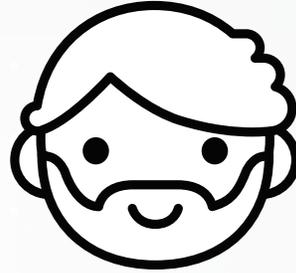
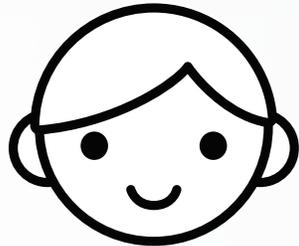
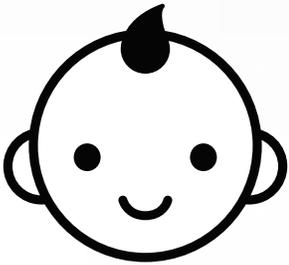
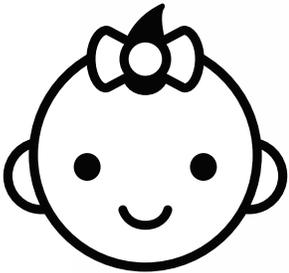


CARING FOR PEOPLE WITH FETAL ALCOHOL SPECTRUM DISORDER



Care across the lifespan



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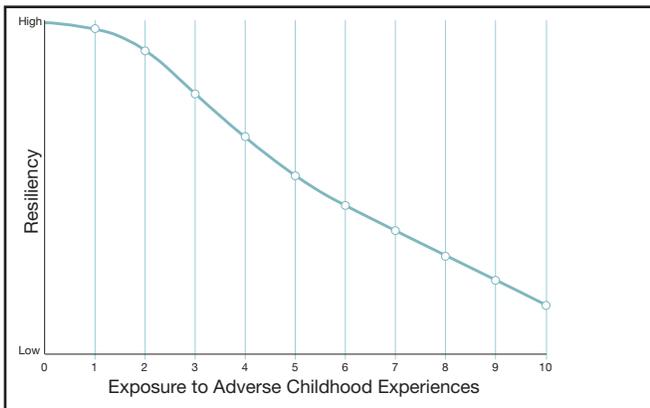
What is Fetal Alcohol Spectrum Disorder?

Exposure to alcohol exposure during pregnancy increases risk for learning disorders, mental health disorders, and growth impairments. In general these problems become more complex over the lifespan. Appropriate diagnosis is essential for development of optimal treatment plans.

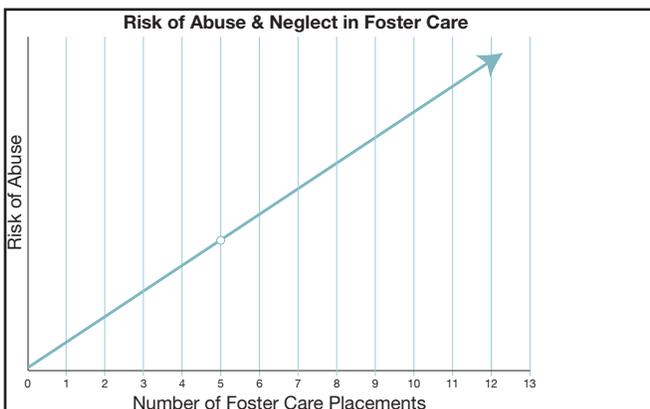
Risk Factors Ahead

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

An important early goal is to prevent future adversity.



The effects of adversity accumulate over time. This has profound consequences over the lifespan. Prevention of these experiences reduces the risk for future health problems.



Complex children with comorbidity are difficult to care for. They have increased risk for multiple foster home placements and abuse in multiple settings.

A Key Feature of FASD is The Presence of Neurobehavioral Disorders Across Lifespan



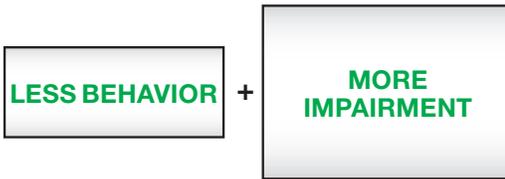
- ADHD
- Depression
- Cognitive Impairment
- Intellectual Disability
- Learning Disabilities
- Substance Abuse
- Judgment Deficits
- Chronic Illness

Don't Confuse /Impairments With Behavior

What we First See



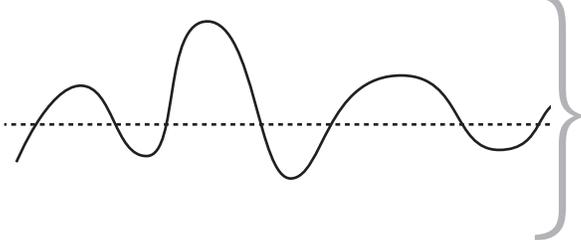
What we should see



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

In FASD, problems tend to occur in episodes or waves. During these periods, we need to increase positive behavior.

Inconsistent Performance



This results in day to day performance that is HIGHLY variable

FASD Management

- Yearly follow-up
- Remember the Familial and Generational Effects of FASD
- Few live independently
- Services MATTER
- Emphasize positive interventions
 - o Reduces risk of escalation
 - o Less likely to burn out staff or parents

Make Adaptations for Impairment

- Attention deficits
- Memory deficits
- Comprehension deficits
- Highly variable performance
- Susceptibility to anxiety

Some Problems Persist Over the Lifespan

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 (treatment, parenting classes after 20+ years who/ what needs to change?)

OVER TIME, FAILURE AT A TASK PRODUCES AVOIDANCE

In Foster Care FASD is Very Prevalent

- Prenatal alcohol exposed (70%)
- Parental alcohol use is often a factor in removal (50%)
- In FASD mortality is increased (mother and children)
- Parents with FASD or prenatal alcohol exposure (42-60%)
- In FASD treatment failure is common

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

- Sleep disorders
- Eating problems
- Developmental disorders needing therapy
- Toilet training
- Temper tantrums
- Comprehension deficits
- School problems
- Difficulty with homework

Often all programs need to be modified.

A Long Term Goal

- Increasing positive and age appropriate behavior
- Identify target behaviors
- Then look for and reward a target behavior

List Behavior	Reward
	
	
	
	
	

Emphasize positive skills and behavior

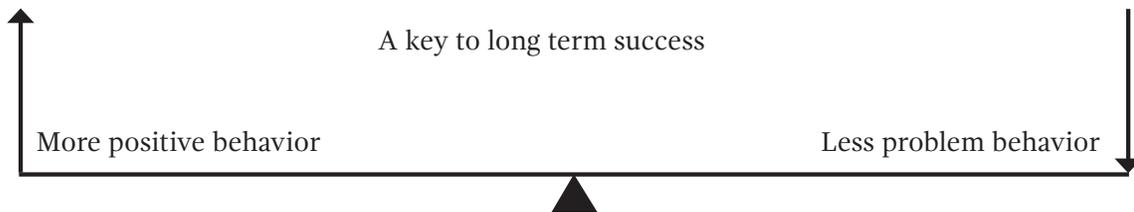
Remember:

- Behaviors you attend to - are likely to increase
- Behaviors you ignore are likely to decrease

Planning Treatment

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

On difficult days we need more positive behavior



Working With Adults or Parents: Important Considerations

Many parents need modified substance abuse treatment

Key points

- Parents with substance use disorders are not stress tolerant
- Reduce reading – increase use of pictures
- Increase time in treatment
- Often all programs need to be modified

Improving their lives will be 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?
- Substance use is an ongoing problem for many women.
- Risk of FASD is increased for younger children in a family.
- Identifying maternal substance use can prevent exposure in the next pregnancy.

Common cognitive impairments in adolescents and adults with FASD

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

Very few forms, consents, agreements, or verbal explanations are at these levels. Comprehension deficits are not improved with long detailed explanations followed by more explanations by another person.

Treatment for Pregnant Women Needs to be Individualized

Each pregnant woman with ongoing alcohol use needs her own individualized treatment plan. If possible, develop this plan with her healthcare providers and family.

The plan should be based on shared decision-making, in which pregnant women seeking treatment and recovery can weigh that information against their personal preferences and values (SAMHSA, 2016b).

The plan should focus on treatment issues that are relevant to the mother, developing fetus, and infant.

- A careful review of which medications are being used and why
- Combined exposure to both smoking and drinking results in large increases in risk for adverse fetal outcomes
- Coordination of care such as help with scheduling and follow-up appointments
- Family involvement
- A plan to treat co-occurring medical or behavioral health disorders that addresses her goals and motivations to engage in treatment (Jones et al., 2016; SAMHSA, 2014, 2015; World Health Organization [WHO], 2014)
- Reduce anxiety and stress
- Reduce reading – increase use of pictures
- Increase time in treatment



Other important resources you may find useful

- FASD: A Guide for Pediatricians and Mental Health Providers
- FASD: For the Courts and Correctional Systems
- FASD: Diagnosis Informed Care
- Changing Behavior

Alcohol Treatment Components for Pregnant Women

Treatment Approaches	Comments	References
	<ul style="list-style-type: none"> Maternal/fetal mortality risk for pregnant women undergoing treatment is unknown. 	
<ul style="list-style-type: none"> Maternal mortality risk for mothers of a child diagnosed with fetal alcohol spectrum disorder is increased by 39 to 44 fold. 	<ul style="list-style-type: none"> Prenatal alcohol exposure is associated with increased risk for fetal alcohol spectrum disorders which is the number one cause of preventable developmental delays in children. 	<p>Schwartz et al., 2016 Li et al., 2012</p>
<ul style="list-style-type: none"> Withdrawal management: Benzodiazepine (e.g., diazepam) for medication-assisted withdrawal. 	<ul style="list-style-type: none"> In non-pregnant patients, behavioral interventions for risky/harmful alcohol use are an effective component of care. The effectiveness of these interventions has not been well studied in pregnant or postpartum women. 	
<ul style="list-style-type: none"> Psychosocial treatment during and after withdrawal 	<ul style="list-style-type: none"> Although pregnant women are counseled to cease drinking alcohol, little specific evidence-based guidance is available on how to manage alcohol withdrawal in pregnancy. Management should be based on alcohol withdrawal for non-pregnant women. Adverse maternal/fetal outcomes during treatment are unknown. 	<p>Bhat & Hadley, 2015 Bhuvanewar, Chang, Epstein, & Stern, 2007 Christensen, 2008 Whitlock, Polen, Green, & Klein, 2004 DeVido, Bogunovic & Weiss, 2015</p>
<ul style="list-style-type: none"> Individualized Treatment Plan 	<ul style="list-style-type: none"> Attention deficit hyperactivity disorder, learning disabilities in reading, understanding, and spelling are common Impaired Cognition Modified treatment for patients with learning impairments Longer time in treatment Anxiety impairs understanding and memory 	
<ul style="list-style-type: none"> Document adverse childhood experiences (ACEs) 	<ul style="list-style-type: none"> ACEs increase the complexity of treatment 	
<ul style="list-style-type: none"> Pharmacotherapy: The US Food and Drug Administration approved naltrexone, disulfiram, and acamprosate to treat alcohol use disorder. 	<ul style="list-style-type: none"> Alcohol withdrawal cannot be managed with behavioral therapies along. A long-acting benzodiazepine similar to one that would be used with benzodiazepine detoxification can be used in addition to behavioral treatments. No published studies have compared with safety or efficacy of disulfiram, acamprosate and naltrexone for alcohol use disorder in pregnant women. 	
<ul style="list-style-type: none"> Treatment may need to be repeated 	<ul style="list-style-type: none"> Success rates are often modest 	