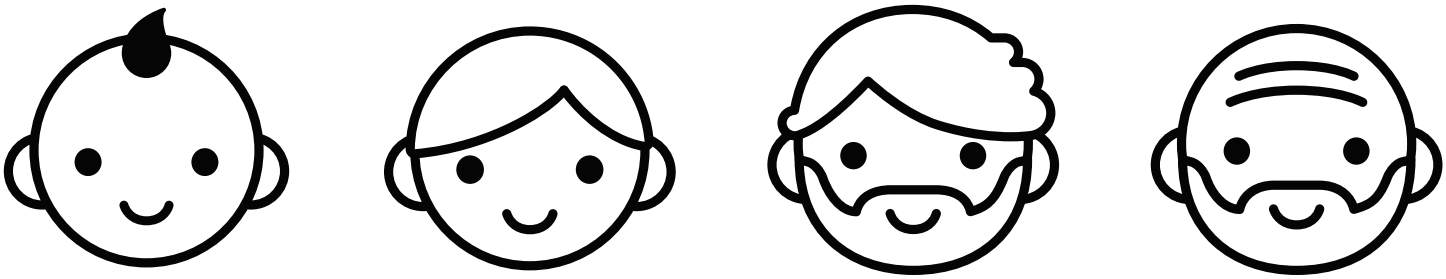
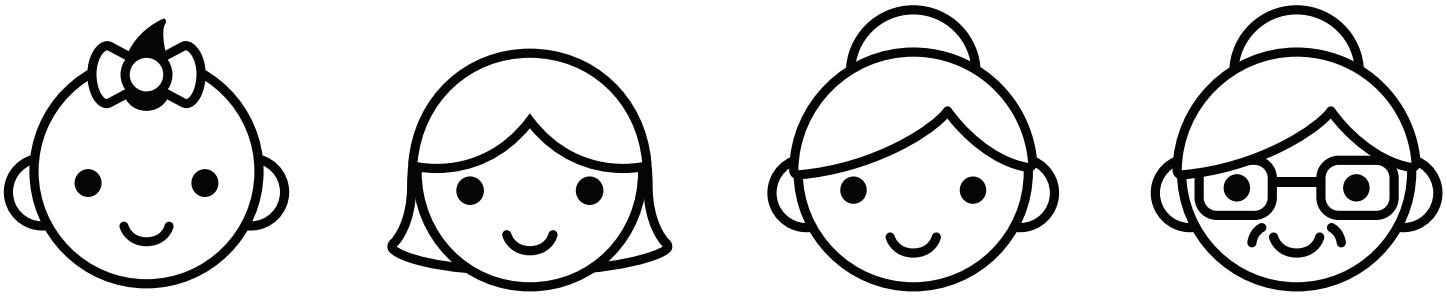
FASD: DIAGNOSIS INFORMED CARE



FASD is a Lifespan Disorder.



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Prenatal Alcohol Exposure

In a population of 10,000 pregnant women:

- 5,000 drank at the beginning of pregnancy (50%)
- 600 drank all three trimesters of pregnancy (6%)
- 100 children can be diagnosed with FASD in community clinics
- 500 more children need ongoing follow-up as a high risk population (alcohol exposed) (5%)

Fetal Alcohol Spectrum Disorder (FASD) Prevalence

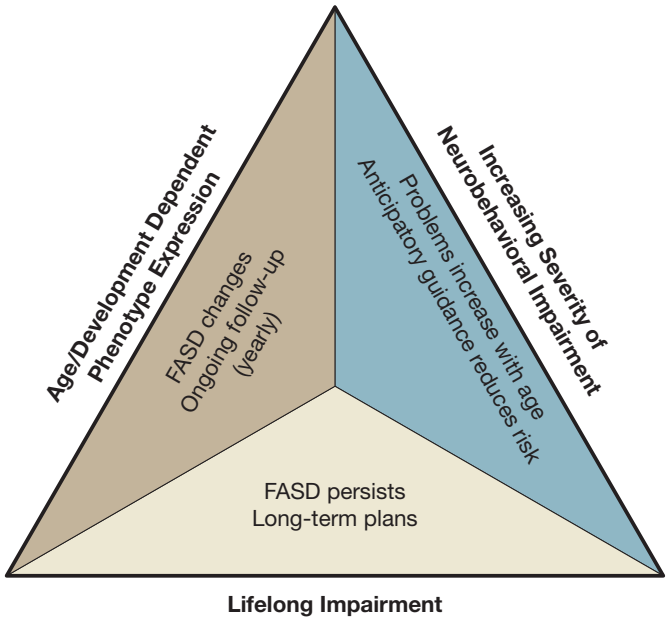
In a population of 10,000 pregnant women:

- 1-4% of live births will have FASD (100 to 400 children)
- 20% recurrence risk
- FASD tends to be more severe in younger siblings
- 95% of people with FASD are undiagnosed
- People with FASD are at an increased risk of neurobehavioral disorders

Fetal Alcohol Spectrum Disorders

FASD is a complex disorder with expression over a person's lifespan. The phenotype of FASD is comprised of increased mortality (beginning during pregnancy) increased risk for neurobehavioral 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 emphasizing risk reduction increases the complexity of care across the person's lifespan.

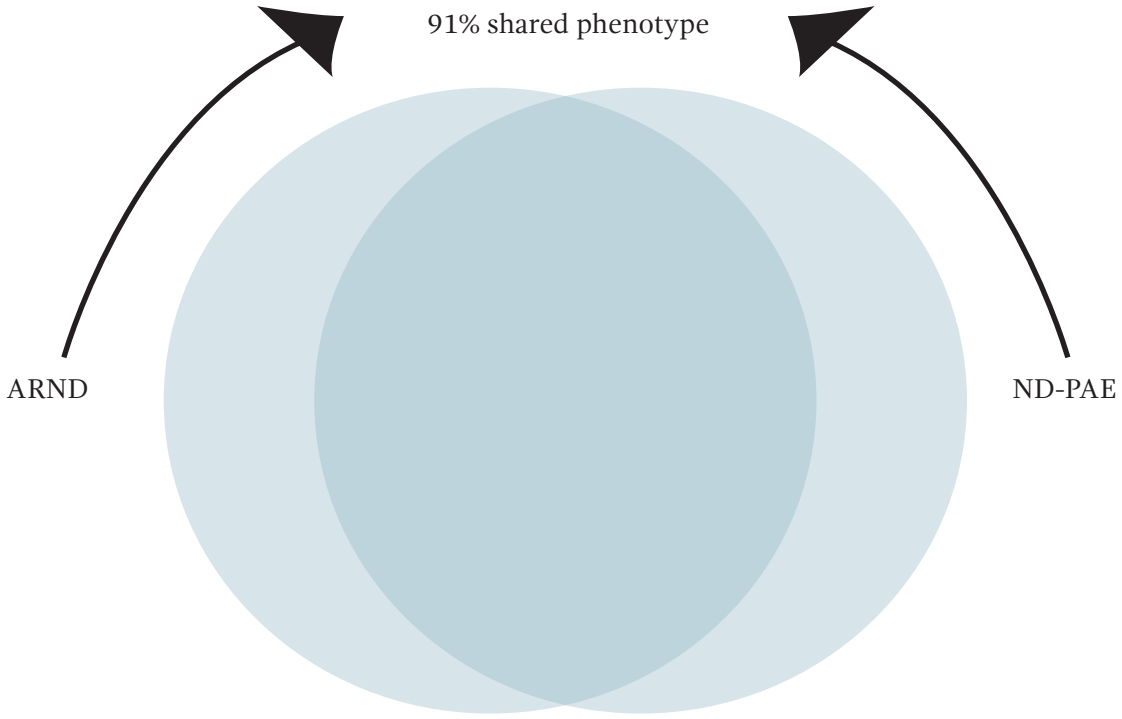
The expression of FASD is highly variable. This diagram depicts the developmental triad of the FASD neurobehavioral phenotype.



Screening and Diagnosis of FASD

Programs should prioritize the identification of children with neurobehavioral disorders. Children with growth impairment and birth defects are very likely to have access to a care pathway to identify their needs.

Screening or diagnosis can be accomplished by using one of two validated tools: the Alcohol Related Neurobehavioral Disorders Behavior Checklist (ARND) or the Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE). These tools measure a very similar phenotype, so either can be used for screening or diagnosis.



Who Should Be Screened for FASD?

Priority populations:

- Children whose mothers have been in a substance abuse treatment program
- Children entering foster care or who are adopted
- Children or adolescents entering juvenile corrections programs

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.

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 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 - fluent 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		
Has 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)		

4) Calculate total score.

Total Checked:

16	20

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

No Reliable Reporter for Prenatal Alcohol Exposure

Consider using the Maternal Risk Score to determine if the mother had characteristics similar to mothers of children with FASD.

If no one is available to report on prenatal exposure to alcohol, we can consider managing the person as having FASD without a formal diagnosis. No history is, of course, different from a confirmed history of no exposure. This is rarely available. The key is that we act on the neurobehavioral phenotype.

Estimating Exposure Risk

Maternal Risk Score

_____ Age over 25 years
_____ Unmarried, divorced, widowed, living with partner
_____ On TANF, WIC, Social Security or income < $16,000 per year
_____ Did not graduate from high school
_____ Poor diet
_____ Smokes more than 1/2 pack per day

Check any - Add 5 _____

_____ Drinks fewer than 2 days/week & fewer than 2 drinks/drinking day

Check - Add 20 _____

_____ Age first drunk before age 15 years
_____ In treatment more than three times
_____ In treatment in last 12 months
_____ Previous child died
_____ Previous child with FASD or developmental disability
_____ Children out of home (foster care or adopted)

Check any - Add 35 _____

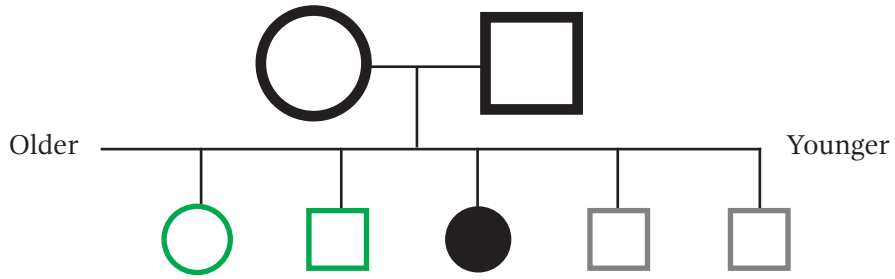
_____ Heavy drinker (drinks 3 or more drinks/day for 3 or more days per week, or more than 5 drinks/day on 6 or more occasions)
_____ Uses inhalants or illegal drugs

Check any - Add 45 _____

Score	Risk Category	Recommendations
0	None	Standard prenatal care
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

Total Score _____

The Epidemiology of Anticipation in FASD



FASD often affects multiple siblings. If a middle child is diagnosed with FASD (solid black in figure), the likelihood of FASD in older siblings (green) is increased 25 times. In the younger siblings (gray) FASD risk is increased more than 50 times.

The Phenotypes of FASD Results From:

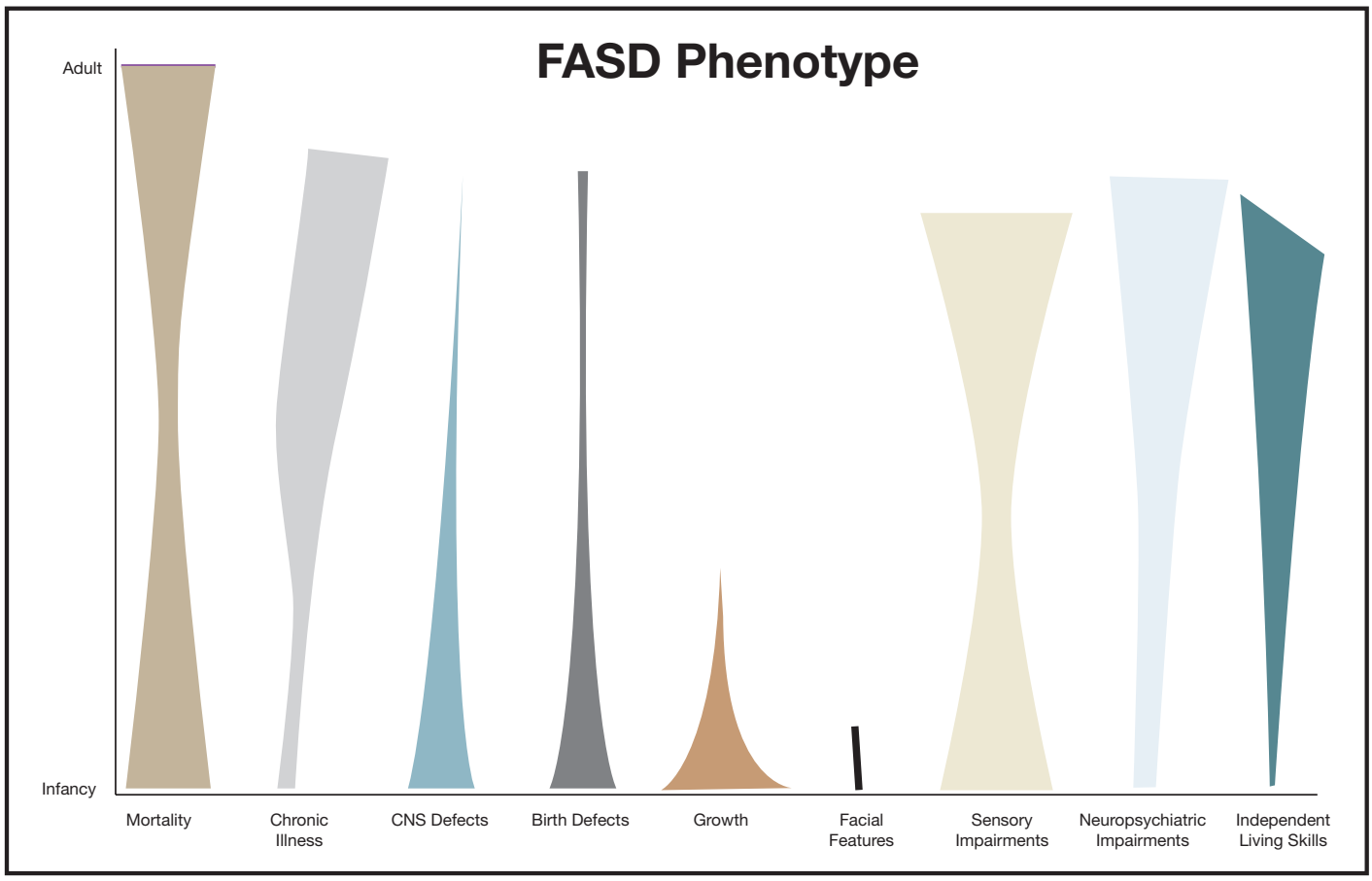
Polysubstance exposure
- Alcohol
- Smoking
- Other drugs

Accumulating Adversity
- ACEs
- Life undiagnosed
- Lack of services

Comorbidity increases
- Complexity of care
- Services needed
- Cost

Diagnosis Leads to Diagnosis-Informed Care: It's Important

Over the Lifespan FASD Involves



FASD IS A MULTISYSTEM DISORDER

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure

Name: _____ Birth Date: ____/____/_____
dd mm year

Gender: _____ Current age: _____

Proposed Criteria

___ A. More than minimal exposure to alcohol during gestation, including prior to pregnancy recognition. Confirmation of gestational exposure to alcohol may be obtained from maternal self-report of alcohol use in pregnancy, medical or other records, or clinical observation.

___ B. Impaired neurocognitive functioning as manifested by one or more of the following:
- ___ 1. Impairment in global intellectual performance (i.e., IQ of 70 or below, or a standard score of 70 or below on a comprehensive developmental assessment).
- ___ 2. Impairment in executive functioning (e.g., poor planning and organization; inflexibility; difficulty with behavioral inhibition).
- ___ 3. Impairment in learning (e.g., lower academic achievement than expected for intellectual level)
- ___ 4. Memory impairment (e.g., problems remembering information learned recently; repeatedly making the same mistakes; difficulty remembering lengthy verbal instructions).
- ___ 5. Impairment in visual-spatial reasoning (e.g., disorganized or poorly planned drawings or constructions; problems differentiating left from right).

___ C. Impaired self-regulation as manifested by one or more of the following:
- ___ 1. Impairment in mood or behavioral regulation (e.g., mood lability; negative affect or irritability; frequent behavioral outbursts).
- ___ 2. Attention deficit (e.g., difficulty shifting attention; difficulty sustaining mental effort).
- ___ 3. Impairment in impulse control (e.g., difficulty waiting turn; difficulty complying with rules).

___ D. Impairment in adaptive functioning as manifested by two or more of the following, one of which must be (1) or (2):
- ___ 1. Communication deficit (e.g., delayed acquisition of language; difficulty understanding spoken language).
- ___ 2. Impairment in social communication and interaction (e.g., overly friendly with strangers; difficulty reading social cues; difficulty understanding social consequences).
- ___ 3. Impairment in daily living skills (e.g., delayed toileting, feeding, or bathing; difficulty managing daily schedule).
- ___ 4. Impairment in motor skills (e.g., poor fine motor development; delayed attainment of gross motor milestones or ongoing deficits in gross motor function; deficits in coordination and balance).

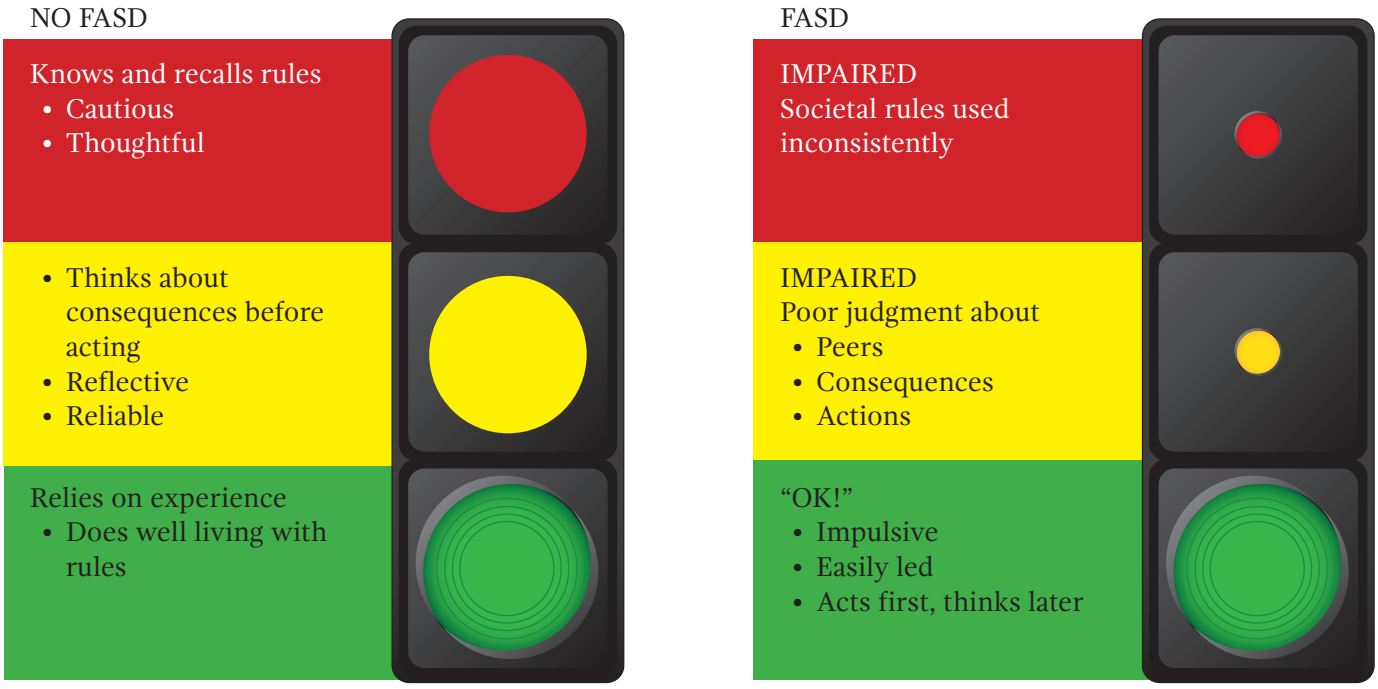
___ E. Onset of the disorder (symptoms in Criteria B, C, and D) occurs in childhood.

___ F. The disturbance causes clinically significant distress or impairment in social, academic, occupational, or other important areas of functioning.

___ G. The disorder is not better explained by the direct physiological effects associated with postnatal use of a substance (e.g., a medication, alcohol or other drugs), a general medical condition (e.g., traumatic brain injury, delirium, dementia), another known teratogen (e.g., fetal hydantoin syndrome), a genetic condition (e.g., Williams syndrome, Down syndrome, Cornelia de Lange syndrome), or environmental neglect.

Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, 2013

The Stoplight Model of Brain Dysfunction in FASD



Make Adaptations for Impairment

Don't confuse impairments (below) with behavior.

- Attention deficits
- Memory deficits
- Comprehension deficits
- Highly variable performance
- Susceptibility to anxiety in stressful situations

The unifying feature across the FASD categorical diagnosis and ND-PAE is the presence of neurobehavioral disorders.

FASD has important neurocognitive features which effect treatment

What we first see

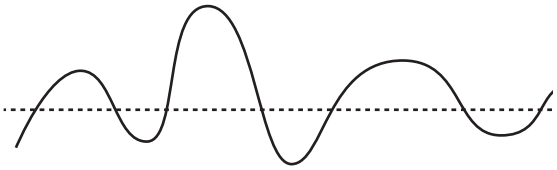
BEHAVIOR + **IMPAIRMENT**

What we should see

LESS BEHAVIOR + **MORE IMPAIRMENT**

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

Inconsistent Performance



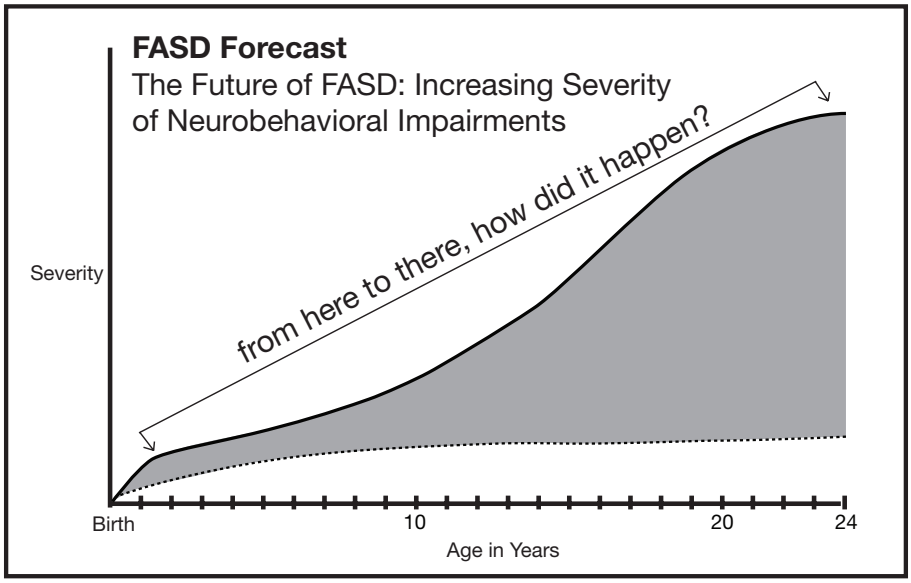
FASD results in day-to-day performance that is HIGHLY variable.

Impairments often persist over the lifespan
Same Problems—Different Age

Age	What impairment looks like
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
22	Same thing over and over with no benefit. Consider this as an impairment.
24	Late or misses meetings; easily overwhelmed; avoidant; social choices are poor; nods in agreement, but doesn't understand; can't finish (ex: substance abuse treatment, anger management, parenting classes). • So, after 20+ years who/what needs to change? • If talking worked, no person would struggle with these problems for decades. • People with FASD need recognition and accommodation.

OVER TIME, FAILURE PRODUCES AVOIDANCE

Important Features in Management

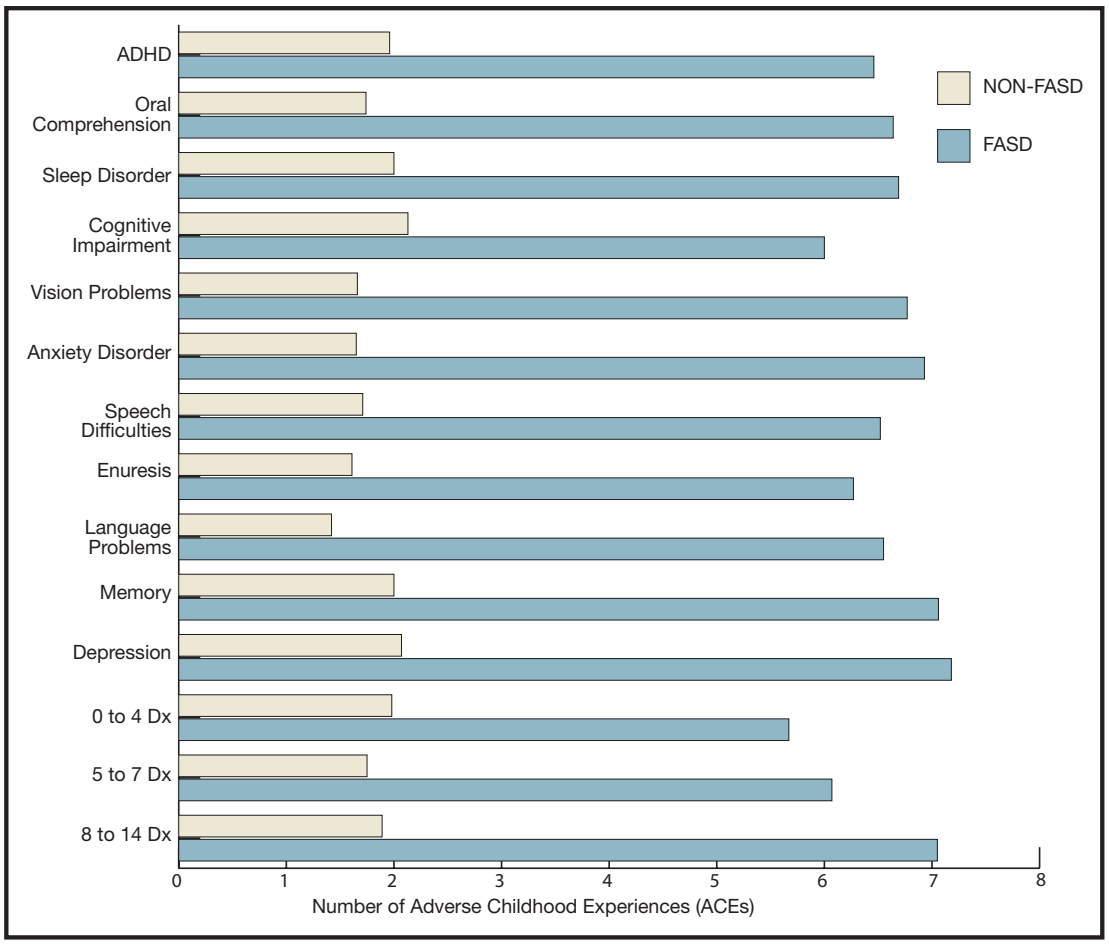


Adverse Childhood Experiences (ACEs) are Common in FASD

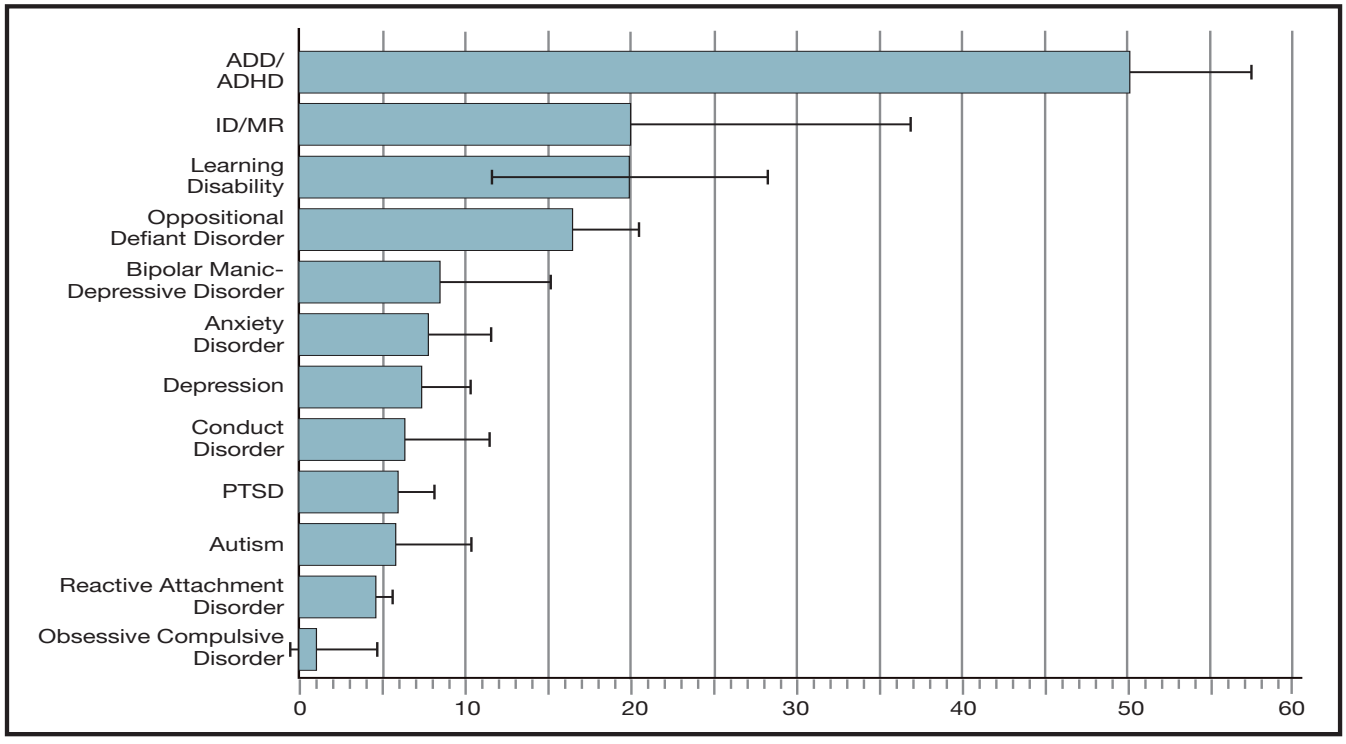
Prevalence of 12 ACE items among children with FASD compared to non-FASD controls.
In FASD: ACEs are often underway before birth.

ACE	FASD %	Non-FASD %	RR	p
Parents Divorced/Separated	72.5	45.7	1.86	<.001
Drinking/Drugs in Home	84.7	22.9	4.96	<.001
In Foster Care	90.8	16.2	9.05	<.001
Neglect	86.7	14.3	6.73	<.001
Unloving Family	68.4	11.4	3.39	<.001
Parental Depression	32.7	35.2	0.94	.810
Physical Abuse	50.0	9.5	2.44	<.001
Verbal Abuse	46.9	7.6	2.44	<.001
Parent in Prison	35.7	7.6	2.07	<.001
Mother Abused	32.7	8.6	1.92	<.001
Sexual Abuse	23.5	5.7	1.84	<.001
In Residential Care	19.4	2.9	1.98	<.001
None or One Year	6.1	58.1		
Two to six Years	39.8	35.2	5.73	<.001
Seven to Twelve Years	54.1	6.7	9.86	<.001

Adverse childhood experiences and prevalence of neurobehavioral disorders are closely related

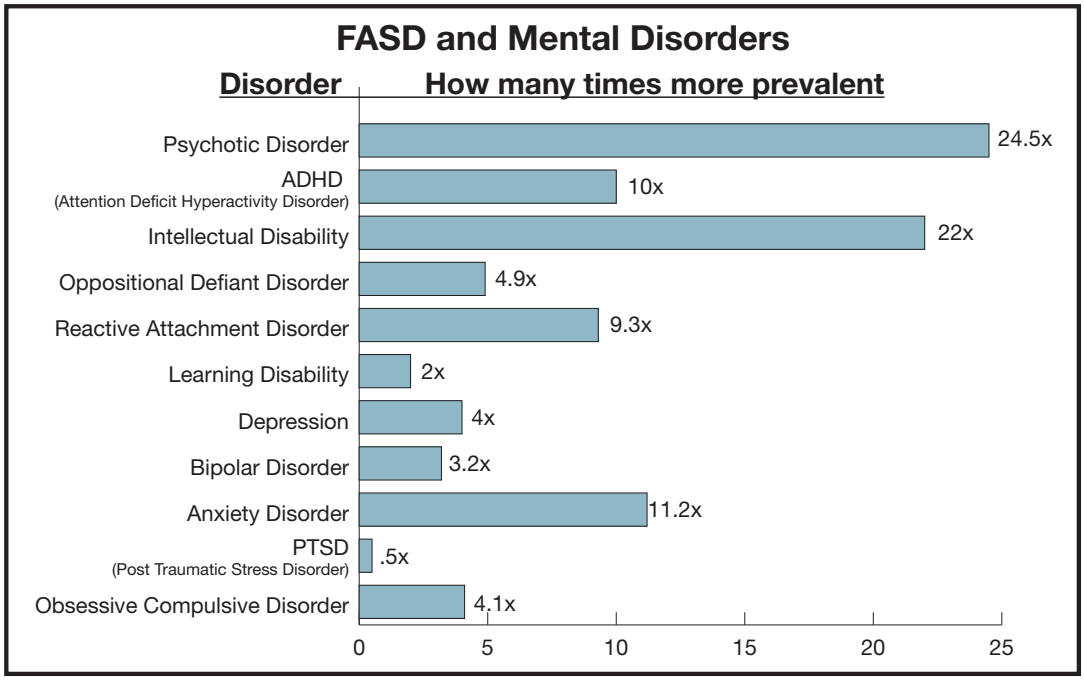


Developmental disorders and mental disorders are greatly increased in FASD.



FASD and Mental Disorders

When compared with expected rates for these disorders, we can appreciate the effects of prenatal alcohol exposure and other adverse experiences on the rates of these comorbid disorders. PAE-FASD appears to be a leading cause of psychosis, intellectual disability, anxiety disorder, attachment disorders, attention deficit hyperactivity disorder, and oppositional defiant disorder.



FASD is Going to Last, So Look Ahead: Make a 10-Year Plan

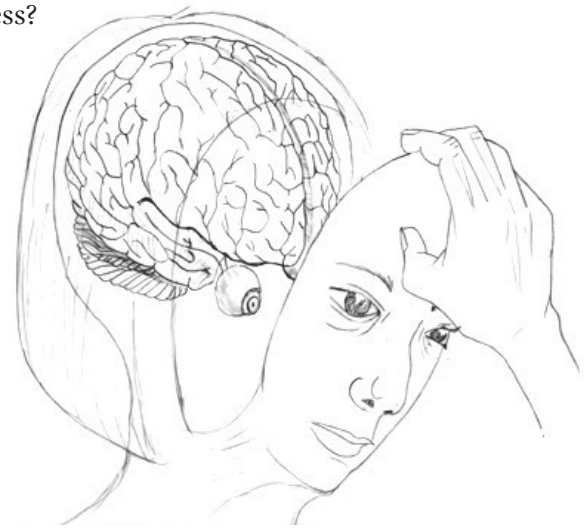
Where are we at now?

Where do we want to be in 10 years?

What specific concerns do we need to address?

FASD is:

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



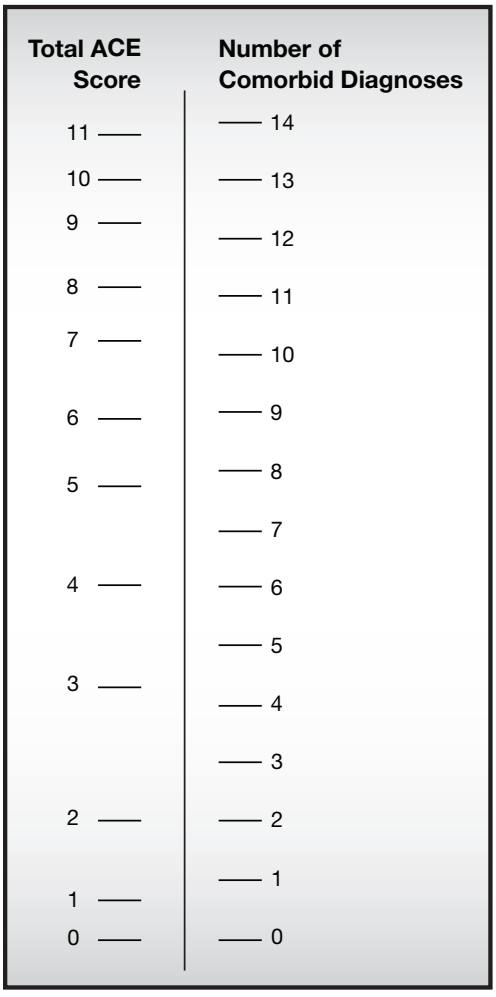
Children With FASD

Think about ACEs early and often.

- Parents Divorced/Separated
- Drinking/Drugs in Home
- In Foster Care
- Neglect
- Sexual Abuse
- Unloving Family
- Parental Depression
- Physical Abuse
- Verbal Abuse
- Parent in Prison
- Mother Abused
- In Residential Care

Adversity accumulates over time. This has profound consequences over the lifespan – prevention of the experiences reduces the risk for adverse outcomes.

ACEs and Neurobehavioral Disorders Are Linked



This chart demonstrates the relationship between ACEs and Comorbid Diagnoses. For example, an ACE Score of 6 suggests increased risk for 9 Comorbid Diagnoses.

What About Foster Care?

Substance use by parents is the most frequent reason children go into foster care.

Impact on Placement in Foster Care

- Prenatal alcohol exposed (70%)
- Parental alcohol use is often a factor in removal (50%)
- In FASD mortality is increased (mother and children)
- Parents have FASD (42-60%)
- Treatment failure due to FASD (50%)

Having one parent without substance use greatly reduces risk of the placement in foster care.

Children With FASD Can Be Difficult to Parent Before, During, and After Foster Care

High rates of

- Sleep disorders
- Eating problems
- Toilet training difficulties
- Temper tantrums
- Developmental disorders needing therapy
- Comprehension deficits
- School problems
- Difficulty with homework
- Increasing severity of phenotype
- Need for medications

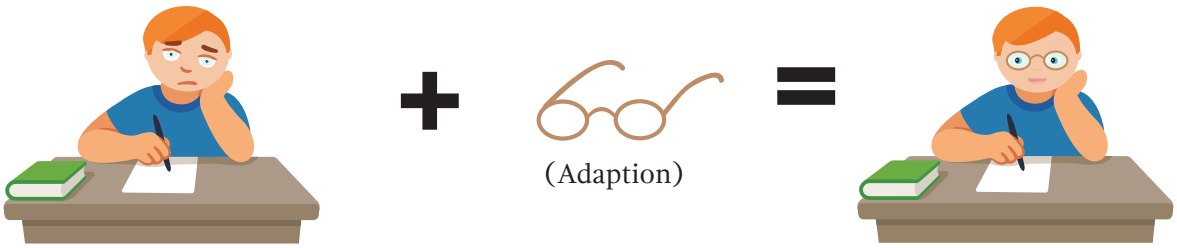
Caregivers require ongoing supports, including respite care.

Treatment of FASD

The key concepts:

- It's going to last.
- FASD tends to increase in complexity.
- Think long term (10-year plan).
- Impairment often looks like behavior.
- In FASD, accommodation for impairments is essential.

An Example



Observed problems:

- Won't read
- Does not like school
- Tries to stay home on school days
- Often angry

Consequences of adaptation

- Doing fine in school

Lesson Learned

- Do not treat impairments like behavior disorders.
- Cost of accommodation (glasses): $350 (they last for two years, or 730 days). Cost of adaptation is about 50 cents per day.

Use Positive Behavior Management Whenever Possible

- Works better
- Parents like it (this may not be a familiar concept for parents)
- Decreases risk for behavior escalation
- Use rewards that work

Working With the Parents: Important Considerations

1. Parents with substance disorders are not stress tolerant.
2. Many parents have been impacted by prenatal alcohol exposure themselves and may have FASD.
3. Over time, failure at a task produces avoidance.
4. Common cognitive impairments in adolescents and adults with FASD:

Characteristics	Grade Level
Reading	5.0
Reading comprehension	4.5
Oral comprehension	5.0

Very few forms, consents, agreements, or verbal explanations are at these levels.

	Percent
Memory	80%
Attention (ADHD)	75%
Executive Function Impairments	80%

Comprehension deficits are not improved with long detailed explanations followed by more explanations by another person.

5. Many parents need modified substance abuse treatment. Often all programs need to be modified.

Adapting Substance Abuse Treatment for People With FASD

Factors increasing complexity

- High rates of ADHD
- Learning disabilities in reading, listening, and spelling
- Anxiety disorders
- Cognitive impairments

Do your written materials and explanations improve understanding?

Adaptions

- Reduce anxiety and stress.
- Reduce reading. Increase use of pictures.
- Increase time in treatment.

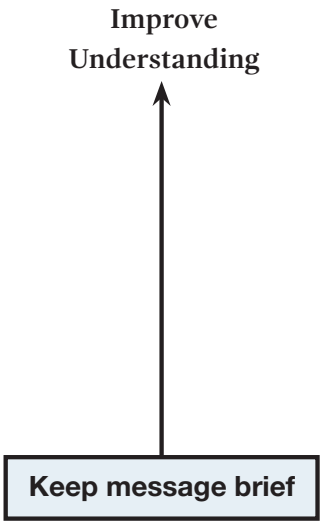
Stress impairs comprehension, memory, and exacerbates ADHD.

Improving the lives of parents is complex. It will require the best that we have to offer them.

- A sure path to failure: **They** have to change.
- A likely path to improvement: Together, **we** can do better.
- Do you make it likely parents want and will use your help?

In FASD, repetition over time works best

1. Short explanations work best.
2. Do not explain your explanations.
3. Shorter conversations are most useful.
4. Assess anxiety, it limits understanding.
5. Can we talk with coffee?
6. The key message:
   - We should talk about having people help you raise the kids.
   - We could think about a team or another family to help raise the children.
   - Who would be a good choice to help raise the children?
   - Can we share this with the court?



To Change Substance abuse we need to remember to:

- Improve treatment for substance use disorders.
- Succeed or fail together.
- Remember that substance use disorders are difficult to treat.
- Remember that success will not be easy.
- Know that anxiety impairs memory and understanding, and increases risk for relapse.
- Use more pictures and fewer words

FASD Management Checklist (what do we need?)

Screen high risk subjects by age 6
Check all that apply.

___ Long term plan (what do we want 10 years from now?)

___ Yearly follow-up

___ Vision screen

___ Impact from comorbidity considered and assessed

___ Sleep disorder

___ ADHD

___ ODD

___ Intellectual functioning

___ Adaptive behavior

___ Learning disorder

___ Speech and language impairment

___ Oral comprehension deficits

___ Inconsistent performance day to day

___ Fine motor impairments

___ Tremor

___ Toilet training

___ Anxiety

___ Reduce substance abuse risk (start thinking about this by age 7)

___ Chronic health problems are being tracked

___ Planning for stable living

___ Care givers need respite care (how many hours per week?)

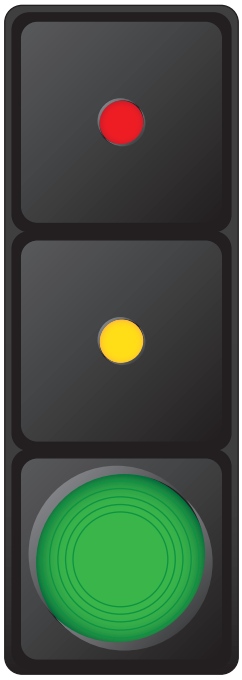
___ Siblings have been screened for FASD?

___ More pictures to replace lengthy explanations

___ Emphasize positive interventions

Here is a Worksheet to Help

Name _____ Date _____



"No, I won't."

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

"OK!"

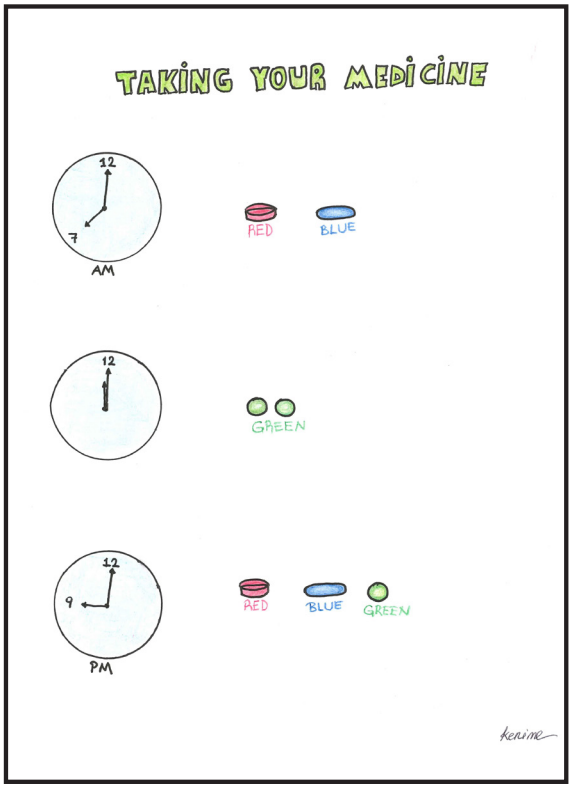
Green Light problems in the last year

1) _____
2) _____
3) _____
4) _____
5) _____

The plan:

1) _____
2) _____
3) _____

Pictures are very helpful to improve comprehension, accommodate for memory deficits, help build routine, and consistently utilize treatment objectives.



For Children/Adolescents in Foster Care or Residential Care:

Can we send our plan home?

Picture schedules

- Bedtime
- Morning routine

- Pictorial behavior plans
- Parents' schedule
- Medication schedules
- Behavior Management
  - Plan to transfer our gains back to the home
  - Preventing relapse
  - Is respite care needed?
  - Avoiding failure

FASD: Implications for the Legal System

Children, adolescents, and adults with FASD are much more likely to have contact with legal systems.

Key point:

- People with FASD often have cognitive limitations and neurobehavioral disorders.
- Basic Cognitive Skills in Adolescents and Adults with FASD

Characteristics	Grade Level
Reading	5.0
Reading Comprehension	4.5
Oral Comprehension	5.0

	Percent with Impairment
Memory	80%
Attention (ADHD)	75%
Executive Function Disorder	80%

An Important Consideration: Don't Utilize Interventions which Increase Severity!

- Use of level systems
- This program works for people who are motivated to change.
- No outcome data, but we are sure this is an effective intervention
- Treatment failure is not our problem, it's their choice.

Impairments may limit the ability of people with FASD to exercise caution during interviews or in court

FASD Checklist for Legal System

Check all that apply.

___ Cognitive deficits
___ Adaptive behavior scores are often lower than IQ scores
___ Impaired listening
___ Impaired understanding
___ Reading deficits
___ Reading comprehension deficits
___ Does not exercise appropriate judgment
___ Does not make well thought out choices
___ Cannot adequately assist in their defense
___ Does not understand sentencing options
___ Will need assistance to follow the conditions of parole
___ Will need assistance to meet the conditions of probation
___ Will need assistance and modification to complete court ordered treatments

FASD may affect behavior in court

___ May look disinterested
___ May appear fidgety
___ May speak out inappropriately on unrelated topics
___ May agree too much
___ May indicate they understand when they do not
___ May have a version of temper tantrums
___ May have limited understanding of court proceedings. Examples:
  ___ "I could ask the judge questions."
  ___ "I can talk during court - if it is important."
  ___ "I can explain things to the judge or jury."
  ___ "The judge is on my side."

Services which may need adaptation

___ Substance use disorder treatment
___ Anger management
___ Parent training
___ Getting and keeping a job
___ Finding housing
___ Taking medications as prescribed

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