

MANAGING BEHAVIOR FETAL ALCOHOL SPECTRUM DISORDERS

FASD

- Present before birth
- Lasts a lifetime

FASD IS LIFELONG

- Interventions needs to be long-term
- Make a 10-year plan

TREAT COMORBIDITY



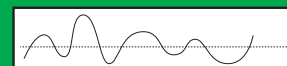
PREVENT THE ACEs

DURING BEHAVIOR STORM

- Talking is over used

FASD PERFORMANCE

- Highly variable
- Day to day



- Week to week

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2019



This book provides our most current intervention strategies

How common is Fetal Alcohol Spectrum Disorder (FASD)?

FASD affects about 1-5% of school-age children. FASD is much more common in some populations

- | | |
|----------------------------------|--------|
| • Foster Care | 50% |
| • Juvenile Corrections | 25% |
| • Special Education | 15% |
| • Residential Care | 40-50% |
| • Inpatient Psychiatric Services | 30% |

Understanding FASD

FASD is strongly associated with an increasing number of associated disorders over the lifespan which:

- Increases complexity of care
- Increases need for diagnosis dependent interventions

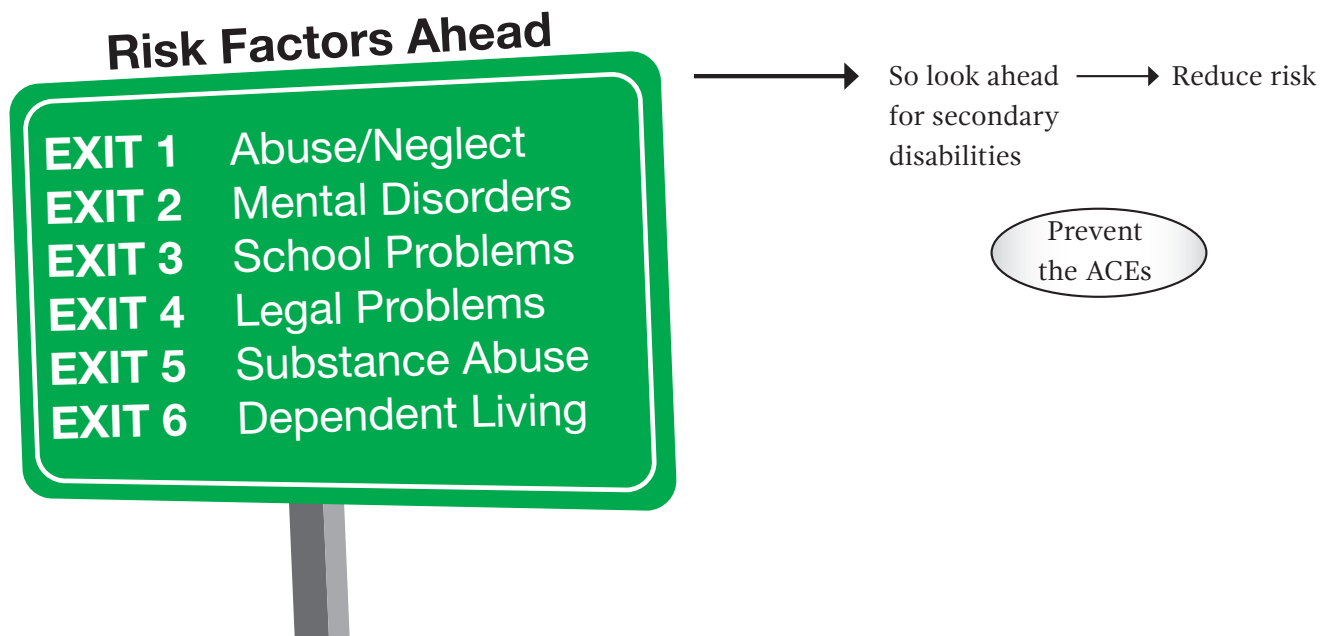
The neurobehavioral basis of the disorder was present before the child was born

- Prenatal alcohol exposure, leads to FASD, and then adverse childhood experiences (ACE's)
- People with FASD cannot make the brain damage go away by trying harder

FASD is

- Familial and generational
- Almost always undiagnosed

FASD increases risk for:



A key feature of FASD is the presence of neurobehavioral disorders across lifespan

- ADHD
- Depression
- Cognitive impairment
- Learning disabilities
- Substance abuse
- Judgment deficits
- Chronic illness

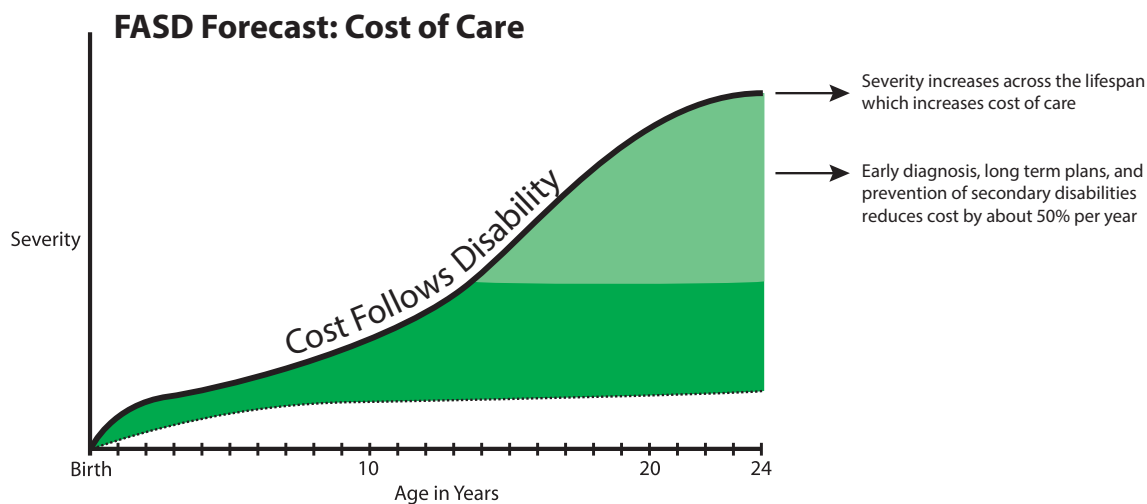


See alcohol, think impairment

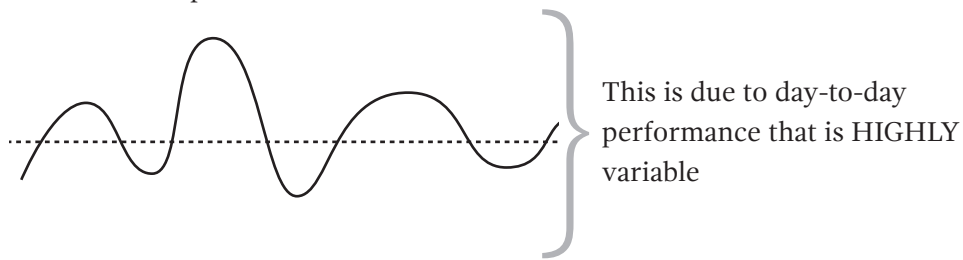
A history of prenatal alcohol exposure increases risk for a broad spectrum of impairments.

What does this cost?

Each year we spend an extra \$22,810 per child with FASD. By 21 years of age we have spent \$479,010. For adults the annual cost is \$24,308, so by age 40 we will have spent another \$461,852. On average we hit the million dollar cost of care for FASD at age 43 years.

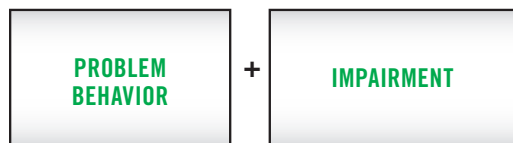


FASD looks unpredictable:

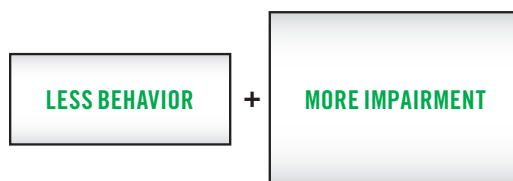


Don't Confuse Impairments With Behavior

What we First See



What we should see



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

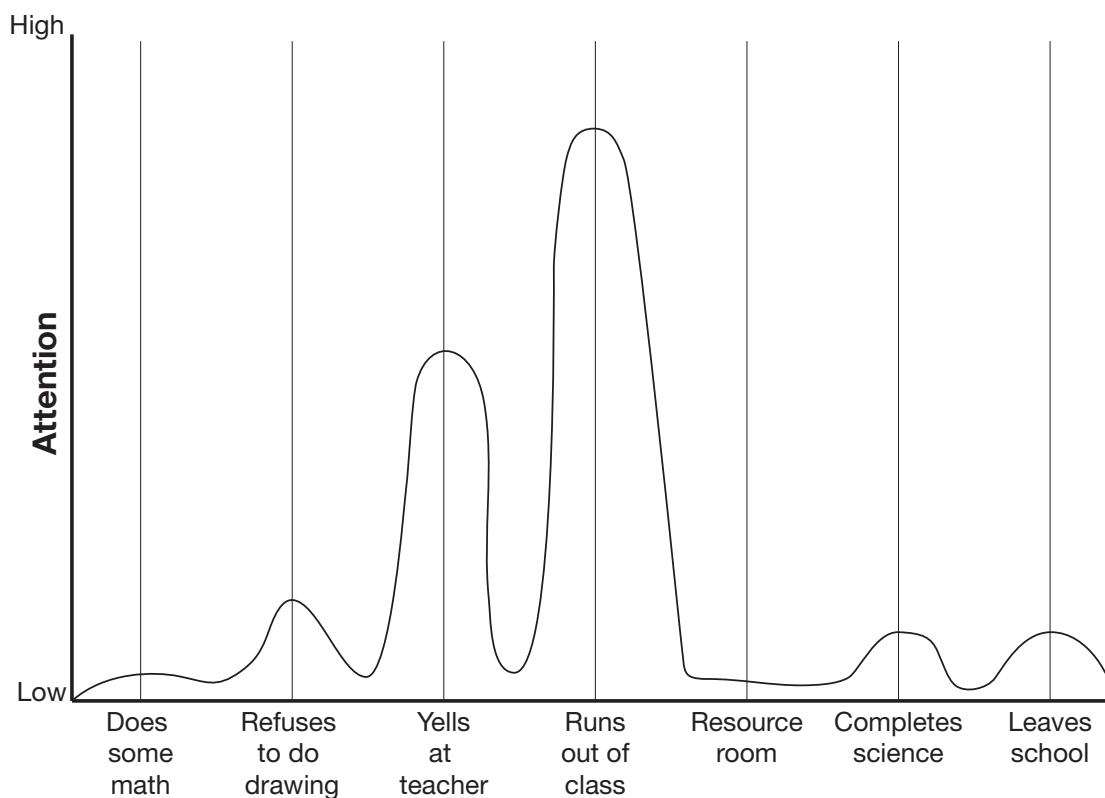
Impairment looks like this:



The Main Principals of Intervention

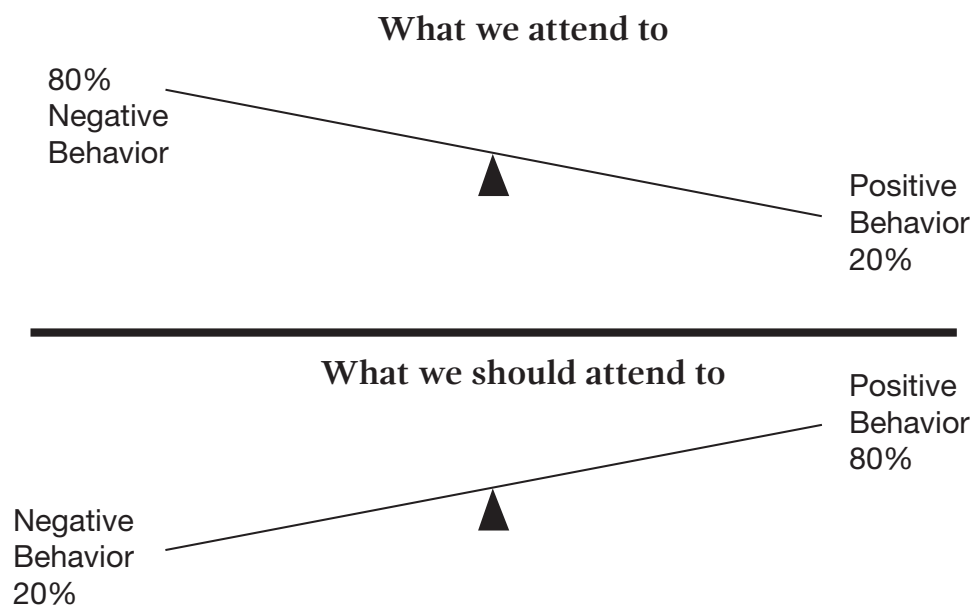
FASD lasts a lifetime so we need

- Long term services
- 10-year plan



Behavior we *attend* to increases - behavior we *ignore* decreases

Use this 80-20 rule



- 80% of attention should focus on positive behaviors
- Increase positive rewards by 50%

**If talking worked,
you would not be reading this**

**If FASD could be fixed by listening,
they would not have problems.**

In most cases:

- If we can't help the visually impaired see better - we accommodate
- If we can't make paralyzed children walk - we accommodate
- We can't repair brain based impairments in FASD, they require accommodations

In FASD, much of the problem behavior presents as storms, waves, or episodes

The Problems

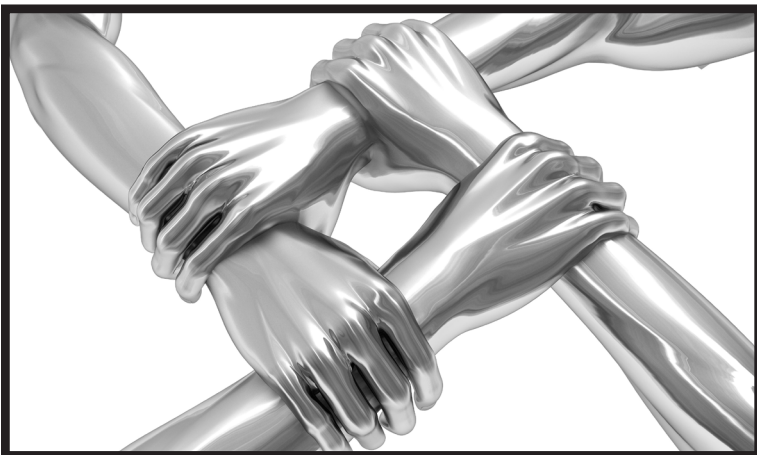
- Escalating behavior gets increased attention
 - Be proactive, not reactive.
- Problem behavior produces lots of talking
- Negative consequences are overused - these often have no history of success
 - What behavior can we ignore?

Goal: Increase attention to positive behavior (80% of our effort)

Steps to success

- Identify building storm
- Use calm down approach
- Find a positive behavior to reward
- Use pictorial behavior guide
- Talk Less

In FASD: YOU don't have to get better to do better!



FASD Across the Lifespan



**Children with FASD can be difficult to parent
(This is also true before, during, and after foster care.)**

High rates of

- ◇ Sleep disorders
- ◇ Eating problems
- ◇ Toilet training difficulties
- ◇ Temper tantrums
- ◇ Developmental disorders-needing therapy
- ◇ School problems
- ◇ Homework problems
- ◇ Increasing severity

In FASD, understanding is often impaired
Pictures often improve understanding

BEDTIME SCHEDULE

	PAJAMAS
	BRUSH TEETH
	GO POTTY
	STORY TIME
	LIGHTS OUT

GETTING UP

	GET UP
	GO POTTY
	GET DRESSED
	BREAKFAST
	GET READY FOR SCHOOL

PICTURES = SAME MESSAGE EVERY TIME

SCHEDULE AND ROUTINE IMPROVE BEHAVIOR AND LEARNING

What makes the most difference in FASD

- Early diagnosis
- Diagnosis driven care
- Prevent the ACEs
- Long-term plan
- Long-term services
- Positive reinforcement
- Accommodations

Rewards, schedules, and attention to positive behavior are keys to success in FASD. Big problems require important rewards. You cannot prioritize many behaviors at the same time.

- Pick 1 or 2 to focus on changing
- See if we can change them
- Try to get 50% improvement
- Pick reward for each behavior
- Rewards may not last
- Keep a list of potential rewards
- If no progress - check the reward

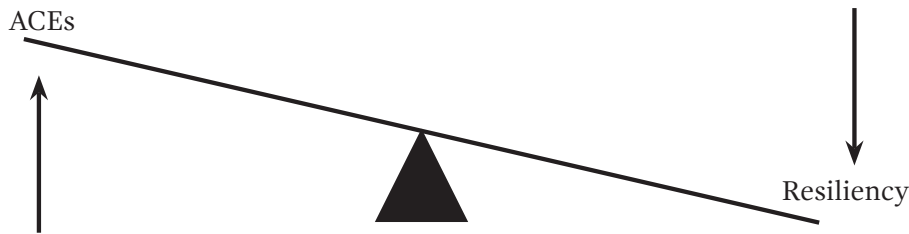
Useful strategy for using rewards

- Rewards are fuel for change. Use the best rewards you have.

Dividing rewards into parts can increase their value in changing behavior



Adverse childhood experiences impact outcomes for a long time.



FASD Management

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

Interventions

- Understand FASD
- Slow pace
- Picture schedules
- Decrease memory burden
- Manage anxiety
- Positive behavior management – less escalation
- Understand effects of multiple impairments
- Future risk reduction - plan ahead
- Respite care for caretakers

After out of home placement

- Picture schedules
 - Bedtime
 - Morning routine
- Pictorial behavior plans
- Parents schedule
- Medication schedules
- Behavior Management
 - Transferring our gains
 - Preventing relapse
 - Respite care
 - Avoiding change
 - What did we learn that can be transferred home?

Caring for Parents and Caretakers

Take some time off

The more difficult the problems, the more time off you need

- Use Respite Care
- Find out what resources are available
- Locate other parents and take time to meet. Talking about your challenges helps.
- What works for you?
- Who helps?
- Build a care team
 - Friends
 - Doctor
 - Psychologist
 - Social worker – great source of services and support

What is your long term plan?

Do you have good assessments of your child's abilities and impairments?

How can you access a support group of similar parents?

Can you join a research project?

Keep copies of all records in a 3-ring binder so they can be reviewed by professionals.

Through adolescence into adult life, it's about a job, the peers, and some help with life's complicated tasks (money management, big decisions, resolving problems, avoiding substance use, and diminishing victimization).

Adult life

- Increased mortality risk
- Problems with independent living
- Problem peer group
- Victimization (exploitation)
- Contact with law enforcement
- Mental health
- Being employment (very important)
- Appreciation of impairments
- Doing well often, means we have a good plan.

Additional information we have available

- FASD - A Guide for Pediatricians and Mental Health Providers
- FASD - Diagnosis Informed Care
- Caring for People with Fetal Alcohol Spectrum Disorder
- Changing Behavior

