

# Fetal Alcohol Spectrum Disorders (FASD) A Guide for Pediatricians and Mental Health Providers



Larry Burd, Ph.D.

[larry.burd@med.und.edu](mailto:larry.burd@med.und.edu)

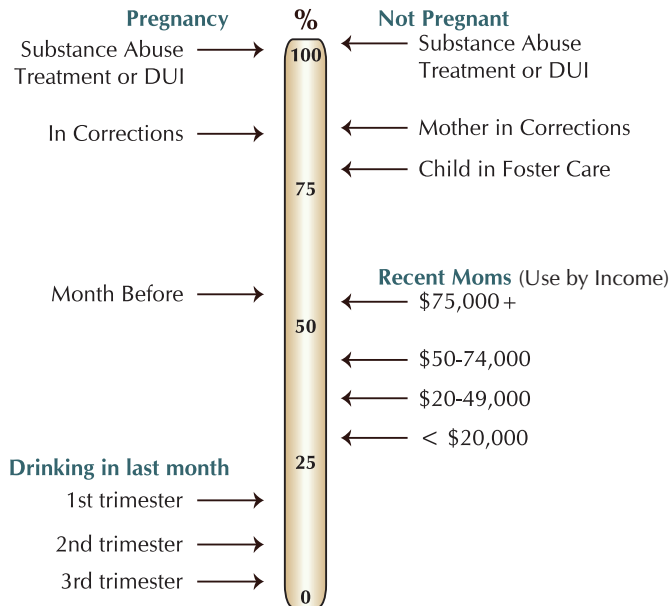
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## Collecting Data About Prenatal Alcohol Exposure (PAE).

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, mental disorders, 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.

### Prevalence of Substance Use/Abuse



The prevalence of drinking during pregnancy is high. Does this woman fit into any of these categories? When taking a history remember that drug use does not exclude alcohol use. It increases risk.

### 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

Drinking four beers results in about 17 hours of fetal exposure to alcohol.

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"> <li>Smoking</li> <li>Drug Use</li> <li>Late and Infrequent Prenatal Care</li> <li>Depression</li> <li>Inadequate Nutrition</li> <li>Miscarriage</li> </ul>	<ul style="list-style-type: none"> <li>Stillbirth</li> <li>Prematurity</li> <li>Birth Defects</li> <li>Hospitalizations</li> </ul>	<ul style="list-style-type: none"> <li>Neglect</li> <li>Abuse</li> <li>Birth Defects</li> <li>Poor Nutrition</li> <li>Smoking</li> <li>Parental Substance Abuse</li> <li>Violence</li> <li>Depression</li> <li>SIDS</li> </ul>

Prenatal alcohol exposure (PAE) is strongly associated with an increased risk for exposure to other environmental adversity and a wide-range of outcomes.

## Screening for PAE

When was your last drink?

	Pregnancy	
Before	Pre-awareness	Post-awareness
Unexposed	Exposed	Exposed & High Risk

Screening for alcohol use begins with one question.

## Charting PAE During Pregnancy

On average, how many days 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)

What is a drink? Alcohol % \_\_\_\_\_ Drink vol \_\_\_\_\_

If drinking is reported, you can provide important information on frequency and quantity of alcohol use. This will be important for other professionals who will need this information for diagnosis and treatment when they interact with the family. Complete as many of these items as you can.



One standard drink is 14 g of ethanol.

## Estimating Exposure Risk

### Maternal Risk Score

_____ Age over 25 years		<b>Score</b>
_____ Unmarried, divorced, widow, living with partner		
_____ On TANF, WIC, Social Security or income < \$16,000 per year		
_____ Did not graduate from high school	Check any one	
_____ Poor diet	Add 5	
_____ Smokes more than 1/2 pack per day		_____
_____ Drinks, but less than 2 days/week & less than 2 drinks /drinking day	Check here	
	Add 20	_____
_____ Age first drunk less than 15 years	Check any one	
_____ In treatment over three times	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 for 3 or more days per week, or more than 5 drinks/day on 6 or more occasions)	Check any one	
_____ Uses inhalants, sniffs or illegal drugs	Add 45	
		<b>Total Score</b> <input type="text"/>

If the mother or other reliable reporter is unavailable, you can provide information to estimate exposure risk for this fetus or baby and their siblings.

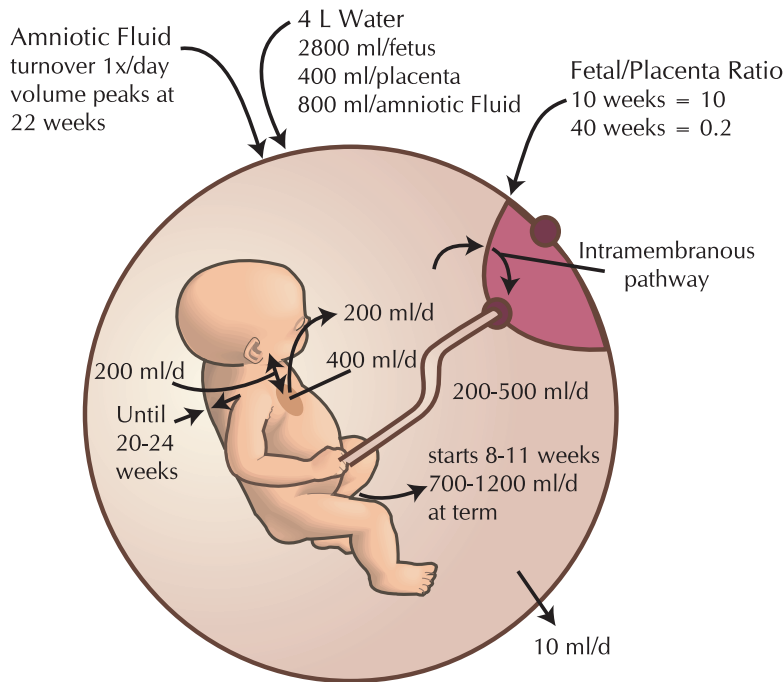
Score	Risk Category
0	None
5	Low
20-40	Moderate
45-50	High
55-105	Very High

Did this person have prenatal alcohol exposure?

- \_\_\_\_\_ Yes. Alcohol use during pregnancy is confirmed.  
 \_\_\_\_\_ Uncertain  
 \_\_\_\_\_ No. We do not suspect PAE.

Very important information.

## Maternal-Fetal Compartment Pathways for Ethanol



See the PAE Pocket card for a detailed explanation of the pathophysiology of prenatal alcohol exposure. Additional information is provided in the papers

Burd, L., Roberts, D., Olson, M., & Odendaal, H. Ethanol and the placenta: A review. *Journal of Maternal-Fetal & Neonatal Medicine* 2007, 20(5), 361-375.

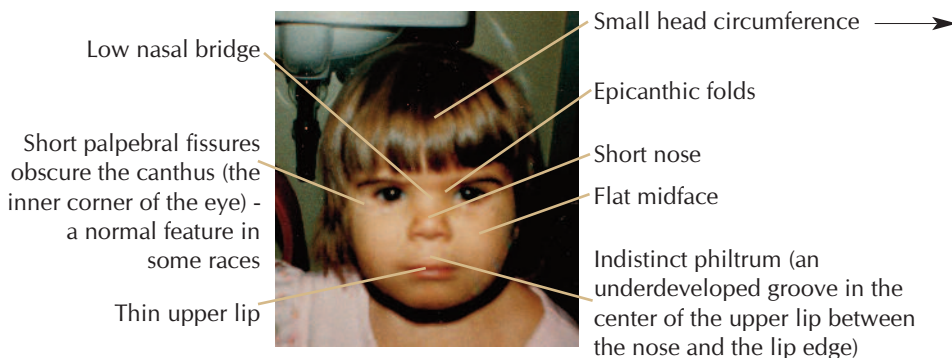
Burd, L., Blair, J., & Dropps, K. Prenatal alcohol exposure, blood alcohol concentrations and alcohol elimination rates for the mother, fetus and newborn. *Journal of Perinatology* 2012, 1-8

## 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 child 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



### 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 7.

The pocket card on diagnosis of FASD provides a useful guide on diagnosis and management.

## 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.

# FAS SCREEN FORM

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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 Folds) DROOPING OF EYELIDS (Ptosis) CROSS-EYES, ONE OR BOTH EYES (Strabismus) FLAT MIDFACE/CHEEKS (Hypoplastic Maxilla) FLAT/LOW NOSE BETWEEN EYES (Low Nasal Bridge) UPTURNED NOSE GROOVE BETWEEN LIP & NOSE ABSENT OR SHALLOW (Flat Philtrum) THIN UPPER LIP CLEFT LIP OR CLEFT OF ROOF OF MOUTH (Present or Repaired)		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 Defect)		4 1 4
ARMS AND HANDS	LIMITED JOINT MOBILITY IN FINGERS & ELBOWS PERMANENTLY CURVED, SMALL FINGERS, ESPECIALLY PINKIES (Clinomicrodactyly) DEEP OR ACCENTUATED PALMAR CREASES SMALL NAILS/NAIL BEDS (Hypoplastic Nails) TREMULOUS, POOR FINGER AGILITY (Fine Motor Dysfunction)		4 1 4 1 1
CHEST	SUNKEN CHEST (Pectus Excavatum) CHEST STICKS OUT (Pectus Carinatum) } EXAM OPTIONAL HISTORY OF HEART MURMUR OR ANY HEART DEFECT		3 1 4
SKIN	RAISED RED BIRTHMARKS (Capillary Hemangiomas) GREATER THAN NORMAL BODY HAIR, HAIR ALSO ON FOREHEAD AND BACK (Hirsutism)		4 1
DEVELOPMENT	MILD TO MODERATE MENTAL RETARDATION (IQ < 70) SPEECH AND LANGUAGE DELAYS HEARING PROBLEMS VISION PROBLEMS ATTENTION CONCENTRATION PROBLEMS HYPERACTIVITY		10 2 1 1 2 5

**COMMENTS:**

	<p><b>Total Score:</b> (Refer if score 20 or above)</p>
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**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

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NAME/ID: \_\_\_\_\_ DOB: \_\_\_/\_\_\_/\_\_\_ AGE: \_\_\_\_\_ SEX (circle one): F M

RACE (circle one): Caucasian Hispanic Native American African American Other

DATE OF EXAM: \_\_\_/\_\_\_/\_\_\_

**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		
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)		

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**TOTAL CHECKED:**

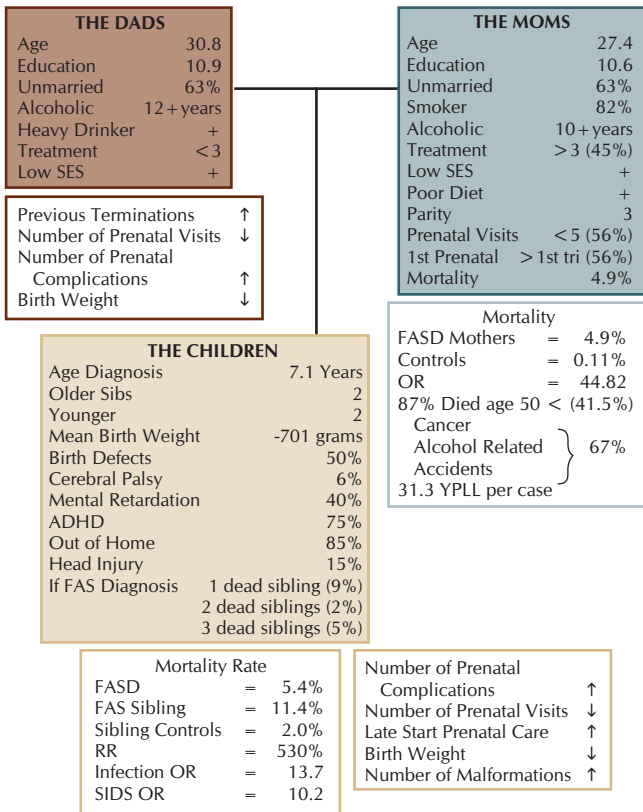
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**16**                      **20**  
**(Continue assessment if score is greater than or equal to above)**

## 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?

- 1 \_\_\_\_\_ Yes, consider referral for FASD evaluation.
- 2 \_\_\_\_\_ No, but person does need monitoring as high risk for future problems.
- 3 \_\_\_\_\_ No reason for concern

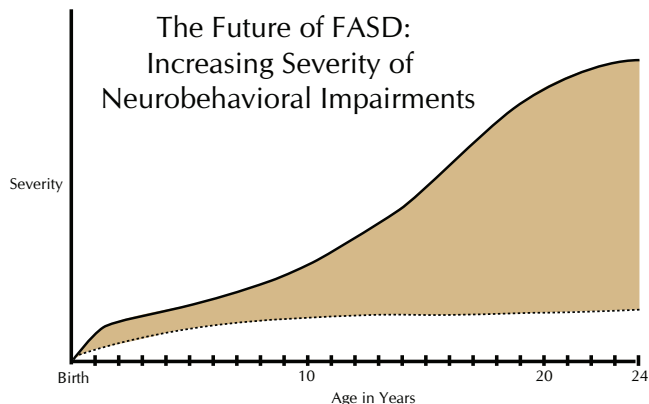
Does this child/family need management for current alcohol related problems, substance abuse for prenatal alcohol exposure or as a person with FASD?

## Risk Factors Ahead



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



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

### 2) FASD: The Keys to Intervention

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

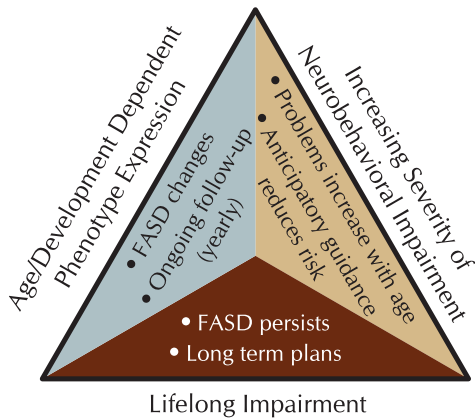


2) Key components of a case management plan.

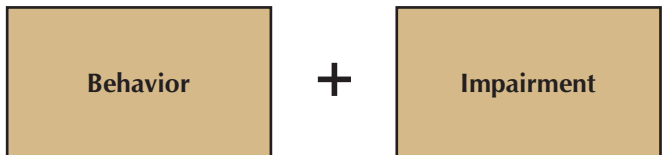
It is crucial to remember that FASD changes over time and that intervention must include plans to prevent future problems.

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

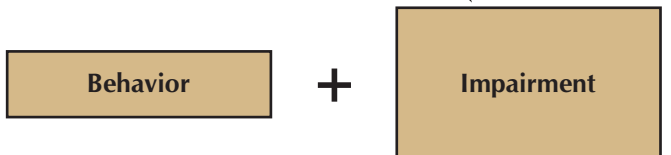
### The Developmental Triad of FASD



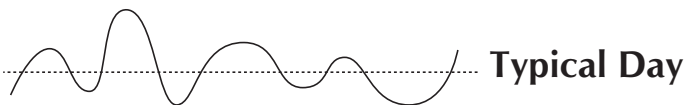
### 3) FASD: What we First See



A Better View



Inconsistent Performance



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

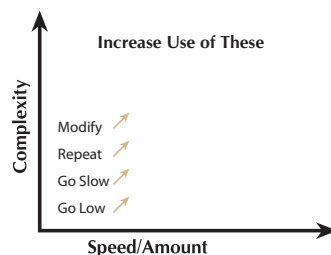
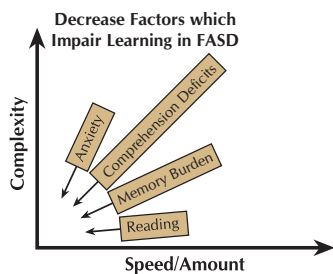
### 1) Does either parent have an FASD?

- 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 comprehension	4.5	Attention (ADHD) 75%
Oral Comprehension	5.0	Executive Function Impairments 80%

### 3) Learning in FASD



### 4) What should we change?

Think family history

*FASD is often familial*

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 after substance abuse treatment is essential

improves generalization of learned behaviors

### 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.

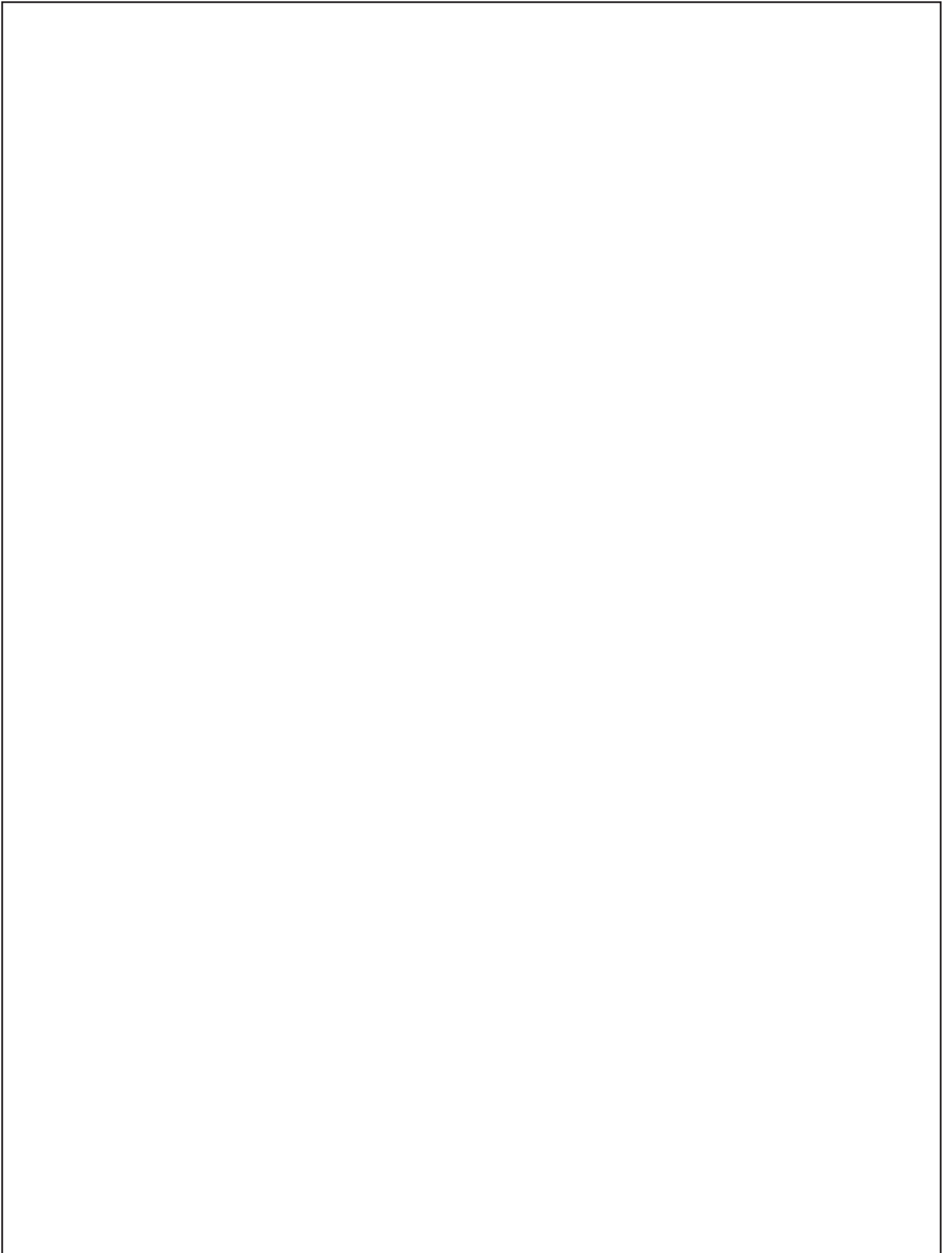
2) We can improve the success rate of treatment programs by building in these treatment keys. See #4 below.

3) Useful strategies:

- Modify 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 readily available to the participants.



# Drinking During Pregnancy

Drinks Per Day	Cumulative Fetal Exposure (Drinks per day x 270)	Fetal Exposure to Absolute Alcohol in Oz.	Full Baby Bottles
1	270	135	15
2	540	270	33
10	2700	1350	168

