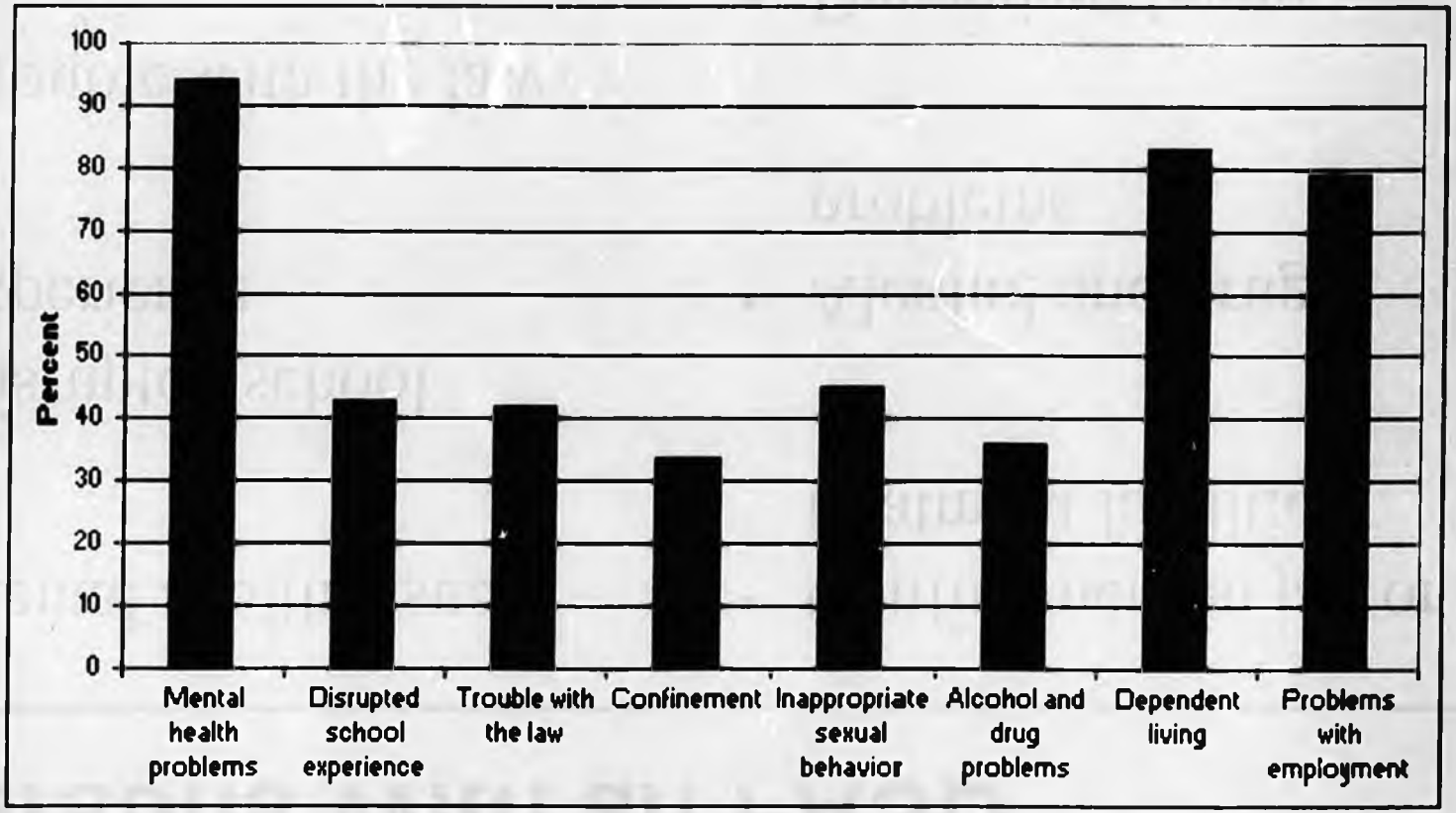
Factors Associated With Reduced Secondary Disabilities

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life

Streissguth, et al. (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+

Secondary Disabilities of Persons With an FASD

- Mental health issues
- Disrupted school experience
- Trouble with the law
- Inappropriate sexual behavior
- Confinement in jail or treatment facilities
- Alcohol and drug problems
- Dependent living
- Employment problems

Streissguth, et al. (1996)

Typical Difficulties for Persons With an FASD

Multiple Issues

- Cannot entertain themselves
- Have trouble changing tasks
- Do not accurately pick up social cues

Typical Difficulties for Persons With an FASD

Self-Esteem and Personal Issues

- Function unevenly in school, work, and development
- Experience multiple losses
- Are seen as lazy, uncooperative, and unmotivated
- Have hygiene problems

Typical Difficulties for Persons With an FASD

Executive Function Deficits

- Go with strangers
- Repeatedly break the rules

- Do not learn from mistakes or natural consequences
- Frequently do not respond to point, level, or sticker systems
- Have trouble with time and money

- Give in to peer pressure

Typical Difficulties for Persons With an FASD

Information Processing Problems

- Say they understand when they do not
- Have verbal expressive skills that often exceed their level of understanding
- Misinterpret others' words, actions, or body movements
- Have trouble following multiple directions

Typical Difficulties for Persons With an FASD

Information Processing Problems

- Do not complete tasks or chores and may appear to be oppositional
- Have trouble determining what to do in a given situation

- Do not ask questions because they want to fit in

Typical Difficulties for Persons With an FASD

Memory Problems

- Multiplication
- Time sequencing

Typical Difficulties for Persons With an FASD

Sensory Integration Issues

- Are overly sensitive to sensory input
  - Upset by bright lights or loud noises
  - Annoyed by tags in shirts or seams in socks
  - Bothered by certain textures of food
- Have problems sensing where their body is in space (i.e., clumsy)

Primary Disabilities of Persons With an FASD

- Lower IQ

Permission to use photo on file.

- Impaired ability in reading, spelling, and arithmetic

- Lower level of adaptive functioning; more significantly impaired than IQ

Streissguth, et al. (1996)

Overall Difficulties for Persons With an FASD

- Taking in information
- Storing information

- Recalling information when necessary

- Using information appropriately in a specific situation

Symptoms and Difficulties of FASD

This section includes:

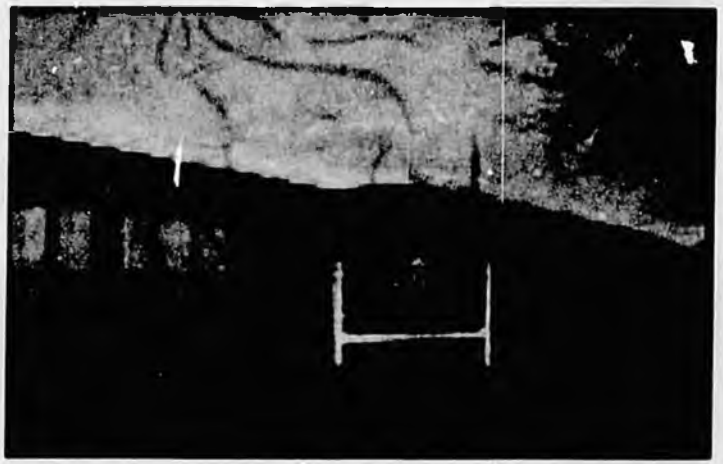
- Overall Difficulties for Persons With an FASD
- Primary Disabilities of Persons With an FASD
- Typical Difficulties for Persons With an FASD
- Secondary Disabilities of Persons With an FASD
- Factors Associated With Reduced Secondary Disabilities

Raise Awareness in the Community

- Post FASD information in doctors' offices, treatment centers, and community centers.
- Promote FASD Awareness Day (September 9). Visit www.fasday.com for information.
- Focus attention on FASD. You can help the entire community.

Raise Awareness in Schools

- Ask the school to put up posters about drinking and pregnancy.



- Include information about FASD in health, science, and physical education classes.

- Hold an assembly to talk about the effects of alcohol on a person and on a baby.

Who Needs To Know

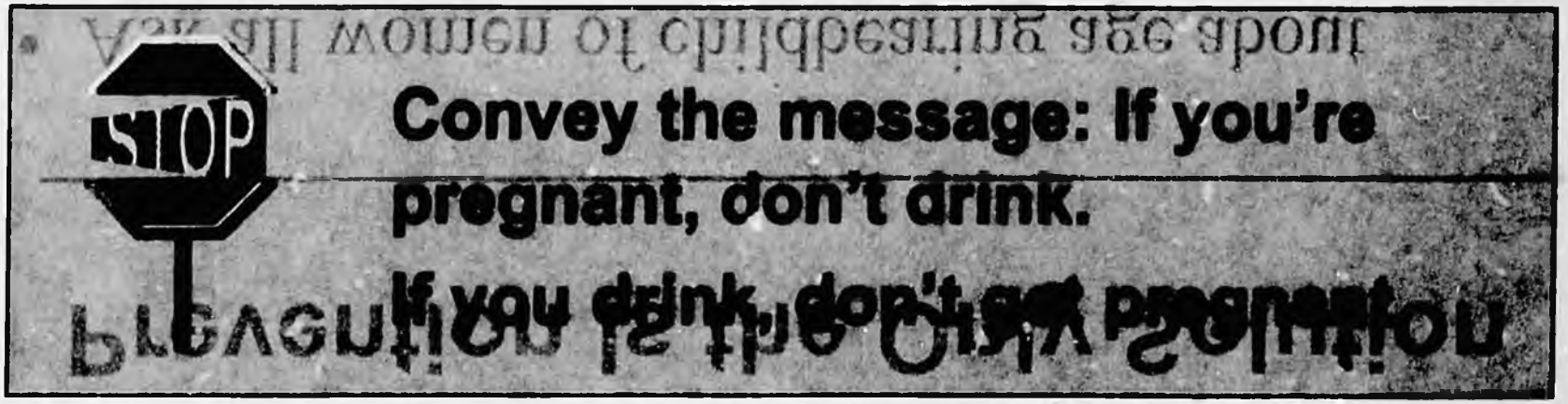
- Women of childbearing age?
- Women who have a history of alcohol or other drug use?
- Women who are at risk?
- Teenagers?
- Men?
- EVERYONE!

DO NOT TAKE THE RISK

DO NOT TAKE THE DRINK

Talk About Alcohol Use

- Talk about the effects of alcohol on an individual and on a fetus:
  - Begin at an early age, such as elementary school.
  - Indicate that stopping drinking at any time during pregnancy will help the fetus.



Prevention Is the Only Solution

- Ask all women of childbearing age about alcohol use:
  - Ask routinely at every medical appointment.
  - Ask at appointments in various systems.
  - Ask in a nonjudgmental manner.
  - Use effective screening tools.
  - Ask about possible prenatal exposure.

Photo courtesy of Microsoft.

Prevention and Risk Reduction

This section includes:

- Prevention Is the Only Solution
- Talk About Alcohol Use
- Who Needs To Know
- Raise Awareness in Schools
- Raise Awareness in the Community

Number of People With an FASD

- No one knows for certain how many individuals are born each year with an FASD.

- No one knows how many individuals are living with an FASD.

Photo property of SAMHSA.

FAS and the Brain

A

These two images are of the brain of a 9-year-old girl with FAS. She has agenesis of the corpus callosum, and the large dark area in the back of her brain above the cerebellum is essentially empty space.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

FAS and the Brain

A. Magnetic resonance imaging showing the side view of a 14-year-old control subject with a normal corpus callosum; **B.** 12-year-old with FAS and a thin corpus callosum; **C.** 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

FAS and the Brain

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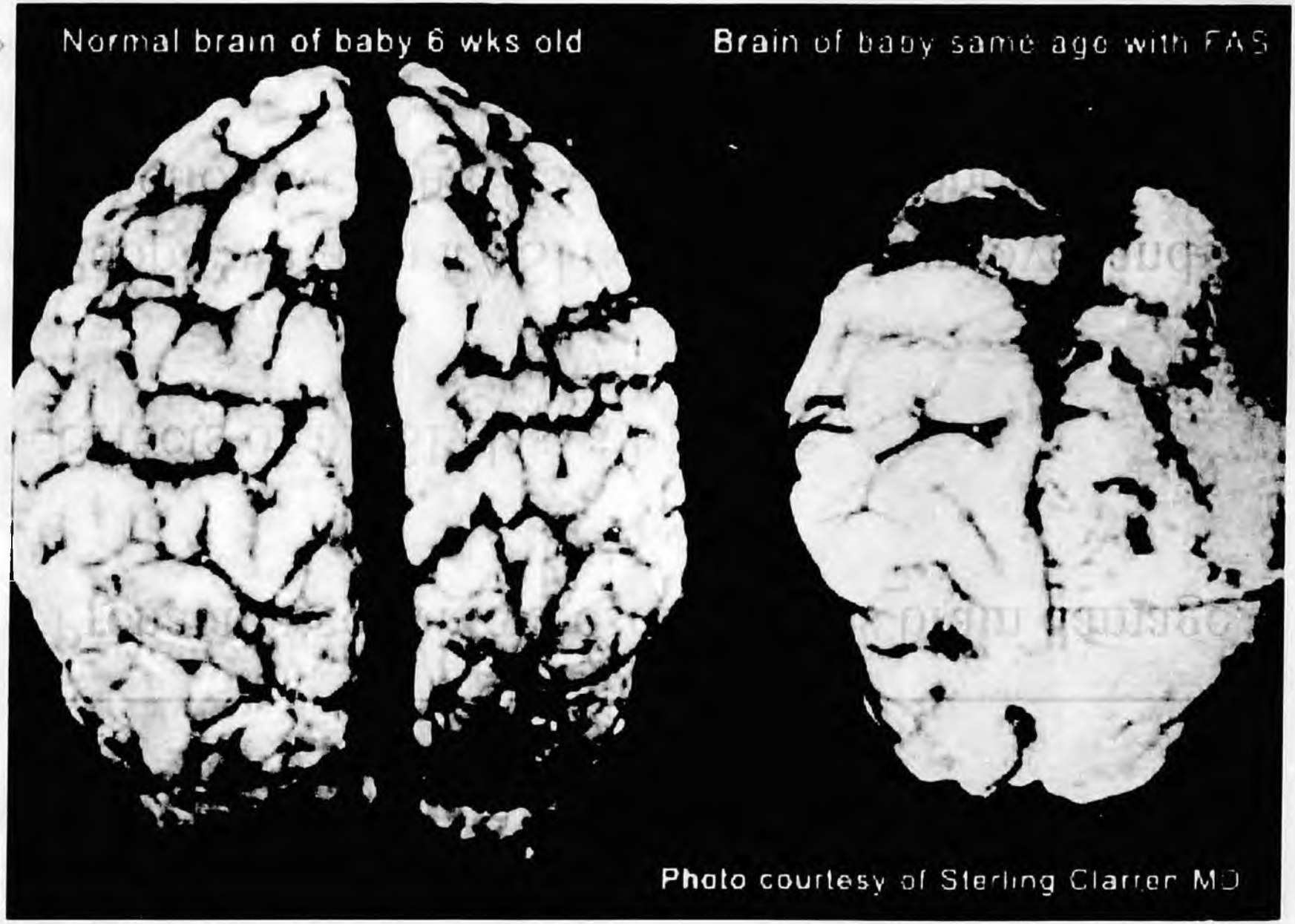


FASD and the Brain

- Prenatal alcohol exposure causes brain damage.
- Effects of FASD last a lifetime.
- People with an FASD can grow, improve, and function well in life with proper support.

Alcohol and Women

- If a woman is pregnant, it does not matter what form the alcohol comes in.
  - Wine spritzers, alcohol pops
  - Beer
  - Wine coolers
  - Light beer, nonalcoholic beer

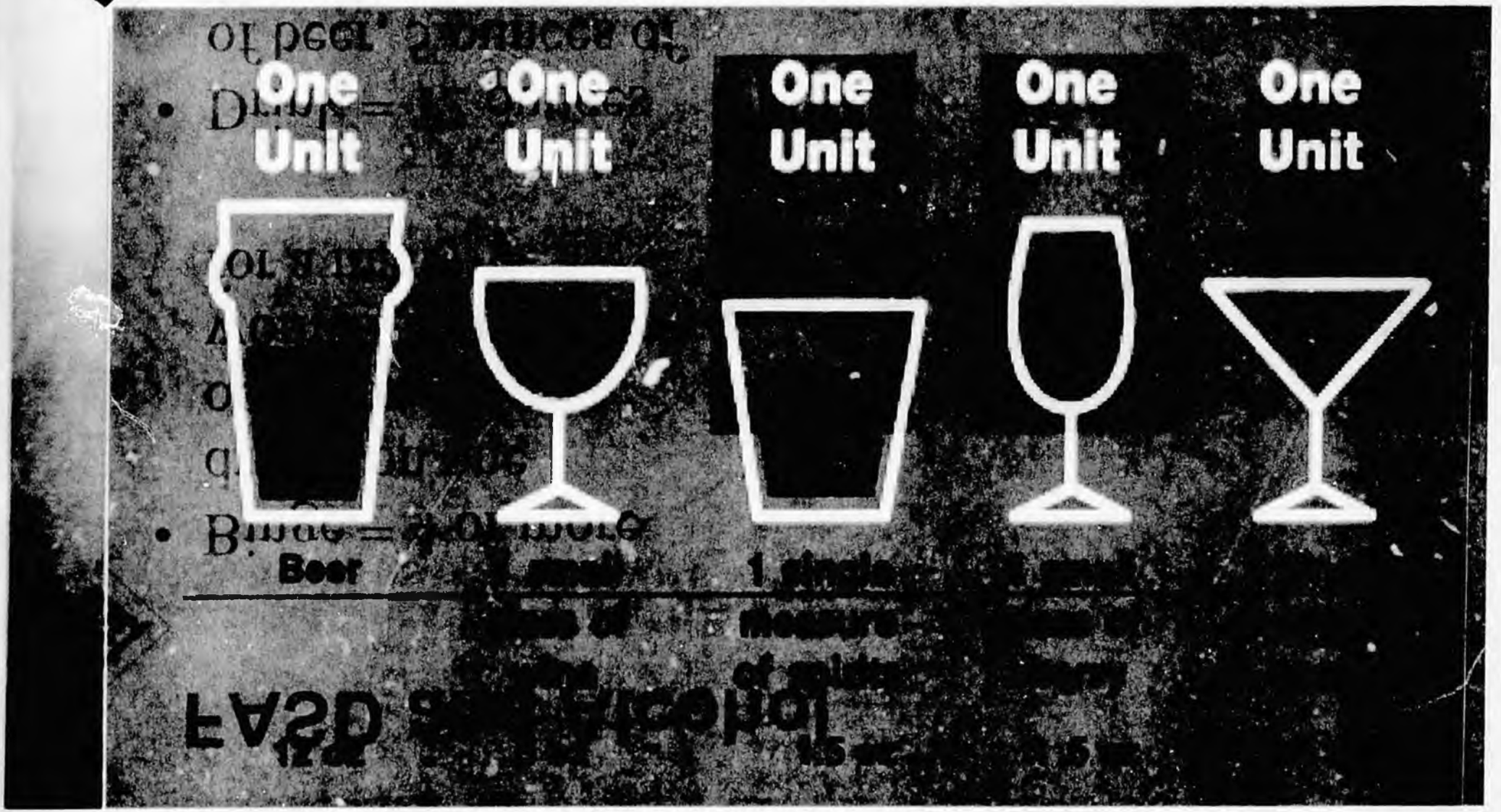
Size Matters

12 oz.

VS.

16 oz.

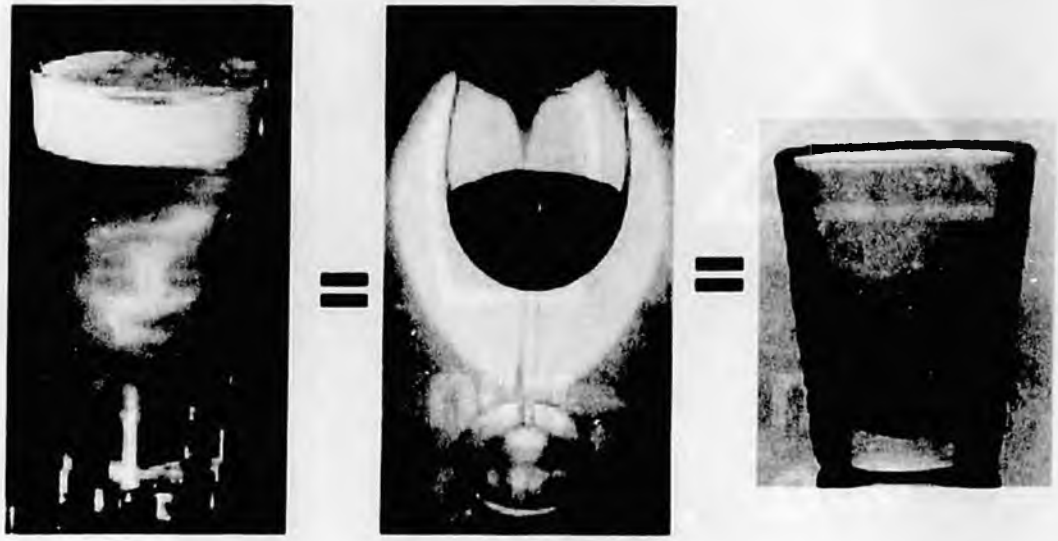
Size Matters



FASD and Alcohol

- Binge = 4 or more drinks on one occasion for a women, 5 or more for a man

- Drink = 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of hard liquor



FASD and Alcohol

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.
- There is no proven safe amount of alcohol use during pregnancy.



Cause of FASD

- The sole cause of FASD is women drinking alcoholic beverages during pregnancy.

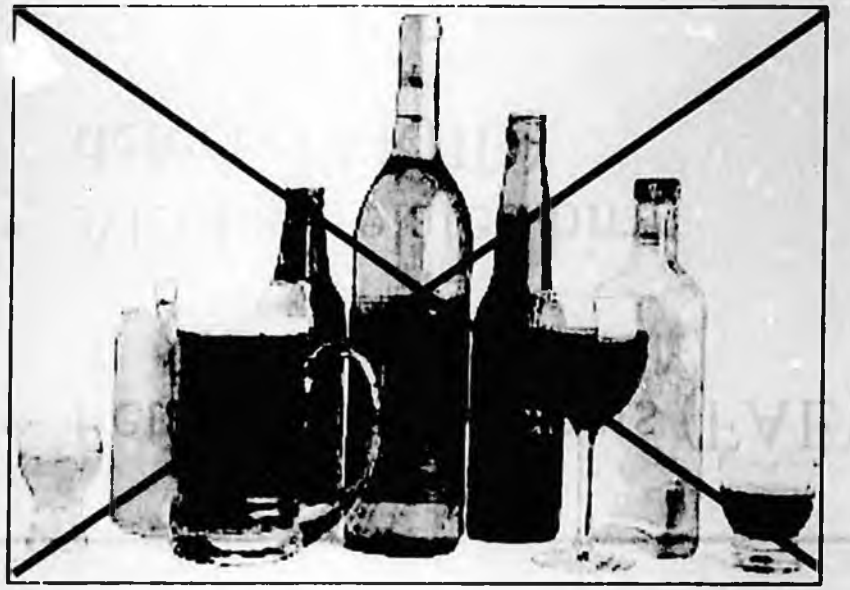
- Alcohol is a teratogen.

"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

FASD Facts

- 100 percent preventable
- Leading known cause of preventable mental retardation
- Not caused on purpose
- Can occur anywhere and anytime pregnant women drink
- Not caused by biologic father's alcohol use
- Not a new disorder



Terminology

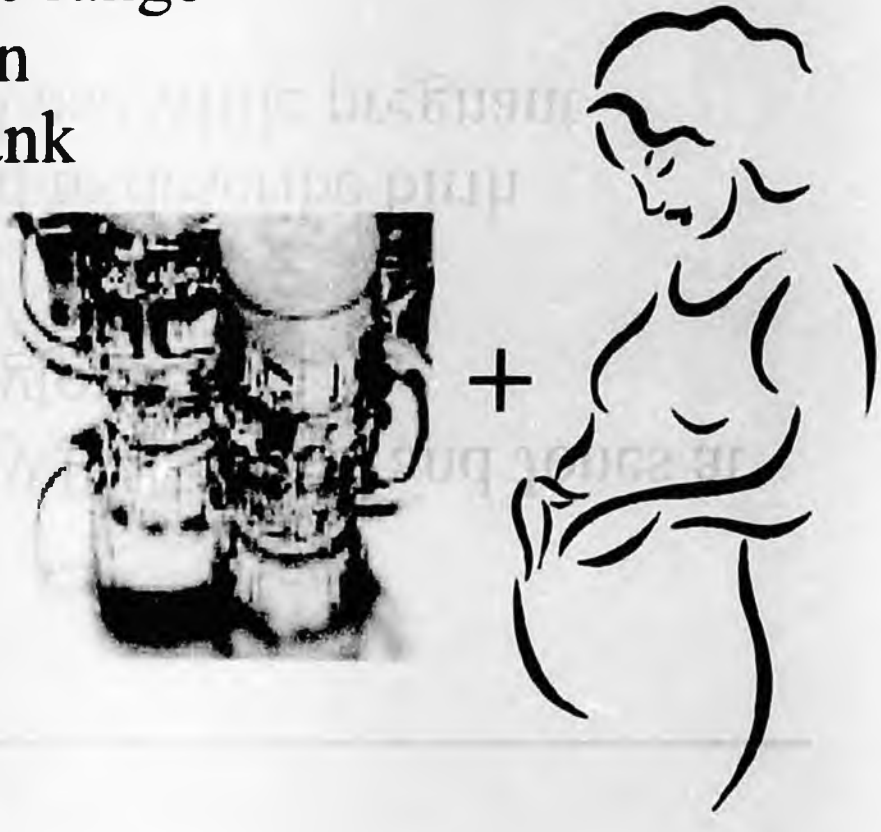
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)

Terminology

- Fetal alcohol syndrome
  - Term first used in 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)

Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy



- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications

- Not a diagnosis

Understanding Fetal Alcohol Spectrum Disorders

This section includes:

- Fetal Alcohol Spectrum Disorders (FASD)
- Terminology
- FASD Facts
- Cause of FASD
- FASD and Alcohol
- Alcohol and Women
- FASD and the Brain
- Number of People With an FASD

FETAL ALCOHOL SPECTRUM DISORDERS

The Basics

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov

Attachment A

Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE),
Final Report, August 1996
Center for Disease Control and Prevention and the University of Washington
And
Secondary Disabilities
www.hss.state.ak.us/fas/info/secondaryDisabilities.htm
and
Fetal Alcohol Spectrum Disorders, Center for Disease Control and Prevention,
www.cdc.gov/ncbddd/fas/protective.htm

Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

Final Report
August 1996

Centers for Disease Control and Prevention
Grant No. R04/CCR008515

September 30, 1992—September 29, 1996

University of Washington School of Medicine
Department of Psychiatry and Behavioral Sciences

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Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

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Final Report

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Table of Contents

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1 Executive Summary

The purpose of this research project was:

- To examine the types and magnitude of secondary disabilities that are associated with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), and
- To assess the risk and protective factors that might alter the rates of occurrence of secondary disabilities.

For the purposes of this study, primary disabilities are defined as those that reflect the CNS dysfunctions inherent in the FAS or FAE diagnosis. Secondary Disabilities are those that a client is not born with, and that could presumably be ameliorated through better understanding and appropriate interventions.

Primary Disabilities associated with FAS/FAE were examined in 473 clients who ranged in age from 3 to 51 years. Those with FAS (n= 178) had an average IQ of 79, average reading, spelling, and arithmetic standard scores of 78, 75, and 70, respectively, and an average Adaptive Behavior standard score of 61. Those with FAE (n= 295) had an average IQ of 90, average reading, spelling, and arithmetic standard scores of 84, 81, and 76, respectively, and an average Adaptive Behavior score of 67. (For both IQ and Adaptive Behavior, a score of 100 is normal.)

Secondary Disabilities were examined with the Life History Interview (LHI), which was developed for this study. Risk and protective factors were assessed primarily from the LHI. The LHI was administered to all available caretakers/informants of 415 clients with FAS/FAE, who ranged in age from 6 to 51 years with a median of 14.2 years. Six main secondary disabilities were studied.

- *Mental Health Problems* (MHP) was by far the most prevalent secondary disability, experienced by over 90% of the full sample.
- *Disrupted School Experience* (DSE) (defined as having been suspended or expelled from school or having dropped out of school) was experienced by 60% of the clients (12 and over).
- *Trouble With the Law* (TWL) (defined as ever having been in trouble with authorities, charged, or convicted of a crime) was experienced by 60% of the clients (12 and over).
- *Confinement* (CNF) (including inpatient treatment for mental health problems or alcohol/drug problems, or ever having been incarcerated for a crime) was experienced by about 50% of the clients (12 and over).
- *Inappropriate Sexual Behavior* (ISB) was noted for about 50% of the clients (12 and over).
- *Alcohol/Drug Problems* (ADP) was noted for about 30% of the clients (12 and over).

In an effort to determine how many clients became self-sufficient as adults, two additional secondary disabilities were evaluated for the 90 clients who were at least 21 years old (median age 26 years):

- *Dependent Living* (DPL) (operationally defined in text) characterized about 80% of the sample (21 and over).
- *Problems With Employment* (PWE) (operationally defined in text) characterized about 80% of the sample (21 and over).

Only seven of the 90 adults in this sample live independently and without employment problems (according to these definitions).

Males have higher rates of Disrupted School Experience, Trouble With the Law, and Confinement than do

females; otherwise, rates of Secondary Disabilities are nearly equal across the sexes. Clients 12 years and older have a higher rate of all Secondary Disabilities except Mental Health Problems than younger clients. Compared to clients with FAS, those with FAE have a *higher* rate of all Secondary Disabilities, except Mental Health Problems.

Adults with FAE have as high a rate of Dependent Living as do those with FAS, but a somewhat *lower* rate of Problems With Employment, which may reflect their higher IQ level.

A low IQ score (70 and below) is a protective factor for Disrupted School Experience, Trouble With the Law, Confinement, and Alcohol and Drug Problems. IQ level has little relationship to Mental Health Problems or Inappropriate Sexual Behavior, but low IQ is obviously a risk factor for Dependent Living and Problems With Employment.

A diagnosis before 6 years of age is a strong protective factor for all Secondary Disabilities except Mental Health Problems

A set of 21 possible risk and protective factors was examined through an analysis of odds ratio plots across the first six secondary disabilities (Table 6.1 and Figure 6.1). For items that involve continuous scores, 1, 4, 5, and 8 below, the sample was divided at the median, which yields the classification appearing in the text below (for these items only). Eight factors emerged that are almost universally protective in terms of secondary disabilities. In order of their strength as "universal" protective factors, they are:

1. Living in a stable and nurturant home for over 72% of life;
2. Being diagnosed before the age of 6 years;
3. Never having experienced violence against oneself;
4. Staying in each living situation for an average of more than 2.8 years;
5. Experiencing a good quality home (10 or more of 12 good qualities) from age 8 to 12 years;
6. Having applied for and been found eligible for DDD (Division of Developmental Disabilities) services;
7. Having a diagnosis of FAS (rather than FAE);
8. Having basic needs met for at least 13% of life.

In addition to being "universal" or "specific," we also categorize risk and protective factors as either "intrinsic" (i.e. attributes of the client or measures of the clients' putative brain damage) or "extrinsic" (i.e. environmental). The following pattern of relationships between specific secondary disabilities and risk and protective factors was found through analysis of odds ratio plots:

Odds of Mental Health Problems are reduced primarily by the universal protective factors.

Odds of Disrupted School Experience are reduced primarily by the universal protective factors.

The rate of Trouble With the Law is related to all the universal protective factors, most notably: DDD eligibility for services.

Confinement also is related to the universal protective factors, especially: living in a stable and nurturant environment and being diagnosed prior to age 6.

Odds of Inappropriate Sexual Behavior are reduced by all universal protective factors.

Alcohol and Drug Problems have one specific protective factor in addition to universal protective factors, namely: having lived with an alcohol abuser less than the median for the group, which was 30% of life.

Odds of Dependent Living are increased over fourfold for clients who had an IQ score of 70 or below, an Adaptive Behavior score below 65, or an IQ/Adaptive Behavior Discrepancy score of over 15 points. Other strong intrinsic risk factors for Dependent Living are: a high FABS score, a Performance Scale IQ minus Verbal Scale IQ score of more than 15 points, and being male. An extrinsic factor that is protective against Dependent Living is having a diagnosis before 6 years of age (Home quality and stability

basic needs met, living with alcohol or drug abusers, or having FAS versus FAE were not associated with Dependent Living as an adult.)

Odds of Problems with Employment are increased more than two to four fold by an IQ score of 70 or below, an Adaptive Behavior Score below 65, an IQ/Adaptive Behavior Discrepancy score of over 15 points, and being FAS rather than FAE. Some universal factors are also protective against problems with employment, namely, an early diagnosis, longer time in a stable and nurturant home, longer duration in each household, and not being a victim of violence.

We note that:

- The correlations reported may or may not be causative. They nonetheless suggest courses of action that may be beneficial both to these clients, and ultimately to society.
- Many environmental influences that appear beneficial for clients with FAS/FAE are, of course, good for all people—all the more reason that society should safeguard them for people born with a birth defect, particularly a "hidden" birth defect like FAS/FAE.
- Seven of the eight universal protective factors are extrinsic and presumably could be modified by society.
- Some of the risk factors are intrinsic, indicating that subgroups of high risk individuals could be detected with special screening techniques.
- Efforts to intervene with alcohol-affected children should proceed simultaneously with efforts to prevent future children from being born with FAS and FAE.

Highlights of Findings

1. Across the full age spectrum of 415 individuals with FAS/FAE, Mental Health Problems characterize 94%, followed by Inappropriate Sexual Behavior (45%), Disrupted School Experience (43%), and Trouble with the Law (42%) (Figure 7.1).

2. As anticipated, the most protective environmental factors *against* secondary disabilities are living in a stable and nurturant home of good quality, not having frequent changes of household, and not being a victim of violence (Figure 6.1).

3. Three intrinsic characteristics are associated with a *higher* level of secondary disabilities: (1) having FAE rather than FAS; (2) having a higher (rather than a lower) score on the Fetal Alcohol Behavior Scale; and (3) having an IQ above 70 rather than below (Figure 6.1). Special attention should focus on clients with these "risky" characteristics in order to prevent secondary disabilities.

4. The 90 adults studied (21 years and over) had an 83% rate of living dependently and a 79% rate of problems with employment (Figure 7.1). Only 10 to 13% of the clients were classified as DDD eligible. The most important environmental factor protecting against these two secondary disabilities is an early diagnosis, suggesting that families and communities may have provided special help and opportunities for those clients identified early in life as FAS/FAE.

   Our search for intrinsic client characteristics that might identify a subgroup among those with FAS/FAE who, despite a higher IQ, are unexpectedly unable to achieve independence and satisfactory employment produced one interesting measure deserving further study. This is the "IQ minus Adaptive Behavior Discrepancy Score", which may hold promise for identifying a subgroup of clients with FAS/FAE for whom early job skills and basic living skills might be especially fruitful.

5. An early diagnosis is a strong universal protective factor for all secondary disabilities, yet only 11% of these individuals with FAS/FAE were diagnosed by age 6 (Figure 6.1). Every effort should be made to provide an early diagnosis for every child with FAS and FAE.

6. Applying for and receiving eligibility for services from the state's Division of Developmental Disabilities