcohol	Spectrum	Disorders	

Adverse outcomes from alcohol use during pregnancy

In the United States about 50% of pregnancies have some alcohol exposure. In most cases women find out they are pregnant and quit drinking. However, around 12% of women drink during pregnancy and 4-5% drink throughout pregnancy. Most of these women also smoke and many have other problematic life circumstances (other substance abuse, smoking, poor diet, late or no prenatal care).

The United States has about 40,000 new cases of fetal alcohol spectrum disorders (FASD) each year. 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.

Fetal Alcohol Spectrum Disorders

Comprised of four diagnostic categories

Fetal Alcohol Syndrome (FAS)

- Growth Impairments (height and weight < 3d)
- Abnormal Facial Features (2+)
- Brain Damage/Dysfunction
- Thought to result from prenatal alcohol exposure

Alcohol Related Birth Defects (ARBD)

- Birth defects though to be due to prenatal alcohol exposure
- Not commonly diagnosed
- Prevalence is as yet unknown

Partial Fetal Alcohol Syndrome (pFAS)

- Missing one or two key findings
- Prenatal Alcohol Exposure

Alcohol Related Neurodevelopmental Disorder (ARND)

- The primary features are brain damage/dysfunction developmental delays, mental illness or cognitive impairments) thought to result from prenatal alcohol exposure.
- Most common FASD
- Often undiagnosed
- Changes across the lifespan

Judicial officers often see people with prenatal alcohol exposure and FASD should be a frequent consideration.

Judicial officers often see people with prenatal alcohol exposure and FASD should be a frequent consideration.

Mortality

People with FASD have increased mortality rates. Mortality risk is also increased for siblings (even if they do not have a diagnosis of FASD). Miscarriage, stillbirth, sudden infant death syndrome (SIDS), birth defects, infectious illness other causes.

Mortality rates are also increased for mothers of cases and siblings.

Prevalence of FASD

- 1% live births
- Highly recurrent in families
- In some families FASD is generational
- Most affected people are undiagnosed

Cost of Care

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 systems. Annual cost in US \$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.

Low rates of independent living

In Canada a juvenile with FASD is 14 times more likely to be in Corrections system than an unaffected peer.

Every day in the United States we have
120 new cases. FASD has a high
recurrence rate and younger siblings tend to be
the most severely affected. Diagnosis matters and
appropriate services improve outcomes.

Actions from the Bench

System-Level Actions

- Make prenatal alcohol exposure (PAE) screening* a regular component of child welfare cases.
- Assess the community's diagnostic capacity.
- Assess interventions and treatment facilities for facilities that have appropriate training on, and service for FASD.
- Train systems of care personnel on FASD and work to expand the community's capacity to screen, diagnose and provide interventions for affected persons.

Case-Level Actions

- Screen all children for PAE.
- Refer children with positive screens or sibling with an FASD for FASD assessments.
- If positive, refer child for developmentally appropriate and proactive treatment. Follow up on service utilization in subse quent hearings.
- When FASD is diagnosed.
- Screen siblings and parents.
- Pick placements carefully. Placements should be safe, stable and loving homes with caregivers willing to adopt if reunification fails.
- Tailor affected parent's case plans to meet their developmental needs.

^{*} To learn more about prenatal alcohol exposure (PAE), please see the PAE Judicial Bench Card.

Policy Recommendations

Judicial Bench Card				
Prenatal Alcohol Exposure				

Prevalence of Alcohol Use

- Non-pregnant women during child bearing years: 54%

Month before pregnancy: 50%Pregnant women: 12% (1 in 8)Third trimester of pregnancy: 4.6%

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

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 fetus. Increasing maternal blood alcohol can be detected in fetus in 1 minute. Maternal-fetal ethanol concentrations reach equilibrium in about two hours after women quit drinking.

Alcohol elimination from the fetus and amniotic fluid relies on mother's alcohol metabolism. The alcohol elimination capacity of the fetus is 5% of the mother's capacity. Promptly after birth, alcohol elimination rates reach 83.5% of maternal elimination rate.

Variation in Blood Alcohol Concentration (BAC)

BAC varies from person to person. For example, BAC varies by about 4 fold for women of the same weight consuming the same amount of ethanol.

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

PAE is associated with increased rates of environmental adversity including other substance abuse, smoking, neglect, abuse, malnutrition, stressful life circumstances and mortality. These often persist throughout infancy and childhood. PAE should also be considered in risk stratification for alcohol exposure in both previous and future pregnancies.

Screening for PAE What we might want to know about drinking during pregnancy

When was your last drink?					
*					
Before	PREGNANCY				
	Pre-awareness	Post-awareness			
Unexposed	Exposed	Exposed & High Risk			

Assessment of exposure during pregnancy

On average how many drinks per week did you drink during pregnancy?	(a)
On an average drinking day during pregnancy how many drinks did you have?	(b)
How many days per month did you have 4 or more drinks during pregnancy?	(c)
What is the most you had to drink on any one day during pregnancy?	(d)

Estimating cumulative exposure during pregnancy

Pregnancy Drinking Days = Estimates number of drinking days during pregnancy	(a x 40)	=	(e)
Percent of Days Exposed During Pregnancy = Estimates number of drinking days during pregnancy	e ÷ 280	=	
Number of Binge Days (4 or more drinks in one day = Estimates number of binge days	(c x 9)	=	
Number of Drinks During Pregnancy = Estimates number of drinks during pregnancy	(a x b x 40)	=	(f)
Ounces of absolute alcohol = Estimates cumulative absolute alcohol exposure during	(f / 2) pregnancy.	=	

Effective intervention NOW reduces risk for alcohol exposure in subsequent pregnancies

Getting Services for Mothers

- Ask "when was your last drink?"
- Ask if she has been in treatment previously. Should she return to the same program or does she need a different treatment provider?"
- Determine if she may have an FASD. If yes, what modifications does she need to improve her response to treatment?
- Ask "what is the success rate of the treatment program for similar women?"
- Ask if planning to create a substance use free environment needs to start now. Who will participate and when will they report back to the court?"

 $^{^{*}}$ If the screening reveals a child was prenatally exposed to alcohol, see the Judicial Bench card on FASD for next steps.