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GENERALIST TRAINING

Learning Objectives

- *Discuss* Ohio's Model of System's Integration
- *Learn* about FASD including terminology; facts; and effects on the body and brain
- *Understand* primary and secondary disabilities resulting from FASD
- *Learn* about strategies and recommendations for problems associated with FASD

History & Timeline

- **2003**

Mrs. Hope Taft, First Lady of Ohio, in partnership with members of the Ohio Family and Children First (OFCF) Cabinet Council, formed the FASD Steering Committee expanding to include Ohio Department of Aging, Ohio Department of Rehabilitation and Correction, institutes of higher education, providers and parents.



September 9, 2004

- Town Hall Meeting to increase awareness of the challenges faced by Ohio's children and families.



Statewide Steering Committee

- 9 State Agencies, 3 Universities, Parents & Providers



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Ohio's FASD
Initiative



August 2005-Strategic Plan

Mission: to establish efficiency in state systems resource allocation, coordination of services and augmentation of **available** resources to address FASD.

The Plan

- Increase awareness regarding the risks associated with alcohol use during pregnancy;
- Provide FASD-specific education and training for agencies, organizations and professionals who provide services to children and families with or at risk of FASD;
- Increase the availability of services for those already affected by FASD and for parents and other caregivers;
- Adopt appropriate FASD screening tools and protocols and increase access to screening; and
- Create and implement a data tracking system to track FASD risk factors, prevalence, and incidence in Ohio, and measure progress toward reaching the other four goals.

August 2005

- Ohio's 1st FASD Conference



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February 10, 2006

- Mrs. Hope Taft, First Lady of Ohio, announced Ohio's FASD Initiative at a press conference. Additional speakers included: Dr. Nick Baird, Ohio Department of Health; Carolyn Givens, Ohio Department of Alcohol and Drug Addiction Services; Hap Hinkle, Ohio Department of Mental Retardation and Developmental Disabilities; and Phil Petrosky, a parent.





February 17, 2006

- Representatives from the state agency partners presented the first draft of their agency's strategic plan for integrating FASD into their agency's service delivery systems after participating in a modified *Partnerships for Success (PfS) Planning Model*.

FASD Building State Systems

San Francisco, CA May 2006

FASD

Ohio's FASD Initiative



April 2006

- The **universal social marketing campaign** kicks off with public service announcements airing on WBNS 10TV, Ohio News Network, Mix 97.1FM and Ohio News Network Radio. Advertisements also will run in Columbus Parent and its sister publications throughout the state.
- Web site: www.notasingledrop.org.



August 15, 2006

- Ohio's FASD 2nd Annual Conference at Greater Columbus Convention Center
- Featured Speakers
 - Ann Streissguth, PhD
 - Edward P. Riley, PhD
 - Diane Malbin, MSW



FASD in Ohio

- It has been estimated, the cost of FASD to Ohio taxpayers for providing special services for education, juvenile justice, medical and mental health services, foster care and unemployment is nearly \$300 million every year. Raising a child with FASD is 100 times more expensive than preventing FASD in a child.
- Due to a combination of factors, most go undiagnosed. In fact, of the estimated 114,000 Ohioans living with FASD, only 300 have been clinically diagnosed.

– *(Source: Ohio Department of Health)*



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**Simple, but a hard
lesson to
learn...Mom Drinks,
Baby Drinks!**



Why Know About FASD?

100%



Did You Know?

At least 5,000 infants are born each year in the U.S. with full FASyndrome, or approximately one out of every 750 live births.

Source:
American Medical Association

Preventable

Alcohol and Societal Attitudes

- Alcohol is often a traditional part of culture.
- Alcohol is used to celebrate, relax, and socialize.
- Stigma attached to receiving treatment.
- Strong legislative lobby.
- Availability and Accessibility.
 - Change of societal norms past 30 years
- Not illegal for adults.

Exercise 1



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How does drinking alcohol during pregnancy affect a developing fetus?



Alcohol is a Teratogen

- **A teratogen is a substance that causes developmental malformations.**
 - “Study of Monsters”
- **Alcohol is a depressant that stops, stunts, or retards the growth of cells.**
 - “A shotgun blast”
- *Alcohol has a direct toxic effect on cells and can produce cell death, thereby causing certain areas of the brain to actually contain fewer cells than normal.*

(Streissguth, 1997, p. 58)



Alcohol Effects

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

—*IOM Report to Congress, 1996*



Terminology

FASD	FAS	FAE	ARND
Fetal Alcohol Spectrum Disorders is an umbrella term used to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.	Fetal Alcohol Syndrome is a specific diagnosis with specific criteria.	Outdated term used to describe individuals who had problems associated with prenatal alcohol exposure, but did not have enough of the outward signs to be eligible for the medical diagnosis of FAS.	Alcohol Related Neurodevelopmental Disorder has been widely used to describe the specific damage that prenatal alcohol exposure can have on the central nervous system.

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What is FAS?

- Medical diagnosis for a permanent condition caused by prenatal alcohol exposure
 - Growth deficiency
 - Head, height, weight
 - Special pattern facial features
 - Signs of central nervous system damage

*Term first identified in international medical literature in 1973 (Jones, K., Smith, D, Recognition of the fetal alcohol syndrome in early infancy. Lancet, 2, 999-1001.)

Terminology

Fetal Alcohol Syndrome

- Term first identified in literature- 1973 by Drs. Smith and Jones at the University of Washington
- One of the diagnoses used to describe birth defects caused by alcohol use while pregnant
- A medical diagnosis (760.71) in the International Classification of Diseases (ICD)

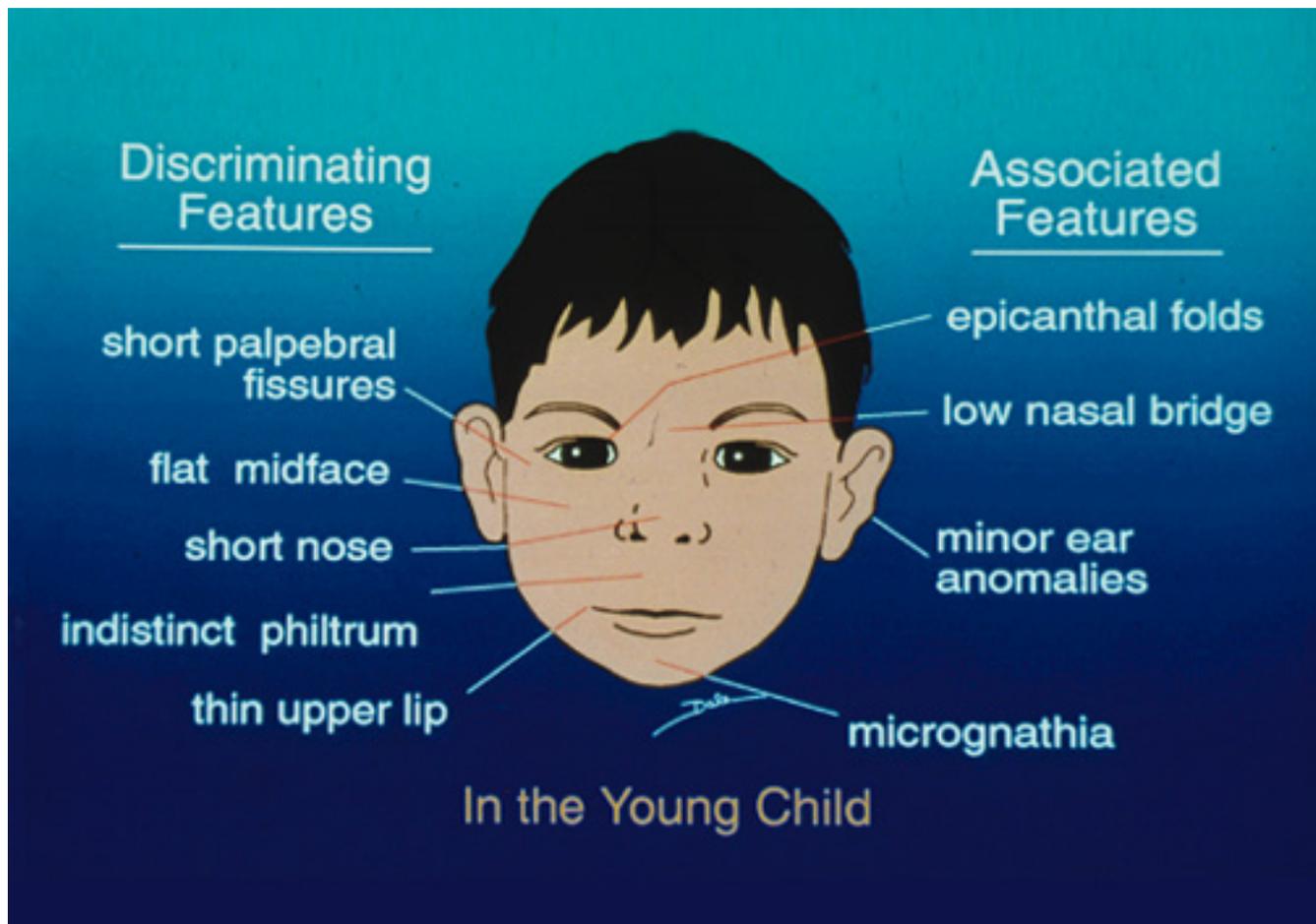
Facial Features

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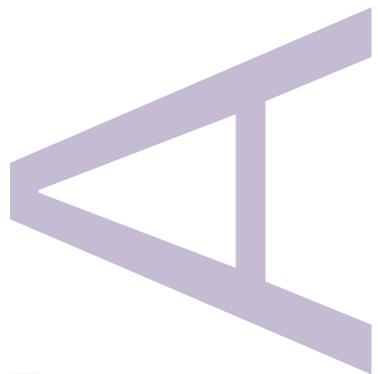
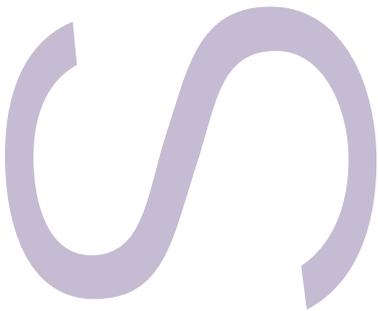
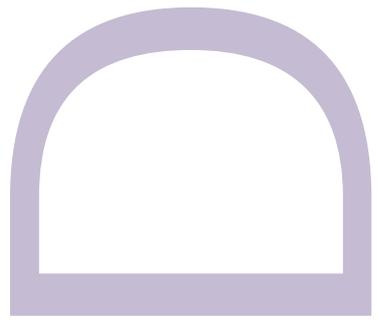
Faces & Stages



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*“It is not the face
that needs the
services.”*

(Streissguth & O’Malley,
2000, p. 178)



False Beliefs About FAS

- FAS is a childhood disorder, people outgrow it.
- Behavior problems associated with FAS and any alcohol effect are the result of poor parenting.
- Mothers of children with FASD are young, careless and are not concerned about their substance abuse and its effects on their developing baby. *DATA on Prevalence*

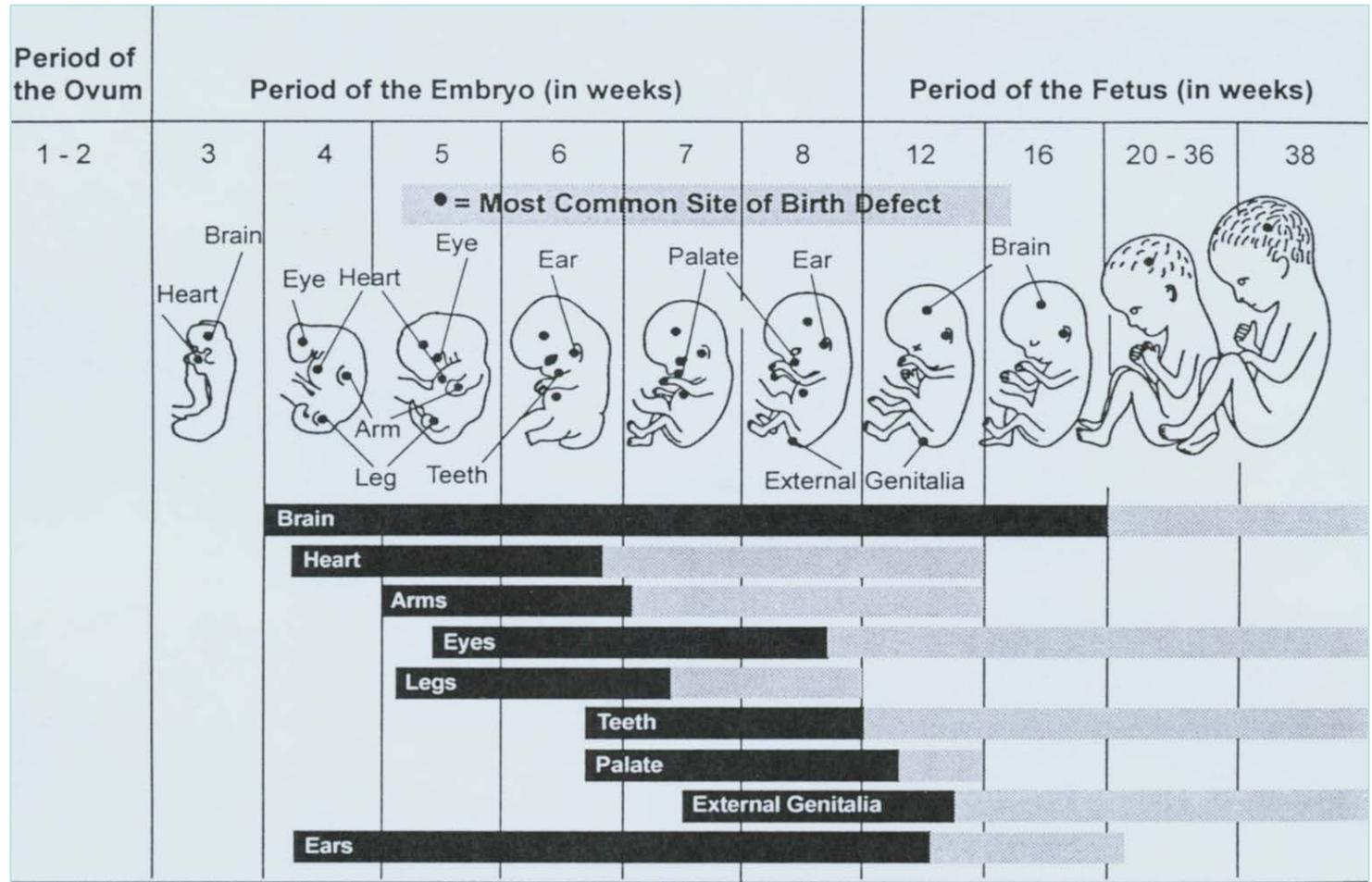
False Beliefs About FASD

- **Nothing works for people with FASD.**
- **FASD can be passed on genetically.**
- **Children are negatively affected by alcohol only if a mother drinks early in her pregnancy.**
- **FASD is specific to certain races or communities.**
- Portions of this section cited from *FASD 101-201 Developing Successful interventions and Supports*, January 2005. The University of Alaska Anchorage, Family and Youth Services Training Academy in partnership with the State of Alaska, Department of Health and Social Services. Office of FAS.

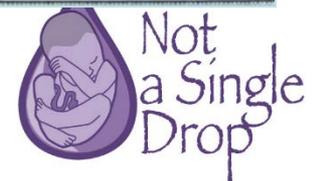
Factors That Impact a Fetus

- When and how much a mother drinks while pregnant
- Mother's genetic make-up
- Baby's genetic make-up
- Mother's nutritional level

Different organs are more vulnerable during different phases of pregnancy



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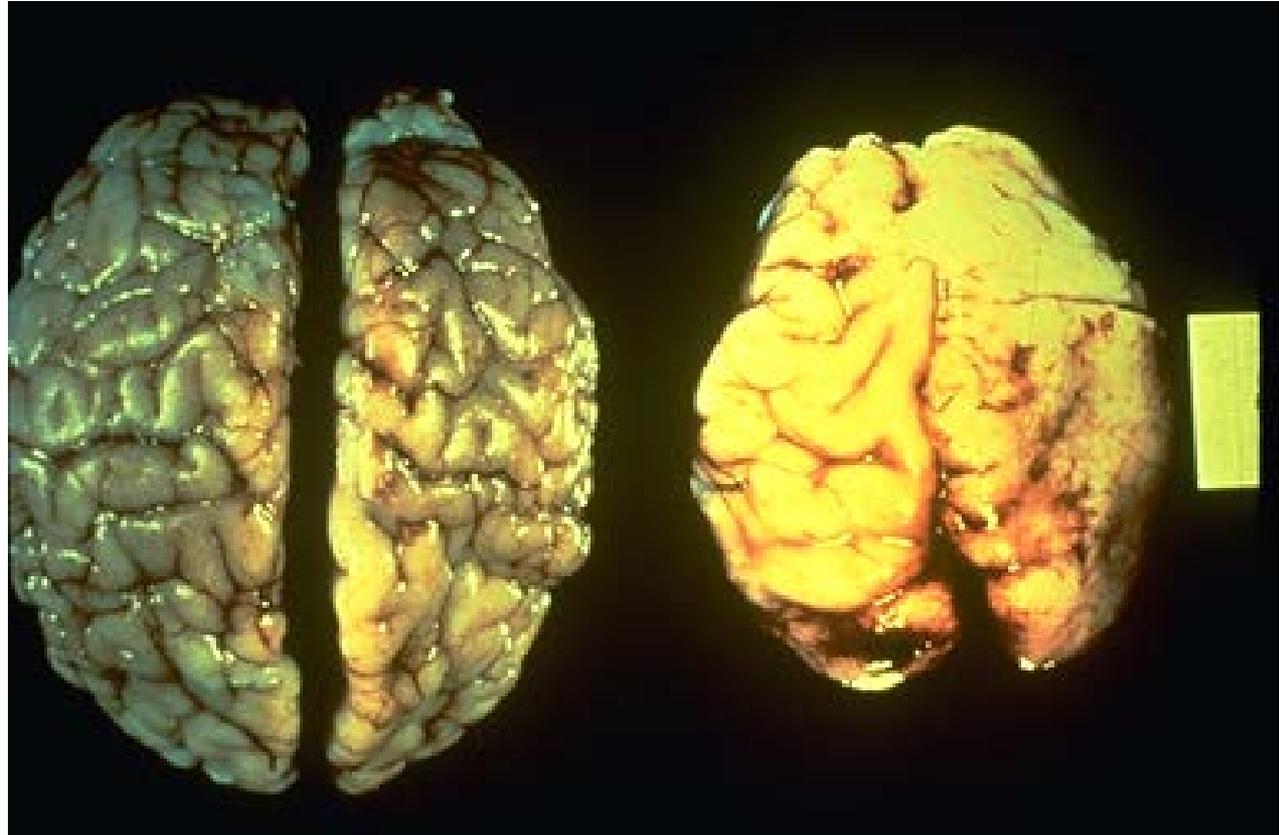


Alcohol and the Brain

“Prenatal alcohol exposure causes brain damage. While this brain damage can’t be undone, people can grow, improve, and be successful.”

Dan Dubovsky, 2004

Range of Possible Damage



© Miller-Fenwick, Inc. (1994).



What We Know

1. **There is no proven safe amount of alcohol use during pregnancy.**
2. **Alcohol can damage the fetus at all stages.**
3. **People with FASD are everywhere and in all systems of care (diagnosed or not).**
4. **FASD can occur in all communities.**
5. **People with the greatest difficulty are often the least recognizable.**

FASD Disabilities: *“The Fall Out- A Cost to Communities”*

- Primary Disabilities
- Secondary Disabilities

Primary Disabilities

- **Processing deficits:**
 - Managing incoming sensory information
 - Sleeping and eating
- **Cognition and learning:**
 - Visual spatial skills, learning, memory
 - Speed of central processing of information
 - Executive functioning
- **Speech and language**

Processing Deficits (Examples)

- Abstract reasoning
- Generalizing information and rules
- Memory deficits
- Time management
- Judgment skills
- Socialization and independence

Abstract Reasoning (Examples)

- Missing meaning, humor, and insight in conversations
- Thinking about the cause and effect of consequences
- Predicting an outcome

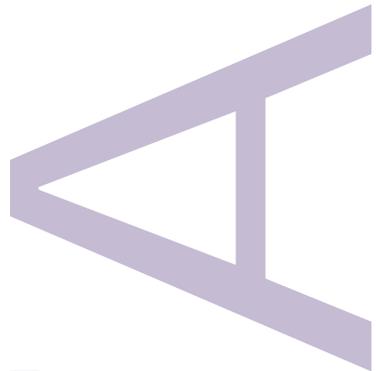
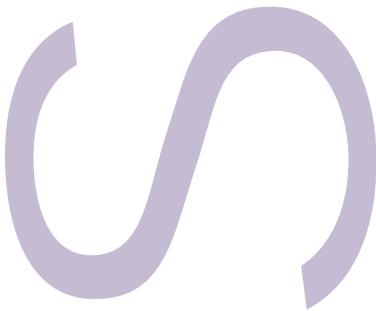
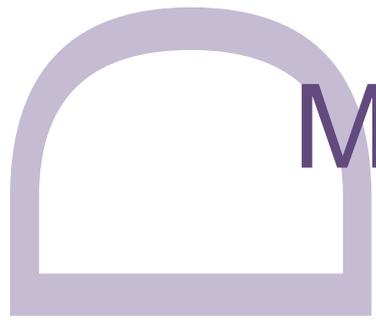


Generalizing Information and Rules (Examples)

- Difficulty forming links
 - *Example: TV Connections*
- Inferential thinking

Memory Deficits

- Poor short term auditory memory
- Slow auditory pace
- Difficulty getting information out of long term memory



Judgment Skills

- Act before they think
 - *Cause & Effect*
- May seem noncompliant and willful when in fact they are simply unable

Socialization and Independence

- Not be able to rely on their own skills
- May have lifelong needs for support and supervision



Ages and Stages

- Socially and developmentally younger than their chronological age.
- People with FAS often can talk the talk but can't walk the walk.
 - *Example: “Don’t talk to strangers”.*

Secondary Disabilities

- Disabilities that a person is not born with and are preventable with the right support, interventions, and accommodations.



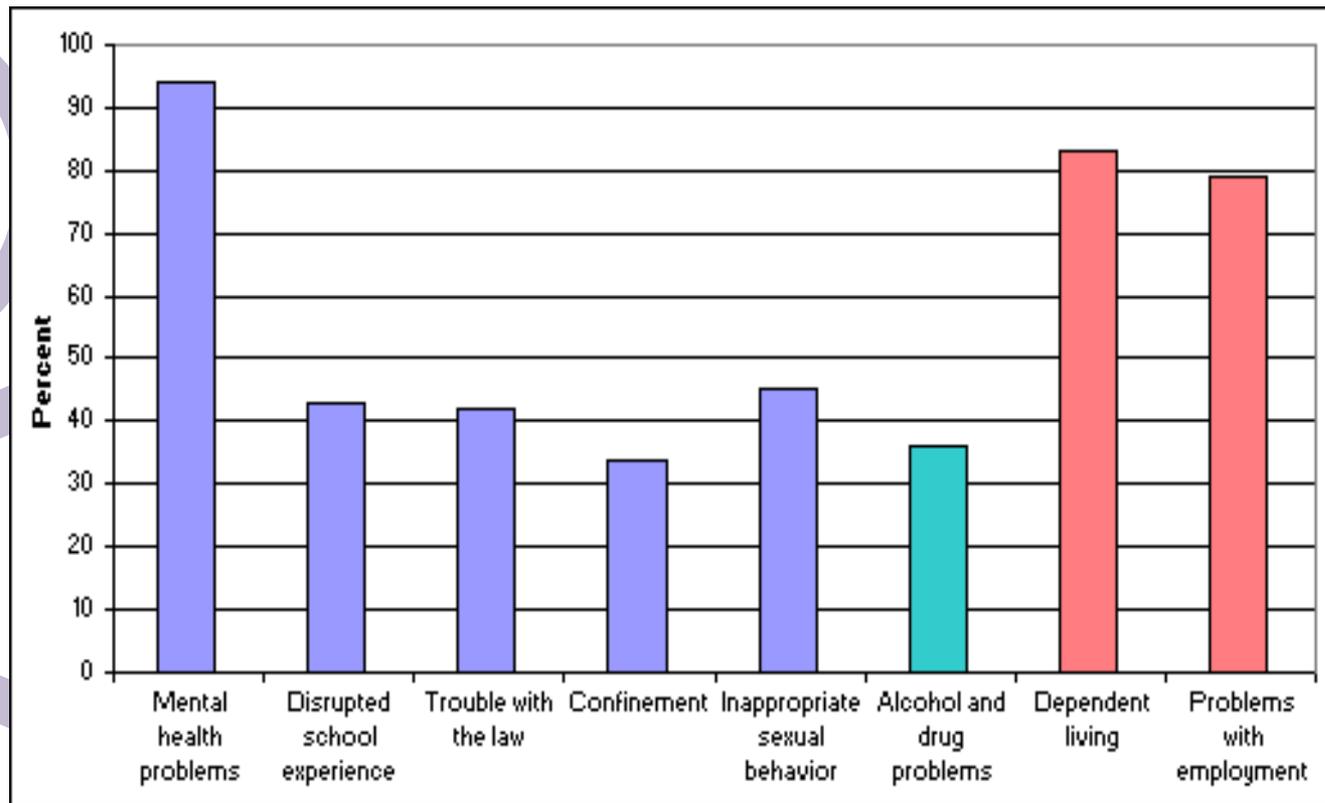
Secondary Disabilities

- Mental health issues – 90%
- Disrupted school experience – 60%
- Trouble with the law – 60%
- Confinement – 50%
- Inappropriate sexual behavior – 49%
- Alcohol and drug problems – 35%

– *Streissguth, Understanding the Occurrence of Secondary Disabilities August 1996*

Secondary Disabilities of Persons With an FASD

Percent of Persons With FAS or FAE Who Had Secondary Disabilities



◆ = Age 6+

◆ = Age 12+

◆ = Age 21+



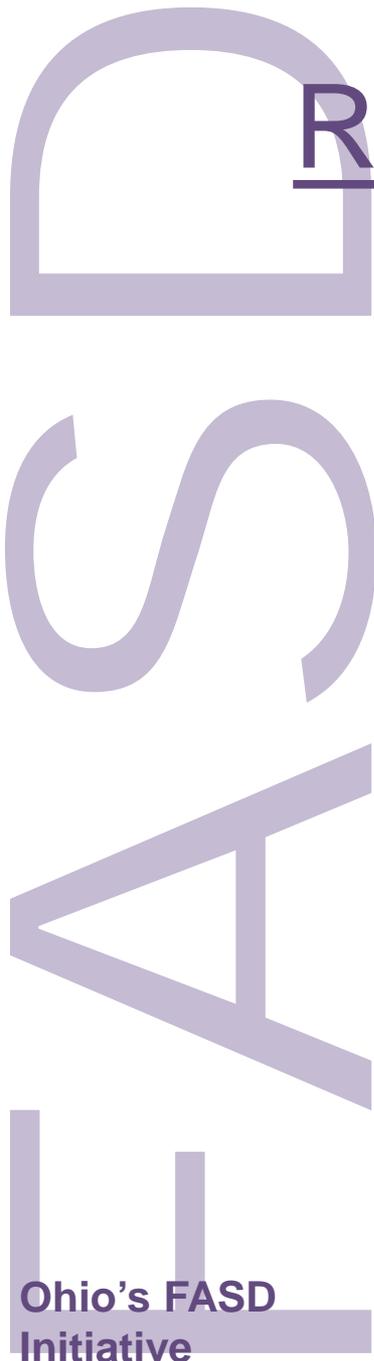
Infancy & Early Childhood: Ages 0-5

Problems and Concerns

- Sleep disturbances; poor sleep/wake cycle
- Poor sucking responses
- Failure to thrive
- Delays in walking and talking
- Delayed toilet training
- Difficulty following directions
- Temper tantrums and disobedience
- Distractibility and hyperactivity

Recommendations

- Early identification
- Intervention with birth and/or foster/adoptive parents
- Education of parents regarding physical and psychosocial needs of an infant or child affected by FASD
- Careful monitoring of physical development and health
- Safe, stable and structured home
- Assignment of a case manager for coordination of services and support to parents
- Placement of child in preschool
- Respite care for caretakers



Latency Period: Ages 6-11

Problems and Concerns

- Easily influenced and difficulty predicting and/or understanding consequences
- Give an appearance of capability without actual abilities
- Difficulty separating fact from fantasy
- Temper tantrums, lying, stealing, disobedience and defiance of authority
- Delayed physical and cognitive development
- Poor comprehension of social rules and expectations

Recommendations

- Safe, stable and structured home or residential placement
- Careful and continued monitoring of health issues and existing problems
- Appropriate educational and daily living skills placement
- Help caretakers establish realistic expectations and goals
- Caretakers support group
- Psychological, educational and adaptive evaluations on a regular basis
- Use of clear, concrete and immediate consequences for behavior
- Respite care for caretakers
- Case manager role expands to include liaison between parents, school, health care providers and social service agents.

Adolescence: Ages 12-17

Problems and Concerns

- Lying, stealing and passivity in responding to requests
- Faulty logic
- Egocentric; has difficulty comprehending and/or responding appropriately to other people's feelings, needs and desires
- Low motivation
- Low Self Esteem
- Academic ceiling which is usually around grade 4 for reading and grade 3 for Spelling and Math
- Depression
- Pregnancy or fathering a child
- Loss of residential placement

Recommendations

- Education of caretakers and patients regarding sexual development, birth control options and protection from sexually transmitted diseases
- Planning and implementation of adult residential and vocational training and placement
- Appropriate mental health interventions as needed
- Respite care for caretakers
- Caretakers support group
- Safe, stable and structured home or residential placement
- Shifting of focus from academic skills to daily living and vocational skills
- Careful monitoring of social activities and structuring of leisure time
- Working towards increased independence by teaching to make healthy choices (taught at the child's level)

Adulthood: Ages 18+

Problems and Concerns

- Residential placement
- Economic support and protection
- Job training and placement
- Depression and suicidal ideation
- Pregnancy or fathering of a child
- Social and sexual exploitation, or in appropriate behavior
- Increased expectations of the person affected by FASD by other people
- Increased dissatisfaction towards the person affected by FASD by others
- Withdrawal and isolation
- Unpredictable behavior

Recommendations

- Guardianship for funds
- Specialized residential and/or subsidized living
- Specialized vocational training and job placements
- Medical coupons
- Acceptance of the person's "world"
- Acknowledgment of the person's skills and limitations
- Advocates to ensure the above occurs

Common Misinterpretations

Behavior	Misreading	Correct Interpretation
<i>Non-compliance</i>	✗ Willful misconduct ✗ Stubborn ✗ Attention Seeking	✓ Difficulty translating verbal directions ✓ Doesn't understand
<i>Makes same mistakes</i>	✗ Manipulative ✗ Willful	✓ Cannot link cause and effect
<i>Often late</i>	✗ Lazy ✗ Poor parenting	✓ Time ✓ Organization
<i>Out of seat behavior</i>	✗ Willful Pest	✓ Sensory integration

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FASD: So what do we do?

PREVENTION

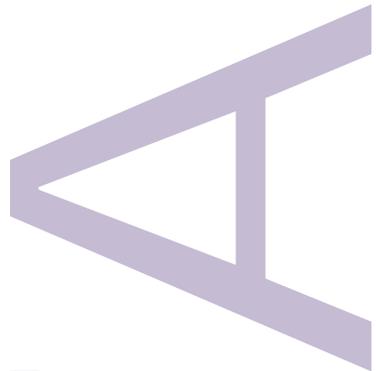
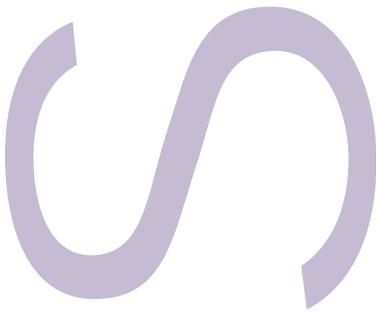
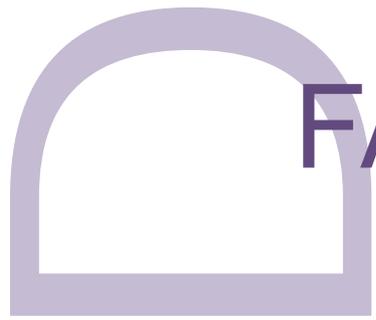
Evidenced Based Strategies

Screening & Diagnosis

Physician selection of
protocols/education

Appropriate Interventions

Utilization & Integration of existing
effort



Try Changing How You Do Things

- **Give people with FASD longer to answer, develop, and achieve**
- **Reteach skills in every environment they will be used – don't assume.**
- **Think differently – use a bouncing chair.**
- **Move from what's wrong with them to what is going on for them.**

Keys to Working With People With FASD

- **Modify the environment.**
- **Modify expectations.**
- **Think younger or think “stage not age.”**
- **Think perpetual innocence.**
- **Make the world make sense.**
- **Rethink, reteach, respect.**

Keys to Working With People With FASD

- Be concrete and specific.
- Keep things simple.
- Repeat directions, rules, etc.
- Have a routine and be consistent.
- Use structure.

Final Thoughts

- See People Not Problems
- Remember that expectations have to be realistic and appropriate to each person with FASD and not a generalization about FASD.

For More Information

- www.notasingledrop.org
- 800-788-7254, *option #2*
- *Kathy Paxton*
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