

FASD: Why Can't We See It?



Larry Burd, PhD
Director, North Dakota Fetal Alcohol Syndrome Center
larry.burd@med.und.edu 701-777-3683

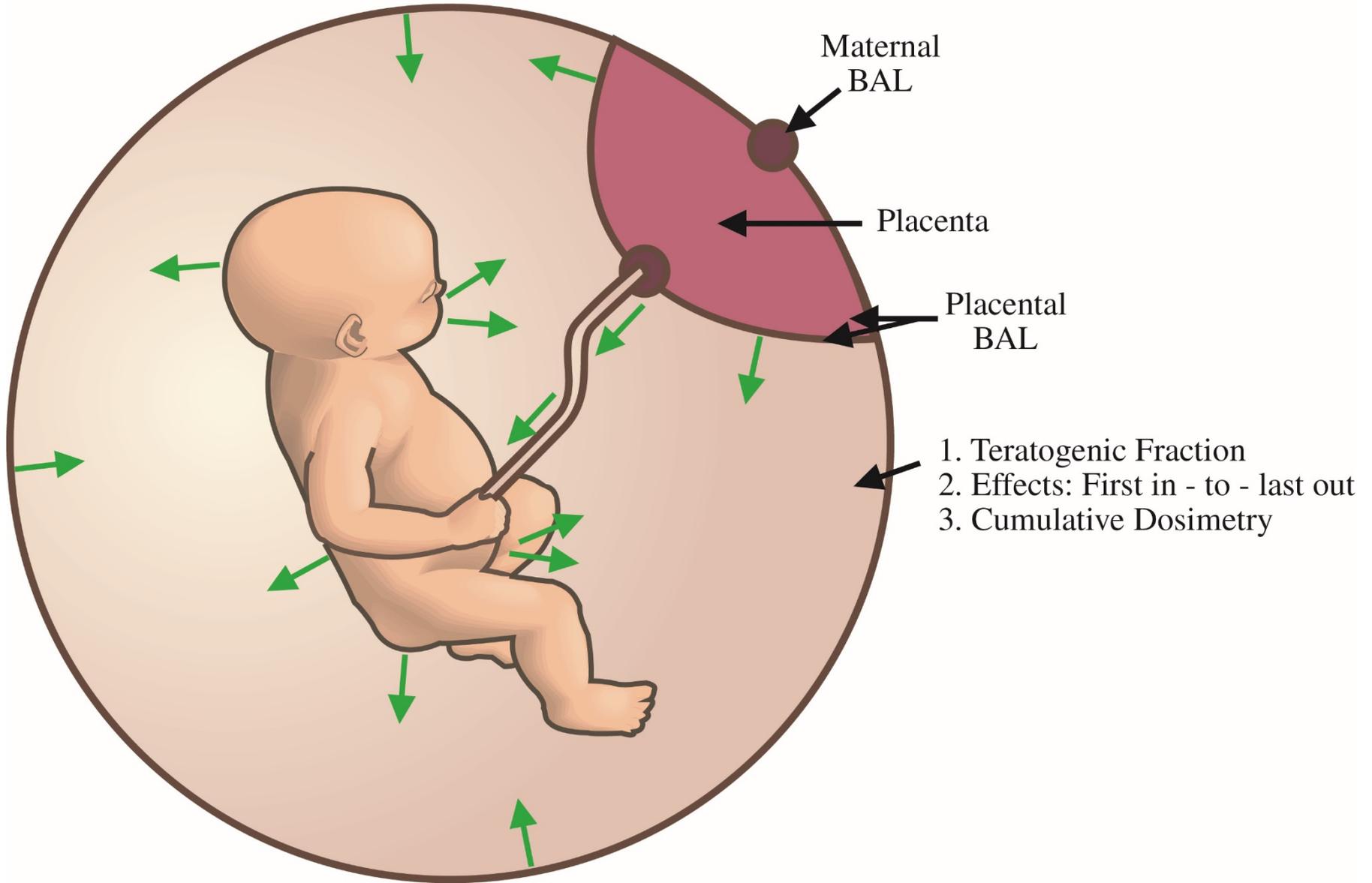
WHY PAE?

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

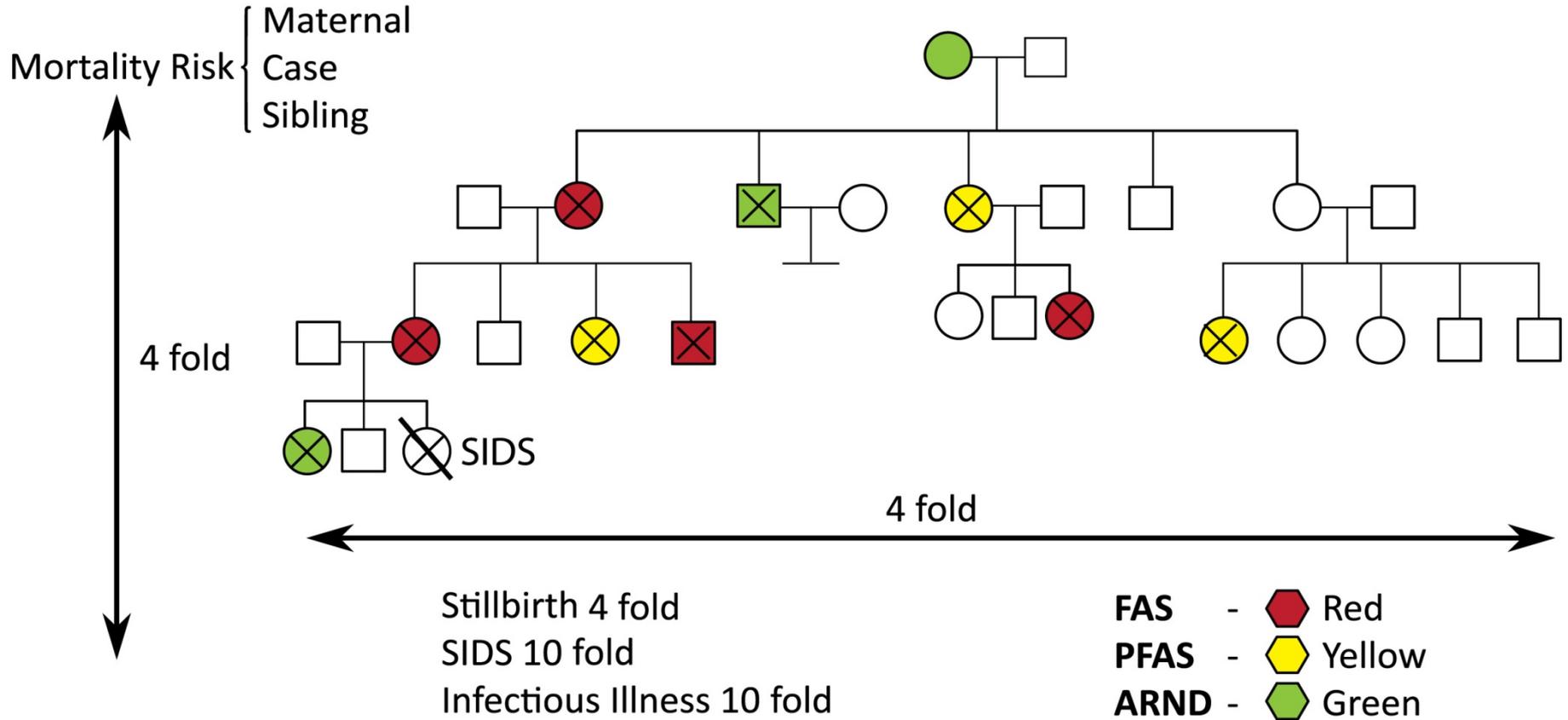
EFFECT	ALCOHOL	MARIJUANA	COCAINE	HEROIN	TOBACCO
Low Birth Weight	●		●	●	●
Impaired Growth	●				
Facial Malformation	●				
Small Head Size	●				
Intellectual & Developmental Delays	●	●			
Hyperactivity, Inattention	●	●		●	●
Sleeping Problems	●	●	●	●	●
Poor Feeding	●		●		
Excessive Crying	●	●	●	●	
Higher Risk for Sudden Infant Death Syndrome	●			●	●
Organ Damage, Birth Defects	●				
Respiratory-Problems	●			●	●



New Concepts on Fetal Exposure



FASD - Familial and Generational Effects



When Mother is missing, dead and no useful historian is available

- ▶ Maternal Risk Score

Estimating Exposure Risk

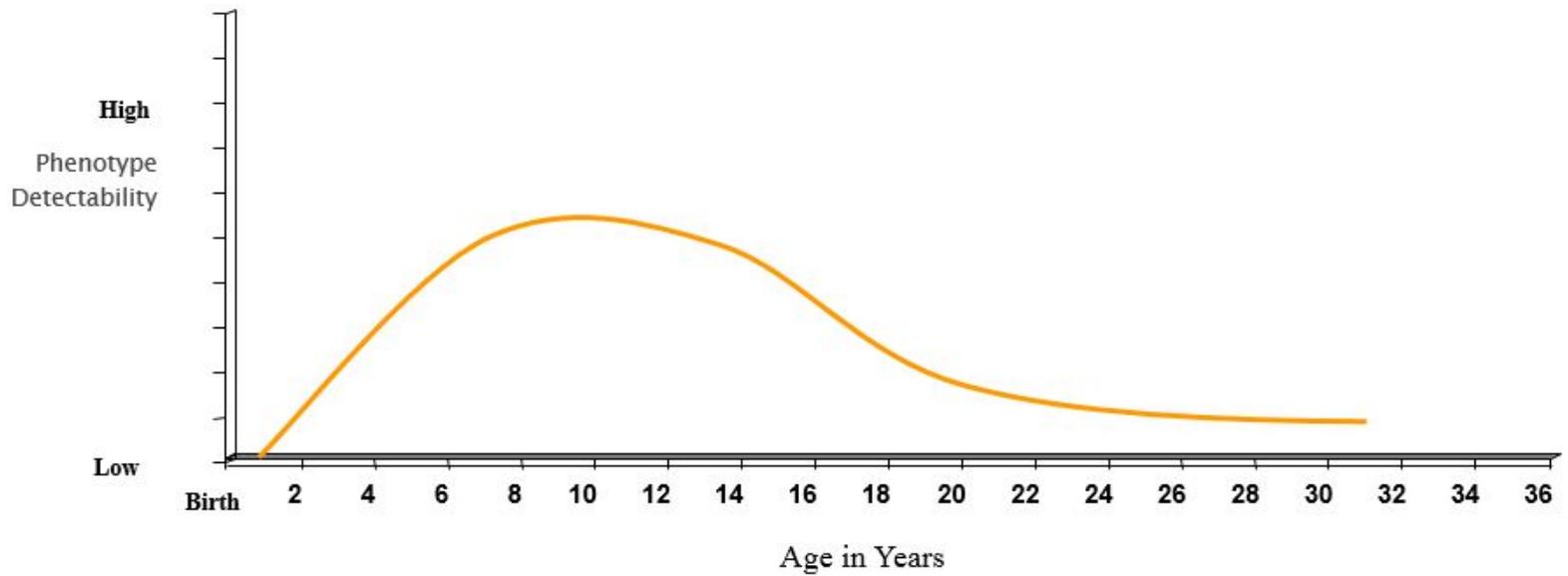
Maternal Risk Score

<input type="checkbox"/>	Age over 25 years		
<input type="checkbox"/>	Unmarried, divorced, widow, living with partner		
<input type="checkbox"/>	On TANF, WIC, Social Security or income < \$16,000 per year		<u>Score</u>
<input type="checkbox"/>	Did not graduate from high school	Check any one Add 5	
<input type="checkbox"/>	Poor diet		
<input type="checkbox"/>	Smokes more than 1/2 pack per day		
<input type="checkbox"/>	Drinks, but less than 2 days/week & less than 2 drinks /drinking day	Check here Add 20	<hr/>
<input type="checkbox"/>	Age first drunk less than 15 years	Check any one Add 35	
<input type="checkbox"/>	In treatment over three times		
<input type="checkbox"/>	In treatment in last 12 months		
<input type="checkbox"/>	Previous child died		
<input type="checkbox"/>	Previous child with FASD, or developmental disability		
<input type="checkbox"/>	Children out of home (foster care or adopted)		<hr/>
<input type="checkbox"/>	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 Add 45	
<input type="checkbox"/>	Uses inhalants, sniffs or illegal drugs		

<u>Score</u>	<u>Risk Category</u>	<u>Recommendations</u>	Total Score
0	None	Standard prenatal care	<div style="border: 2px solid black; width: 100px; height: 60px; display: flex; align-items: center; justify-content: center;"> </div>
5	Low	Standard prenatal care	
20-40	Moderate	Standard prenatal care and FASD education	
45-50	High	High risk pregnancy, alcohol-drug abuse treatment	
55-105	Very High	High risk pregnancy, alcohol-drug abuse treatment	

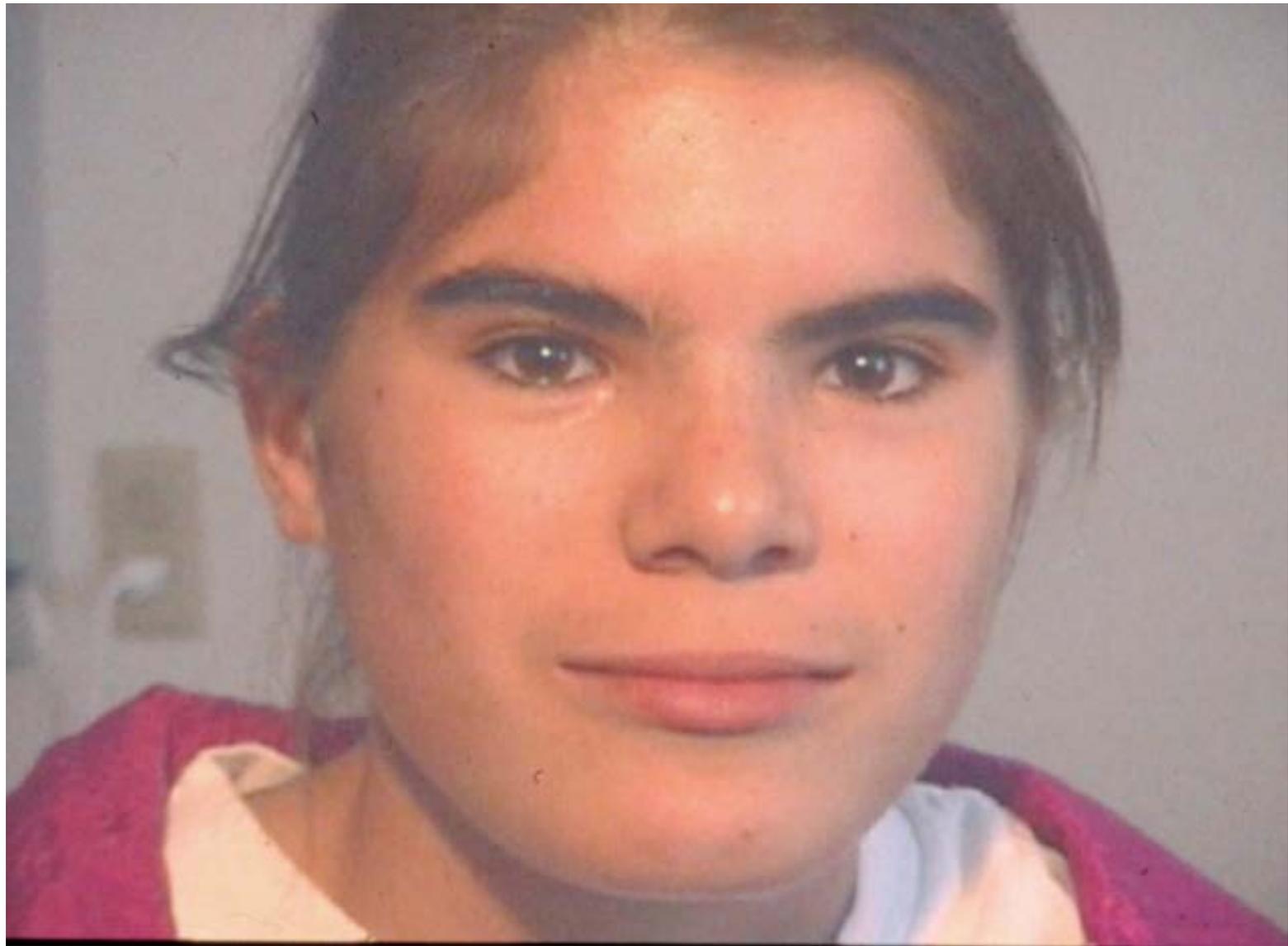
Diagnostic Criteria for FASD

	CNS	FACE	GROWTH	HISTORY
FAS	YES (3+ Domain Deficits)	YES (3 of 3)	YES ($\leq 10\%$)	N/A
PFAS	YES (3+ Domains Deficits)	YES (2 of 3)	N/A	YES (Confirmed)
ARND	YES (2+ Domain Deficits)	N/A	N/A	YES (Confirmed)



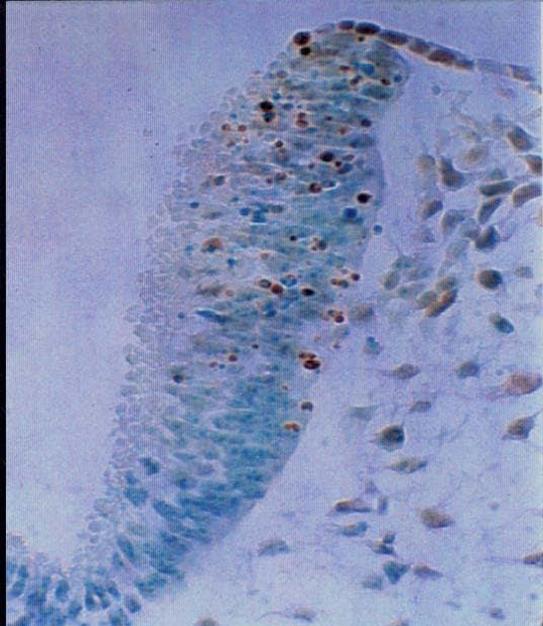
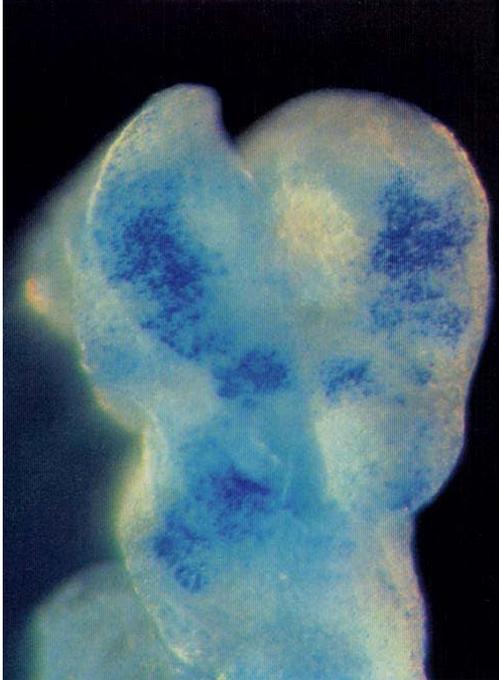
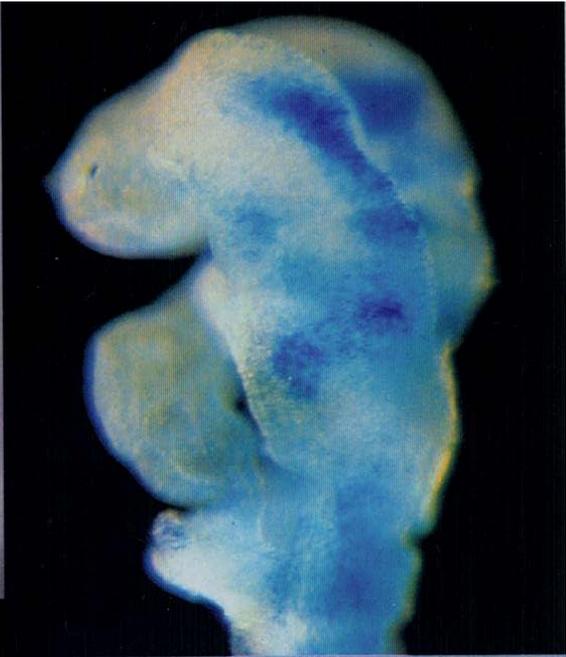
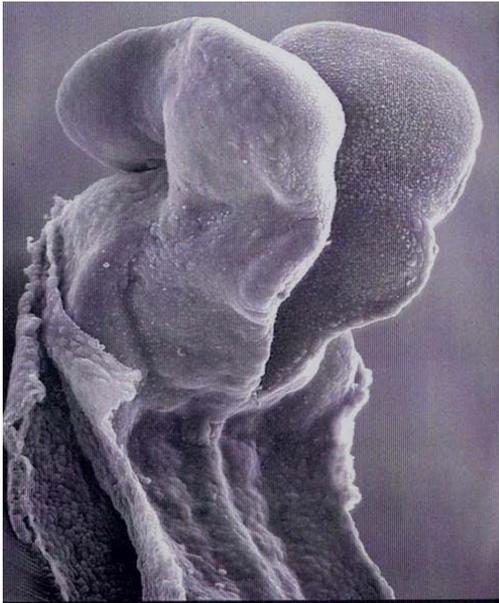
Criteria are Age Dependent





FASD Prevalence

- ▶ 1% of live births
- ▶ 20 % recurrence risk
- ▶ More severe in younger sibs
- ▶ 5% ever diagnosed
- ▶ Increasing rates of neuropsychiatric disorders





Neurobehavioral Expression of FASD

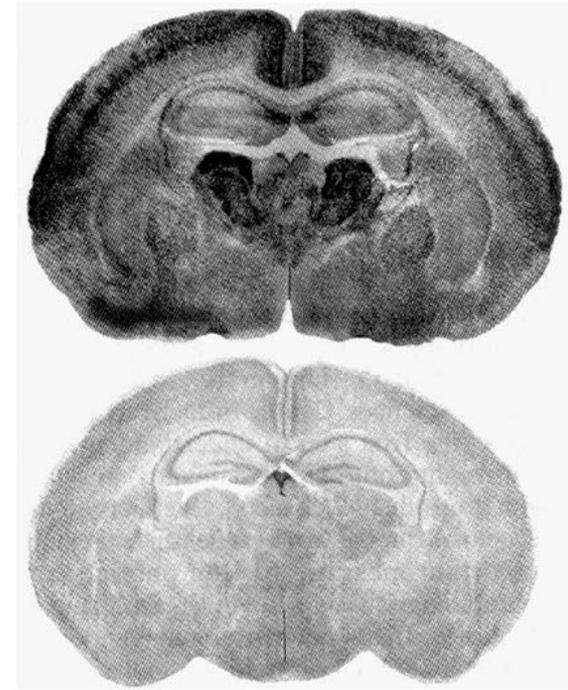


"No, I won't."

**"Let's wait; I want
to talk this over..."**

"OK!"

Fetal Alcohol Spectrum Disorders (FASD)



See PAE, Think Impairment



ARND: Risk Factors Ahead

- Exit 1 Abuse/Neglect
- Exit 2 Mental Disorders
- Exit 3 School Problems
- Exit 4 Legal Problems
- Exit 5 Substance Abuse
- Exit 6 Dependent Living

Name _____

Date _____



"No, I won't."

**"Let's wait; I want
to talk this over..."**

"OK!"

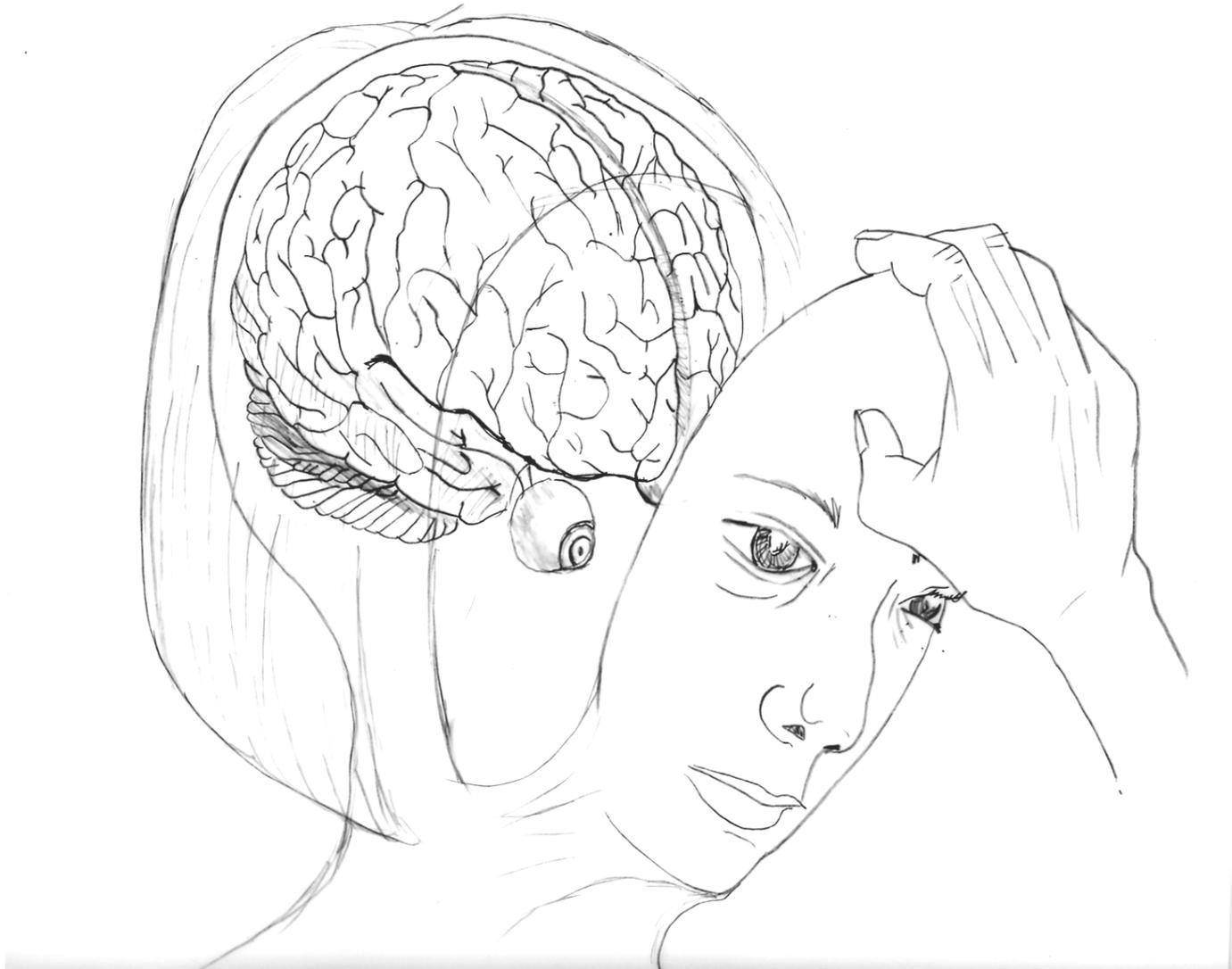
Green Light problems in the last year

-
-
-
-
-
-

My plan:

- 1)
- 2)
- 3)

Typical FASD: Look for Impairment

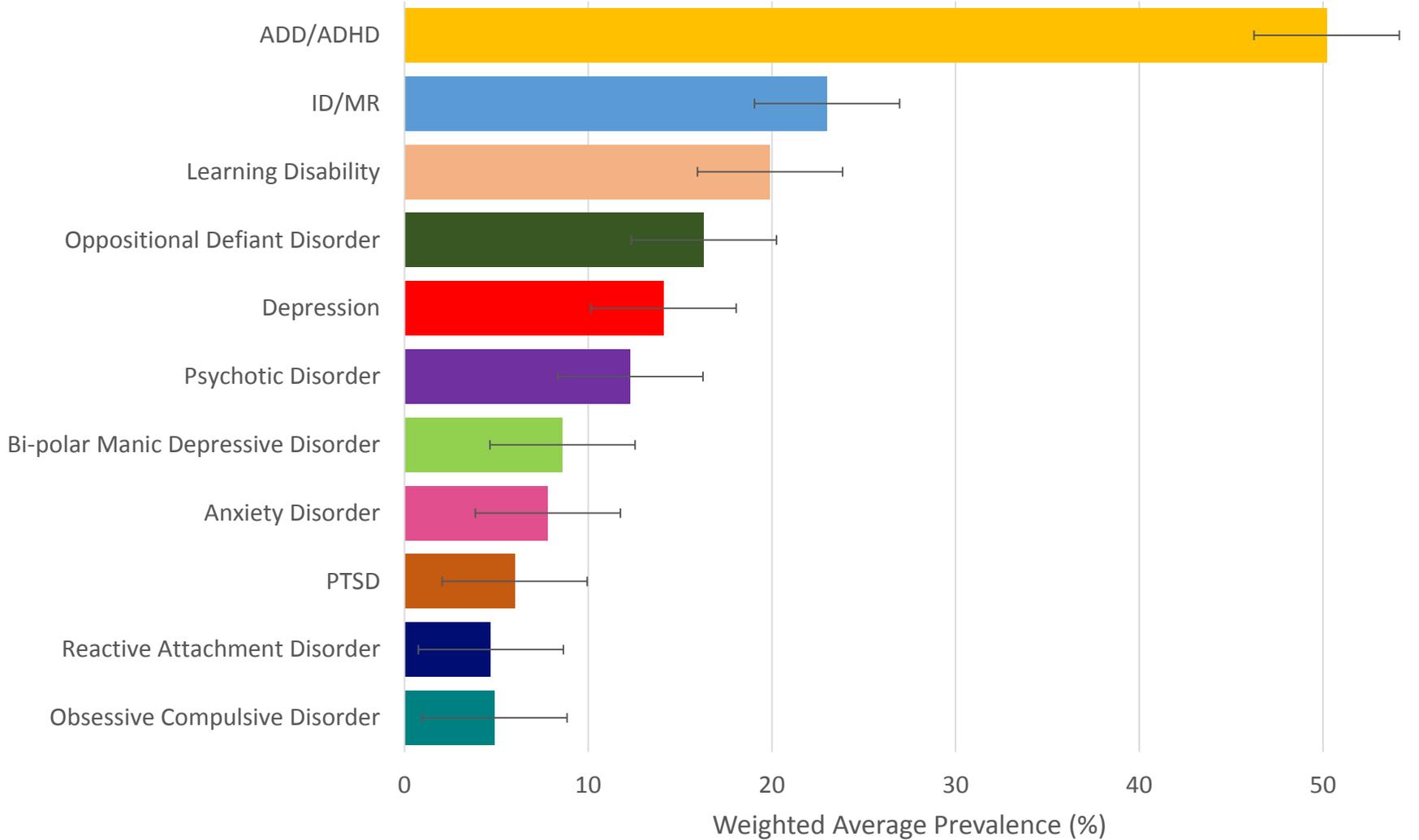


Behind the Face of FASD: We See

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



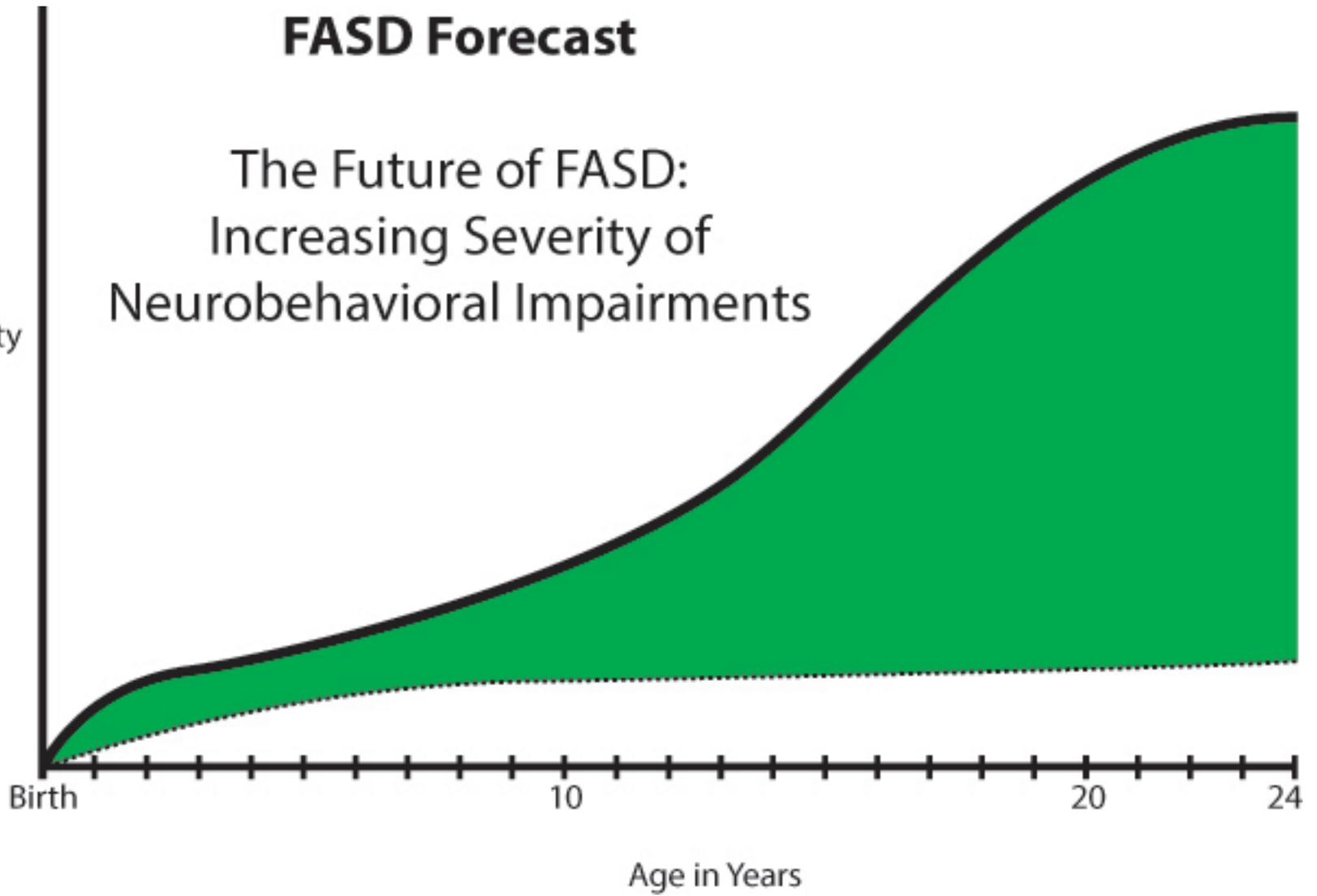
FASD and Comorbid Mental Disorders



FASD Forecast

The Future of FASD:
Increasing Severity of
Neurobehavioral Impairments

Severity



Birth

10

20

24

Age in Years

Incarceration Risk For FASD

- ▶ In Canada youth 12–18 years of age with FASD have a 19 fold increase risk of incarceration.

Popova L., Am J Epidemiol ,2012

THE ARND BEHAVIORAL CHECKLIST

NAME/ID: _____ DOB: ___/___/___ AGE: _____ SEX (circle one): F M

RACE (circle one): Caucasian 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) Interviewee needs to have known the person being assessed for at least one month.

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 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)		

For additional forms or information on ARND, contact:

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

TOTAL CHECKED:

--	--

16 20

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

Management of FASD?

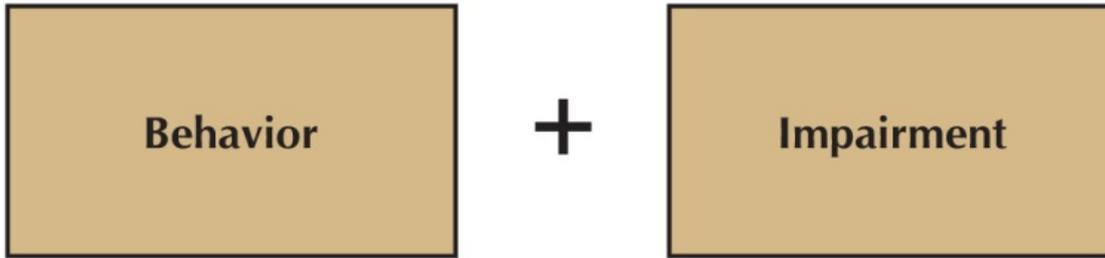
DIAGNOSIS

- ▶ Think ARND (90 – 95%)
- ▶ Not FAS (<5%) – diagnosis very complex
- ▶ Almost everyone is undiagnosed

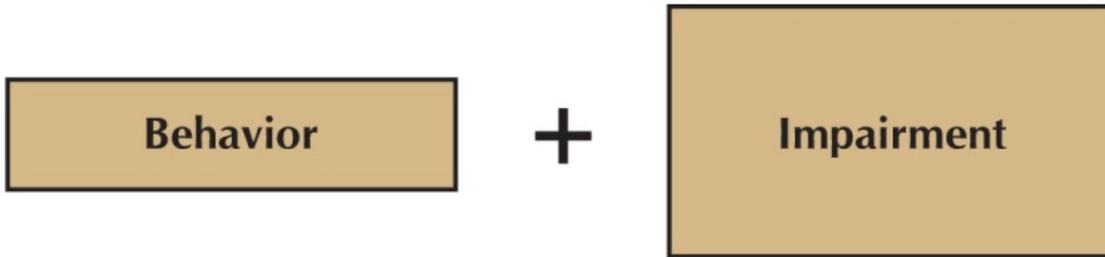
Risk Factors Ahead

Exit 1	Abuse/Neglect
Exit 2	Foster Care
Exit 3	Impairments
Exit 4	Legal Problems
Exit 5	Substance Abuse
Exit 6	Dependent Living

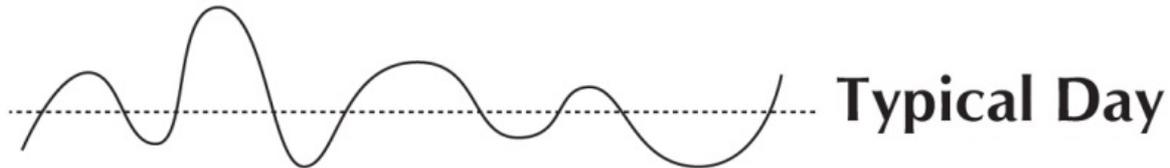
3) FASD: What we First See



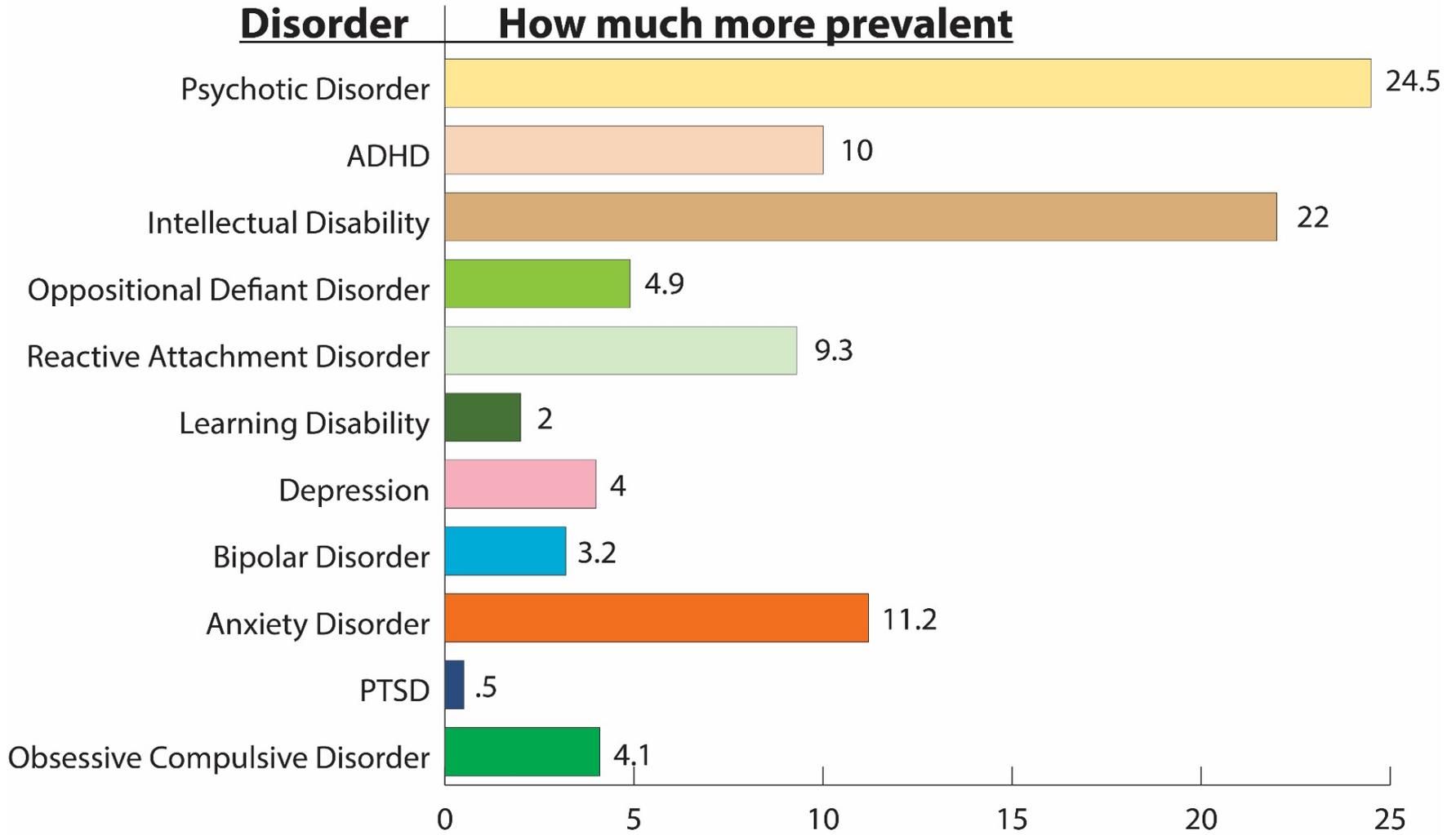
A Better View



Inconsistent Performance



FASD and Mental Disorders



Behavior often persists over the lifespan

Same Behavior Different Age

Age	Behavior
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, parenting classes after 20+ years who/what needs to change?)

FASD Management

- ▶ Yearly follow-up
- ▶ Few live independently
- ▶ Remember the Familial and Generational Effects of FASD
- ▶ Services MATTER

2) **Basic Cognitive Skills in Adolescents and Adults with FASD**

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

Children With FASD Can Be Different to Parent

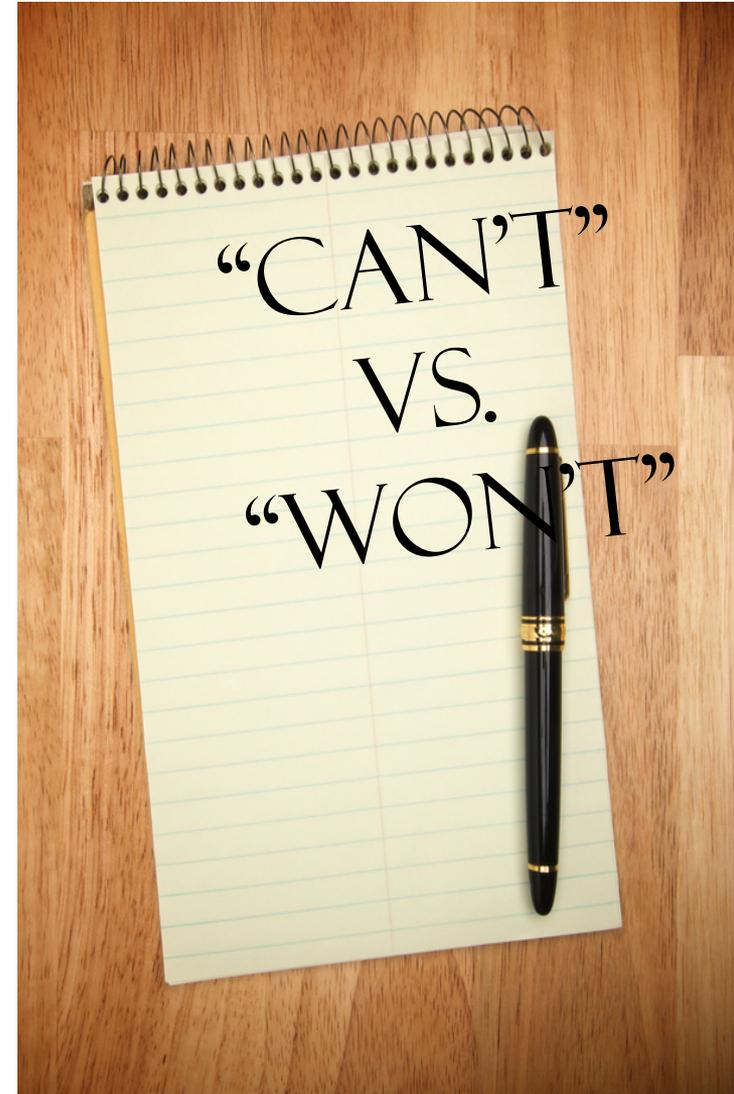
- ▶ High rates of
 - Sleep disorders
 - Eating problems
 - Toilet training difficulties
 - Temper Tantrums
 - Developmental disorders–needing therapy
 - School problems
 - Homework problems
 - Increasing severity of phenotype

Interventions

- ▶ Understand FASD
- ▶ Slow pace
- ▶ Picture schedules
- ▶ Decrease memory burden
- ▶ Manage anxiety
- ▶ Positive behavior management – less escalation
- ▶ Understand effects of comorbidity
- ▶ Comorbidity and future risk reduction
- ▶ Respite care for caretakers

General Strategies

- Plan long-term
- Teach the child/parent to ask for help
- Focus on strengths
- Use praise constantly
- Identify someone (or a team) to serve as the “external brain”



We Should Not Increase Severity

- ▶ Level Systems
- ▶ Positive Reward Deficits
- ▶ Complex Requirements
- ▶ If you ever do it = You can always do it.
- ▶ Lack of Support and Advocacy

BEDTIME SCHEDULE



PAJAMAS



BRUSH TEETH



GO POTTY

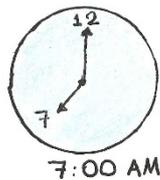


STORY TIME



LIGHTS OUT

GETTING UP



GET UP



GO POTTY



GET DRESSED

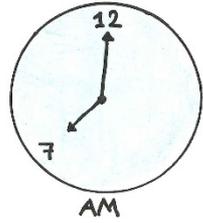


BREAKFAST



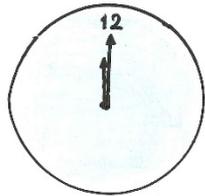
GET READY FOR SCHOOL

TAKING YOUR MEDICINE

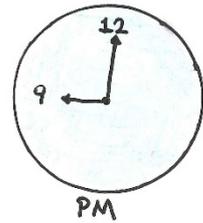


RED

BLUE



GREEN



RED

BLUE

GREEN

Calm Down Book

For

Say:

“I want to leave!”

**Do Not
Talk!**

Go to your spot.

Adolescents

▶ Think:

- Impairment
- Substance Abuse
 - **Monitor for this**
 - **Track Peers**
 - **Treat First Time and Every Time – It's a grave threat**
 - **Modify Treatment**
- Where will they live and work
- Environment is key
- Do Not Lose Hope

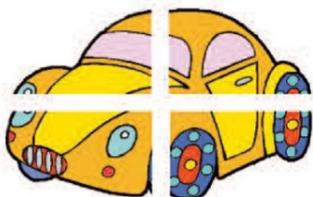
What Behavior to Start With

- ▶ Frequent
- ▶ Easy to Identify and Count
- ▶ Has a Negative and Positive Consequence
- ▶ Try to avoid infrequent behaviors to start with

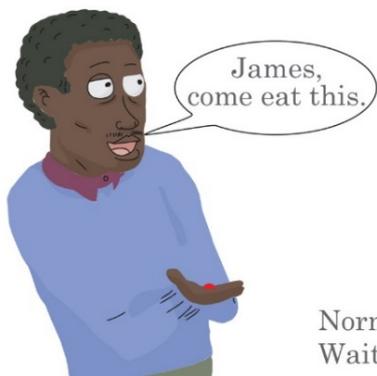
Behavior Management

POSITIVE BEHAVIORS

1. Increasing specific behaviors
2. Pick behavior which competes with negative behaviors



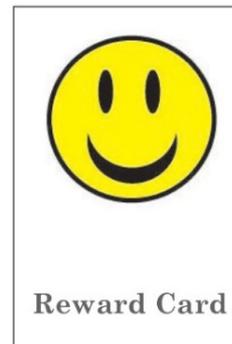
- Schedule rewards at first. Then go to random chances.
- Big problems require potent rewards.



Better Listening
It's in your bed.
It's by the TV
It's on the table

Normal voice.
Wait 30 seconds. No repeats.

- When Nathaniel has this card, he can earn rewards.
- Remove card for low level of inappropriate behavior
- 3 minutes only
- **NO Card. NO reward.** Offer frequent rewards.
- This is a signal that behavior is not appropriate. Can be done many times per day.



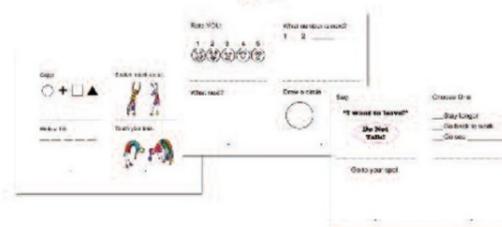
NEGATIVE BEHAVIORS

Frequent verbal behaviors - tear off one for each target behavior



Calm Down Book

For



- Have a plan.
- Practice
 - Limit talking
 - Reward all steps

YOU don't have to get better to do better!



Accommodations