SB

267

Alaska State Legislature

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Senator Bettye Davis

Sponsor Statement

SB 267 mandates that health care professionals record an infant's pre-natal exposure to alcohol, if consent is given by the mother, in the infant's medical file. This information is desired to assist with early FASD diagnosis's when applicable. The benefits of early detection of FASD are immeasurable in comparison to late detection, misdiagnosis, or possible failure to diagnose. Early diagnosis and intervention has shown to reduce the risk of developing "secondary disabilities" such as difficulty in school, trouble maintaining employment, mental health problems, drug an/or alcohol addiction, etc.

Due to the ambiguous nature of many of the symptoms of FASD, misdiagnoses are common. In the cases of misdiagnosis, the benefits of early intervention are rendered ineffectual. A documentation of pre-natal alcohol exposure in the child's medical file will assist medical professionals in making more accurate diagnoses.

This bill limits use of information pertaining to prenatal alcohol use by the mother to purposes of diagnosis, treatment, or care. This legislation comports with the FAS Surveillance Project recommendations found in *Fetal Alcohol Syndrome Prevalence in Alaska*: "Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart."

FISCAL NOTE

STATE OF ALASKA
2008 LEGISLATIVE SESSION

Fiscal Note Number:
Bill Version: SB 267
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ID(File name) SB267-DHSS-BHA-02-22-08
Dept. Affected: Health & Social Services
Title DOCUMENT PRENATAL ALCOHOL EXPOSURE
RDU Behavioral Health
Component Behavioral Health Administration

Sponsor DAVIS
Requester SENATE HES
Component No. 2665

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below

	Appropriation Required	Information					
OPERATING EXPENDITURES	**FY 2009**	**FY 2009**	**FY 2010**	**FY 2011**	**FY 2012**	**FY 2013**	**FY 2014**
Personal Services							
Travel							
Contractual							
Supplies							
Equipment							
Land & Structures							
Grants & Claims							
Miscellaneous							
TOTAL OPERATING	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
CAPITAL EXPENDITURES							
CHANGE IN REVENUES (0)							

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts							
1003 GF Match							
1004 GF							
1037 GF/Mental Health							
Other(Specify Type-do not abbreviate)							
Other(Specify Type-do not abbreviate)							
TOTAL	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Estimate of any current year (FY2008) cost:

POSITIONS

Full-time							
Part-time							
Temporary							

ANALYSIS: *(Attach a separate page if necessary)*

The intent of this legislation is to improve and enhance the ability of service providers to identify, screen, assess and diagnose individuals impacted by prenatal exposure to alcohol. This will be accomplished by requiring certain persons licensed by the State Medical boards to document an infant's prenatal exposure to alcohol in the infant's medical file. This has no fiscal impact on the Division of Behavioral Health.

Prepared by Melissa Stone, Director
Phone 269-3410
Division Behavioral Health
Date/Time 02/21/2008
Approved by Karleen Jackson, Commissioner
Date 02/22/2008
Agency Department of Health and Social Services

Don Burrell

From: Rutherdale, Jan A (LAW) [jan.rutherdale@alaska.gov]
Sent: Sunday, February 24, 2008 4:01 PM
To: Thomas Obermeyer
Cc: Laughlin, Wilda J (HSS); Sen. Bettye Davis
Subject: DOL comments to SB 267

Tom,
As noted in my earlier email to you, I understand from Mike Ford that you would like an outline of what concerns the Department of Law has with SB 267. Below is a recap of what the bill is trying to accomplish and our position that it does not accomplish that result; in practice, it may accomplish the opposite. In addition, since this issue has already been addressed in a 2006 addition to the reporting statutes, we don't believe that there is a need for this bill.

1. Problem sought to be addressed:

SB 267 requires that a health care professional record an infant's pre-natal exposure to alcohol, if the mother so consents, in the infant's medical file. According to the sponsor statement, "This information is desired to assist with early FASD diagnosis's when applicable . . . A documentation of pre-natal alcohol exposure in the child's medical file will assist medical professionals in making more accurate diagnoses. . . . This legislation comports with the FAS Surveillance Project recommendations found in Fetal Alcohol Syndrome Prevalence in Alaska: "Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart."

There is no question that documentation is important in diagnosing FASD. In my experience, the FASD evaluators will not even begin an assessment of a child or adult suspected to have FASD unless there is some sort of documentation that the mother of the person to be evaluated drank during pregnancy. For example, if someone saw the mother drinking during pregnancy or if the mother admits to drinking during pregnancy, the evaluators would want this fact documented, such as in a letter or records of some kind, including medical, police or OCS records.

Usually, FASD symptoms don't appear until the child is in school or older. The biggest problems of documentation arise when the child is an adult and 20-30 years have passed since the pregnancy. This bill tries to ensure that a health professional documents drinking behavior when the child is still an infant.

2. This bill does not solve the need for increased documentation because it allows the mother to prevent such documentation:

Instead of providing more documentation, this bill may have the unintended effect of making it more likely that the documentation of pre-natal exposure to alcohol exposure will not be made. If, as the sponsor statement states, it is important that the documentation is made in the first place, asking the mother and giving her veto power over this documentation creates a possibility that the documentation will not be made. The file is the infant's and this would prevent the doctor to do what is best for the infant. In other words, if making the documentation is good medical practice, the documentation should be made regardless of the mother's wishes.

3. AS 47.17.024 already addresses this issue:

AS 47.17.024, enacted in 2006, requires a "practitioner of the healing arts" (which includes a doctor) involved in the delivery or care of an infant to make a report to OCS if the practitioner determines that the infant has been exposed to alcohol. If the doctor makes a report of harm the doctor

will undoubtedly note this fact in the infant's file. Therefore, there is no need for this bill, since the documentation is already being made. In addition, given the reporting statute, OCS is going to have this prenatal exposure documented in their files, which will be helpful in later making an FASD diagnosis (at least when OCS is involved, which is often the case).

4. This bill may create confusion for doctors who are trying to follow AS 47.17.024.

If the mother objects to any documentation about prenatal exposure in the infant's file, the doctor is still obligated to make a report of harm under AS 47.17.024. but if the mother refuses to allow documentation, the doctor may be under the false impression that he/she does not have to comply with AS 47.17.024. Alternatively, the lack of documentation due to mother's refusal may make it more likely that the doctor will forget to make a report to OCS, or it will require the doctor to create a filing system apart from the infant's file so that the doctor can honor the mother's request but still keep a record that he made the report of harm pursuant to AS 47.17.024.

5. This bill is a departure from normal licensing requirements.

Normally, the state does not legislate best practices for a doctor. If it is good practice for doctors to document exposure to alcohol, the doctors will probably already be doing this. If more education is needed for doctors, there are better ways to satisfy this need than by legislation.

Thank you for providing this opportunity to share my concerns about this bill. Please feel free to call or email me if you have any questions are wish to discuss this matter further.

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Secondary Disabilities

Other problems, or secondary disabilities, arise when needs go unmet for children with alcohol-related birth defects.

In a 1996 study of 415 FAS/FAE patients ranging in age from 6 to 51 years, Dr. Ann Streissguth of the University of Washington identified a number of secondary disabilities that a person is not necessarily born with. These include:

- 90% had mental health problems
- 80% of those over 21 were dependent on others for daily needs
- 80% (21 and older) had employment problems
- 60% (12 and older) were expelled or dropped out of school
- 60% (12 and older) had trouble with the law
- 50% (12 and older) inappropriate sexual behavior
- 50% (12 and older) were incarcerated or confined for mental health reasons
- 30% (12 and older) had alcohol or drug problems

This study also identified several universal "protective factors" that - if addressed early on and consistently - helped minimize the secondary disabilities.

- Living in a stable nurturing home for over 72% of life
- Being diagnosed before the age of six years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years
- Experiencing a good quality home from age six to twelve years
- Having applied for and been found eligible for Developmental Disability Services
- Having a diagnosis of FAS rather than FAE
- Having basic needs met for at least 13% of life

Family Health Dataline

IN THIS ISSUE:

- Approximately 126 infants born each year in Alaska are identified as having been affected by maternal alcohol use during pregnancy.
- During 1995 through 1998, an average of 14 Alaskan infants per year were born with Fetal Alcohol Syndrome (1.4 per 1000 live births).
- FAS surveillance resulted in higher FAS prevalence findings than previously reported for Alaska Natives - 4.8 per 1000 live births for children born in 1995 through 1998.
- Women 30 years of age or older are significantly more likely to have an FAS child than younger women.

Fetal Alcohol Syndrome Prevalence in Alaska: New Findings From The FAS Surveillance Project

Background

Fetal Alcohol Syndrome (FAS) was first identified as a clinical condition in 1973. FAS has drawn considerable attention in Alaska. During the 1980's, the Alaska Area Native Health Service of the Indian Health Service began FAS surveillance among beneficiaries. In 1990, the Alaska Area Native Health Service joined the Alaska Department of Health and Social Services and the Centers for Disease Control and Prevention in establishing the Alaska FAS Prevention Project. The Alaska FAS Prevention Project developed methods for FAS case identification from multiple data sources, documented issues associated with improved FAS surveillance and published the first population-based FAS prevalence for the state[1].

The Section of Maternal, Child and Family Health established the Alaska Fetal Alcohol Syndrome Surveillance Project in 1998. The Surveillance Project is part of a collaborative effort with the Centers for Disease Control and Prevention (CDC) and four other states (NY, WI, CO, AZ). These five states make up the National FAS Surveillance Network (FASSNet). FASSNet has developed a standardized surveillance case definition for FAS surveillance[2]. Participating states (with the exception of Wisconsin) use the same case definition and the same case abstraction methods; however, each of the five states uses varying methodologies for identifying potential FAS cases. FASSNet will soon publish surveillance findings for birth years 1995-97 in the CDC's Morbidity and Mortality Weekly Report. This issue of the Dataline summarizes FAS prevalence in Alaska for birth years 1995 through 1998.

Methods

FAS surveillance in Alaska is based on reports to the Alaska Birth Defects Registry. The Alaska Birth Defects Registry is population-based and uses a multiple source methodology for recording all reportable birth defects. The FAS Surveillance Project and the Alaska Birth Defects Registry are housed in the Division of Public Health's Section of Maternal Child and Family Health, MCH Epidemiology Unit.

Children reported to the Alaska Birth Defects Registry with the International Classification of Diseases, 9th revision (ICD-9) code 760.71 (infant affected by prenatal alcohc exposure) or 742.1 (child with microcephaly) are considered to be potential cases of FAS. Trained medical record abstractors review the medical records of each potential case. Extensive medical and risk factor information abstracted from medical records for each reported child is entered into standardized abstraction software developed by the CDC FASSNet group.

FAS surveillance case definitions were developed by FASSNet, in consultation with a committee of dysmorphologists, pediatricians, psychologists, epidemiologists, and public health officials. The FASSNet database uses an algorithm for determining FAS case status based on abstracted information. The case categories established by FASSNet are:

- Confirmed FAS phenotype with or without confirmed maternal alcohol exposure
- Probable FAS phenotype with or without confirmed maternal alcohol exposure; and
- Suspect FAS (reported children who do not meet the criteria for a confirmed or probable case).

To meet the criteria for confirmed FAS phenotype, a child must have medical record documentation of the following: facial features associated with FAS (small palpebral fissures, thin upper lip and smooth/abnormal philtrum); central nervous system impairment, either structural or functional (head circumference less than or equal to the 10th percentile at birth, low intellectual functioning, developmental delay, mental retardation, or attention deficit disorder); and height, weight or weight for height below the 10th percentile for age. Probable FAS phenotype differs from the confirmed FAS phenotype in that a child may have either central nervous system impairment, or height and weight below the 10th percentile in addition to the facial features associated with FAS.

In this report all children who were reported to the Alaska Birth Defects Registry with ICD-9 codes 760.71 or 742.1, and for whom a medical chart review was conducted, are described as "at risk of FAS." An "FAS case" is defined as a child who was classified as confirmed or probable according to the definitions above.

Records of children identified as being at risk for FAS were linked to birth certificates to eliminate duplicate cases and to obtain additional epidemiological information. Birth certificate data were used to compute rate ratios (rr) for potential maternal risk factors and to compare the prevalence of adverse birth outcomes among FAS cases with other Alaskan children born during the study period (1995 through 1998).

Results

As of July 1, 2001, 543 Alaska children, born in 1995-98, were reported to the Alaska Birth Defects Registry as potential FAS cases. Of the 543 children, 505 (93%), had at least one medical chart abstraction. Among these 505 children, 55 met the FAS surveillance case definition for either a confirmed or probable case.

Table 1. FAS Surveillance Case Finding Results, by Birth Year, Alaska, 1995-98.

Birth Year	Children At Risk of FAS	Confirmed FAS Cases	Probable FAS Cases	Total FAS Cases	Percent of At Risk Children with FAS
1995	67	9	6	15	22.4
1996	126	14	4	18	14.3
1997	138	9	4	13	9.4
1998	174	6	3	9	5.3
Total	505	38	17	55	10.9

Table 2. FAS Prevalence by Mother's Race, Alaska, 1995-98.

Mother's Race	Children At Risk of FAS			Children with FAS		
	n	Rate per 1000 Live Births	95% Confidence Interval	n	Rate per 1000 Live Births	95% Confidence Interval
White	74	2.7	(2.1, 3.4)	5	0.2	(0.0, 0.3)
Alaska Native	390	40.9	(36.9, 45.0)	46	4.8	(3.4, 6.2)
African American	5	2.9	(0.4, 5.4)	0	-	-
Asian/Pacific Islander	9	4.6	(1.6, 7.5)	0	-	-
Unknown	27	-	-	4	-	-
Total	505	12.6	(11.5, 13.6)	55	1.4	(1.0, 1.7)

The proportion of children reported "at risk of FAS" who met the case definition decreased for each subsequent birth year (Table 1). The overall FAS prevalence for Alaska, for children born in 1995-98, was 1.4 per thousand live births (95% C.I.: 1.0 – 1.7).

All races were represented among children who were reported "at risk of FAS", but only whites and Alaska Natives met the FAS surveillance case definition. Children born to Alaska Native women were significantly more likely to be reported to the Alaska Birth Defects Registry as having an alcohol related birth defect than children of other races. Among the 55 children with confirmed or probable FAS, 84% were Alaska Natives and 9.1% were white (Table 2).

Maternal characteristics (as indicated on the birth certificate) that were associated with having a child with FAS were: alcohol use during pregnancy, cigarette smoking during pregnancy, Alaska Native race, maternal age of 30 or more years, and 12 or fewer years of education. Maternal residence in Anchorage or Fairbanks, the two census areas in Alaska with the largest populations, was not associated with FAS (Table 3).

Twenty-two percent of children with FAS were born at less than 33 weeks gestation and 25% were born between 33 and 37 weeks of gestation. Fifty percent of children with FAS were born with low birth weight. The prevalence of low birth weight and prematurity were significantly higher among children with FAS than other infants born over the study period (relative prevalence = 8.9 (95% CI: 6.7,11.9) and 4.8 (95% CI: 3.6, 6.4) respectively). FAS was not associated with sex of the child.

Discussion

The statewide FAS rate presented in this report (1.4 per 1000 children born in 1995-98) is higher than that found previously by the Alaska FAS Prevention Project (0.8 per 1000 children born in 1977-92)[1]. Differences in the case finding methodology used by the two projects may have contributed to the higher rate found by the Alaska FAS Surveillance Project. Routine public health surveillance provides a system for identification of all potential cases based on standardized surveillance protocols. Ongoing surveillance also provides for systematic updates to the FAS prevalence for any given birth cohort. Children may not be diagnosed with FAS or reported "at risk of FAS" until they are as old as six years; additionally, future medical chart abstractions on children previously reported to the registry may change case status findings. Because of this, the Alaska FAS Surveillance Project may report higher FAS prevalence in the future as the birth cohort ages.

Our surveillance findings substantiate previous reports that Alaska Natives have a vastly higher reported prevalence of FAS than other races[3,4,5]. Increased awareness of maternal alcohol use and excellent documentation by Alaska Native health organizations may result in more vigilant reporting of potential cases of FAS. Diagnostic bias may also play a role in explaining the high FAS rate for Alaska Natives: growth curves for Yup'ik Eskimos, one of the largest Alaska Native groups, indicate that this group tends to have shorter stature than the standard US population (State of Alaska, unpublished data). Furthermore, some Yup'ik Eskimo facial features resemble those characteristic of FAS, such as small palpebral fissure.

Another finding of this study that is substantiated by previous reports is the association of older maternal age with FAS. This

study demonstrates that while the association holds true for FAS cases, there is no significant association with maternal age among children who are reported to the Alaska Birth Defects Registry as "at risk" for FAS. These findings suggest that maternal age may be a co-factor in the risk of developing symptoms consistent with FAS. Further study of the interaction between risk factors, such as age, race and maternal alcohol use during pregnancy is needed. Continued collection and analysis of FAS surveillance data over time will increase the power of risk factor analysis.

This analysis showed that children whose birth certificate's recorded maternal alcohol use during pregnancy were 51 times more likely to have FAS. The birth certificates of 15 of the children who met the case definition for FAS did not record maternal alcohol use. Retrospective assessment of maternal alcohol use is difficult; birth certificate information may be unsubstantiated and often, the medical charts of children reported to be at risk of FAS do not contain adequate information on maternal drinking. Interestingly, data from a population based survey of women who have recently had a live birth in Alaska show 3.7% of Alaska Native women reported drinking during the last three months of pregnancy compared to 4.6% of white women.[6]

Because the FAS rates reported here are derived from surveillance data, they are affected by the degree to which health care providers comply with birth defects reporting requirements. It is important to recognize that the

Table 3. FAS Risk Ratios (rr) for Selected Maternal Characteristics, from Linked Birth Certificate Information, Alaska, 1995-98.

Potential Risk Factor	Children with FAS		
	n	Rate per 1,000 Live Births	rr (95% CI)
Maternal Race			
Alaska Native	46	4.8	29.6 (11.76, 74.42)*
Non-Native	5	0.2	ref.
Maternal Age			
>= 30 years	37	2.6	4.9 (2.68, 9.15)*
< 30 years	14	0.5	ref.
Maternal Residence			
Anchorage or Fairbanks	27	1.6	1.5 (0.89, 2.66)
Other Regions	24	1.0	ref.
Maternal Education			
High School or less	38	1.7	5.0 (2.1, 11.7)*
More than High School	6	0.4	ref.
Smoked during Pregnancy			
Yes	39	5.0	16.2 (8.1, 32.5)*
No	10	0.3	ref.
Alcohol Use During Pregnancy			
Yes	32	19.9	50.6 (27.5, 93.2)*
No	15	0.4	ref.

*Statistically significant

ICD-9 code 760.71 is not specific to FAS. This code means only that an infant has been identified as having been prenatally affected by maternal alcohol exposure, and may or may not be identified at birth or in later years as a child with FAS. The relative interpretation of which cases to report under ICD-9 code 760.71 effects the sensitivity and specificity of FAS surveillance. Efforts to increase awareness and understanding of mandated birth defects reporting should be continued.

The proportion of FAS cases among children reported as "at risk of FAS" decreased for each successive birth year under study. Children reported at birth with maternal alcohol exposure may not initially meet the FASSNet case criteria, but may meet the definition later in life. Many tests and assessments for developmental delay may not be effective until after a child has reached the age of three or older. Since most children with FAS are diagnosed between ages 3 and 5, the prevalence of FAS for any given birth year may increase as the birth cohort ages. This illustrates the importance of abstracting medical data over time for children reported with prenatal alcohol exposure. An important feature of the Alaska FAS

Surveillance Project is our ability to continue medical chart abstraction for all children reported at risk of FAS up to the sixth birthday. Completion of medical chart abstractions for all reported children and follow-up abstractions on suspect cases is a central component of on-going FAS surveillance.

FAS prevalence in Alaska is higher than in other FASSNet regions.[7] In the first FASSNet report on FAS prevalence, estimates of FAS prevalence for birth years 1995-97 ranged from 0.26 per 1000 in the Denver-Boulder metropolitan area, to 1.5 per 1000 in Alaska. For Alaska Natives the FAS prevalence is 5.6 per 1000 live births for birth years 1995-97. We found a similar overall FAS prevalence in our analysis of children born in 1995-98 (1.4 per 1000) but a lower prevalence for Alaska Natives (4.8 per 1000). The higher race-specific finding in our FASSNet report for birth years 1995-97 illustrates how case ascertainment may be more complete for older birth cohorts.

Alaska's high FAS prevalence and the presence of ongoing surveillance provide the opportunity to implement and monitor intervention programs. The relatively small number of women who give birth to children with FAS may make targeted intervention programs the most cost-effective method of decreasing FAS prevalence. Future analysis of FAS surveillance data on maternal characteristics of mothers of children with FAS will help to focus these efforts.

Recommendations

- The Alaska Birth Defects Registry should continue provider education efforts to encourage consistent and timely compliance with birth defects reporting requirements.
- Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart.
- The Fetal Alcohol Syndrome Surveillance Project should implement a plan for completion of medical chart abstractions for all reported children and for routine and follow-up abstractions on suspect cases.
- The Section of Maternal Child and Family Health should conduct further study of the interaction between FAS risk factors.
- The Section of Maternal Child and Family will monitor trends in FAS prevalence through periodic analysis of FAS surveillance data.
- The Section of Maternal Child and Family Health should work with the Office of FAS to develop mechanisms to make FAS surveillance findings widely available to prevention programs for use in planning and evaluation.

Submitted by Janine Schoellhorn and Denise Podvin

References

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Fetal Alcohol Syndrome

Last Christmas I talked with a pregnant woman drinking a cup of spiked eggnog.

"I've heard of fetal alcohol syndrome," she said. "You have to be an alcoholic and pregnant for your baby to be born with it. Besides, my Ob/Gyn told me it is safe to drink alcohol during my pregnancy to relax, as long as I only drink occasionally."

Her comment startled me. I realized how little many women know about the dangers of drinking alcohol when pregnant. Indeed, one study found that although nearly two thirds of women had heard of fetal alcohol syndrome, 70 percent of them thought it meant an infant was born addicted to alcohol.

Fetal alcohol syndrome (FAS) is the most clinically recognizable form of a larger group of problems caused by prenatal alcohol consumption, termed fetal alcohol spectrum disorders (FASD), which also includes the more diagnostically elusive alcohol related neurodevelopmental disorder (ARND). Children with FAS have some tell-tale facial anomalies, growth deficiencies and various levels of brain damage; behavioral and learning problems result, and the consequences are generally lifelong. ARND describes a similar behavioral and cognitive syndrome without the characteristic facial abnormalities or growth deficiencies of FAS. With fewer physical clues, diagnosis of ARND is more complicated; only a doctor who is an expert in ARND can determine whether a child's behaviors or disabilities are alcohol related.

Each year, as many as 40,000 babies in the U.S. are born with FASD—as many as one out of every 100 births—costing the nation about four billion dollars. Neurological and learning challenges range from severe to mild, and symptoms often resemble those for attention deficit hyperactivity disorder (ADHD). Children with FASD also have lower IQ—although only 25 percent of children who have FAS have mental retardation (IQ of 69 or under). A recent Michigan study focused on the IQ of 300 children who were followed from before birth to more than seven and a half years of age. For every two additional drinks per day consumed by a mother while pregnant, the child's IQ dropped an average of three points. Children of mothers over the age of 30 who drank were most at risk of having a child with a lower IQ.

How Much Alcohol Is Safe to Drink When Pregnant?

While the medical literature has been clear for some time that there is no safe amount or period for alcohol consumption during pregnancy, some doctors have continued to suggest that limited use during later stages may not be harmful. Nevertheless, studies suggest even a single episode of consuming as little as two drinks may lead to loss of fetal brain cells (one drink = 12 ounces of beer, 5 ounces of wine or 1.5 ounces of hard liquor).

Recently, Surgeon General Richard Carmona urged national attention to the importance of complete abstinence during pregnancy. Said Dr. Carmona, "We must prevent all injury and illness that is preventable in society, and alcohol-related birth defects are completely preventable. We do not know what, if any, amount of alcohol is safe. When a pregnant woman drinks alcohol, so does her baby. Therefore, it's in the best interest for a pregnant woman to simply not drink alcohol." The Surgeon General also noted that despite public health advisories, significant numbers of women continue to drink during pregnancy. In a survey by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, 10 percent of women aged 18 to 44 reported drinking during pregnancy, and two percent reported drinking in a binge fashion, with more than five drinks per episode.

The FASD syndromes are not hereditary; neuron damage and cell loss in the fetal brain occurs through the direct effects of alcohol as a toxin. Nevertheless, there seems to be a genetic predisposition to problem drinking, and how rapidly and completely a woman's body breaks down alcohol depends to some extent on genetics. Whether from genetic or other factors, the risks for FASD are increased in women older than 30 years and women with low socioeconomic status. How Can Parents and Teachers Help?

FASD cannot be cured, but early intervention helps improve children's learning and medical outcomes. Ideally children diagnosed or suspected of having FAS or ARND are referred to a multidisciplinary team including specialists such as a clinical geneticist, a developmental pediatrician, mental health professionals, social workers and educational specialists.

Treatment involves coordination of multiple community services. Social services can ensure a safe home environment and help parents learn what problems to expect and how to constructively respond to them, and special educational techniques may help children overcome learning problems.

Parents and teachers often struggle to understand the challenging or maladaptive behavior of children with FASD, and they need help learning effective management techniques for learning and behavior problems. The FAS Diagnostic and Prevention Network is currently evaluating an intervention model based on two complementary elements: 1) individualized, supportive behavioral consultation for parents and school staff of children with FAS/ARND and 2) a school-based social communication intervention provided directly to children with FAS/ARND that targets critical deficits in social communication and peer relations.

"Each child is as different as a tiny snowflake," says Bonnie Buxton, author of the book

Damaged Angels and adoptive mother of a child diagnosed with ARND. However, some core problems result from damage to the frontal lobe and deeper structures of the brain, and these problems continue into adulthood. Areas most affected include organizational skills, social interaction, memory, perception and coordination.

Kate's Story

Many children with FASD also experience sensory, developmental and medical problems. As an infant and toddler, Kate, who was later diagnosed with ARND, could not tolerate loud noises, bright lights or crowds. Her mother had to avoid these triggers so her daughter would not go into sensory overload. Kate could not even go to a grocery store without screaming. She also had developmental problems, such as delayed speech and difficulty learning how to roll over, crawl and walk. Learning the alphabet was a major hurdle, and she was never able to learn multiplication or cursive writing. But in terms of health, Kate was fortunate. Although she has a heart murmur and slight scoliosis, Kate had few medical problems beyond frequent earaches. (Ear infections are common in people who have FASD because the Eustachian tubes are poorly formed and the fluid does not drain out, leaving a perfect environment for infection.)

As Kate grew older, more difficulties arose. She had mood swings and rages and had trouble making and keeping friends. By the time she was nine years old, her impulses were so out of control that her doctor concluded she must have ADHD and prescribed Ritalin. The medication helped Kate with her impulse control and hyperactivity, but the other problems persisted. School became increasingly frustrating because she was unable to think abstractly. She also kept losing and forgetting things. Other children were progressing in school, and Kate knew that she could not keep up with them. Unfortunately, the origin of her problems was not known until she was 17 years old. Interventions are thought to be most successful when started before the age of six.

Now 3[illegible], Kate is the mother of two children who have FAS. Despite the knowledge that alcohol was the cause of many of her own problems, she lacked the judgment or ability to abstain from alcohol during her pregnancies. After numerous parenting difficulties, Kate moved with her two daughters into her mother's home.

Kate has held [illegible] jobs, but she has never lasted more than three months in a work situation. Her mother could not afford to support all of them, so she fought to get Social Security for Kate and the children. The process was complicated. Kate was applying for disability for mental health reasons, but FAS is a medical diagnosis, not a [illegible]. Because neither FAS nor ARND is listed separately in the DSM-IV, the Diagnostic and Statistical Manual, Fourth Edition, [illegible] Kate's mother had to use her daughter's ADHD diagnosis [illegible] FAS [illegible] "If you don't have a code in the DSM, you don't exist," she explained.

Fetal alcohol syndrome

Laura Maria Denning

Definition

Fetal alcohol syndrome (FAS) is a group of birth (congenital) defects occurring in an infant as a result of maternal alcohol abuse during pregnancy.

Description

Fetal alcohol syndrome was first recognized and identified in 1968. It is currently the leading cause of mental retardation in western civilization, outranking Down Syndrome. In the United States, more than 5,000 infants are diagnosed each year. It is 100% preventable but has no cure.

Congenital effects associated with FAS include:

- Neurologic abnormalities: mental retardation (average I.Q. of 63), small head (microcephaly), problems with movement (motor retardation), poor muscle tone, and hearing disturbances.
- Facial abnormalities: small eyes and/or short eye openings (palpebral fissures), underdevelopment of the upper lip, and flattening of the upper lip ridges (flat philtrum).
- Growth disturbances: small size and weight with growth lag before and after birth.
- Behavioral disturbances: infant irritability, childhood hyperactivity, and attention deficit.
- Cardiac defects: heart murmur, which may subside by one year of age, and heart defects, including ventricular or atrial septal defect.

Causes & symptoms

The cause of FAS is alcohol abuse during pregnancy. The exact amount of alcohol consumption causing FAS has not been identified; however, binge drinking is known to be very harmful. Drinking during the first trimester has been linked to congenital defects, while drinking in the last trimester is known to result in premature birth and low birth weight. FAS occurs among people of all social and economic backgrounds.

Infants born to women who drink heavily during pregnancy show the most signs of FAS. Infants born to heavy drinkers have a 50% risk of harmful effects, while infants of moderate drinkers are at a 10% risk. It is not uncommon for children to be diagnosed later in childhood when there is a noticeable lag in school performance, and possibly hyperactivity and attention deficit.

Children and adults of women with a history of alcohol abuse during pregnancy may display behavioral problems, thinking and reasoning (cognitive) deficits, and psychological and social disturbances without facial abnormalities or growth retardation. These individuals are frequently diagnosed with fetal alcohol effects (FAE).

Low birth weight and preterm delivery may be seen in infants of women who used alcohol in low to moderate amounts during pregnancy.

Diagnosis

Diagnosis of FAS is most often made by a genetic specialist. Diagnosis is made by looking for a history of alcohol use by the mother; reviewing the baby's growth before and after birth; examining physical facial characteristics; and assessing behavioral problems, attention deficit, and speech problems. Tools for the accurate diagnosis of FAS are being developed. Some cases remain undiagnosed for many years.

Treatment

Ideally, women planning to become pregnant should stop drinking several months before the pregnancy. Women who are pregnant should stop drinking as soon as possible in their pregnancy. The highest risk to the developing fetus is in the first trimester; however, heavy drinking at later stages of pregnancy can also cause serious harm. Discontinuing alcohol consumption even as late as the last trimester of pregnancy show improved outcomes for the infant. During the last trimester, the fetus normally has the greatest brain growth.

Fetal alcohol syndrome is completely preventable. The treatment of FAS is in response to symptoms. For example, cardiac defects can be treated surgically. Early diagnosis is essential for optimal treatment of behavioral related problems. Motor and speech issues may be addressed by developmental specialists including physical, speech, and occupational therapists. Problems with hearing and vision are followed up by medical specialists.

Prognosis

Prognosis depends on the degree of mental and neurological development, as well as the timing of diagnosis, and family and social support. Many children with FAS are placed in adoptive or foster homes by age five. Family support and interaction is crucial for promoting more positive outcomes. FAS is a life-long illness with no cure.

Follow up studies in a group of adolescents with an age of 18 showed that the average academic functioning was at a fourth-grade level. Deficits in arithmetic were common. Additionally, adolescents in the group studied displayed poor judgment and were easily distracted.

Prevention

FAS is completely preventable with the avoidance of alcohol during pregnancy. No one knows exactly how much alcohol is harmful. Ideally, women planning to conceive should stop drinking prior to becoming pregnant. Most specialists and researchers agree that the best prevention is complete abstinence of alcohol use during pregnancy.

Family and community education is necessary to prevent FAS. Obstetricians should get a complete history of maternal alcohol use and promote prenatal education. Although most obstetric providers ask about the use of alcohol in pregnancy, few probe in depth.

FAS is a public health issue. Currently, warnings are placed on the labels of alcoholic beverages, but research shows that alcoholics and heavy drinkers frequently ignore these warnings. Many states have made public education of alcohol use in pregnancy a priority.

Key Terms

Congenital

Present at birth.

Further Reading

For Your Information

Books

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- March of Dimes. 1275 Mamaroneck Avenue, White Plains, NY 10605. (914) 428-7100.

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Fetal Alcohol Spectrum Disorders

Fetal Alcohol Spectrum Disorders

Protective Factors for Children with FAS

Several positive factors have been identified that might help reduce secondary conditions that result from fetal alcohol syndrome (FAS). Some of these protective factors are:

Early Diagnosis - Children with FAS who are identified early have an improved prognosis. A child who is identified early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. In addition, early diagnosis helps families and school personnel understand why the child might act or react differently from other children in some situations.

Involvement in Special Education and Social Services - Children who receive special education geared towards their specific needs and learning style are more likely to achieve their developmental and educational potential. Children with FAS show a wide range of behaviors and severity of symptoms. Special education allows for individualized educational programs. In addition, families of children with FAS who receive social services, such as respite care or stress and behavioral management training, have more positive outcomes than families who do not receive such services.

Loving, Nurturing, and Stable Caretaking Environment - While all children benefit from a loving and stable home life, children with FAS can be particularly sensitive to disruptions, transient lifestyles, or harmful relationships compared to children who do not have FAS. Community and family support are needed to prevent secondary conditions in individuals with FAS.

Absence of Violence - Individuals with FAS who live in stable or non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives. Children with FAS need to learn and be taught other ways of showing their anger or frustration.

Source:
Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)." Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

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Date: May 2, 2006
Content source: National Center on Birth Defects and Developmental Disabilities

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- Home
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- FAQs
- Fact Sheets
- Materials
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- National Task Force

Quick Links

Read about the Science Ambassador Program and available lesson plans on FAS for middle and high school classrooms

FAS Guidelines for Referral and Diagnosis
Click here to view or download the Guidelines. [PDF document]
Find out how to order copies

Surgeon General's Advisory on Alcohol Use in Pregnancy [PDF document]

MMWR Recommendations and Reports - Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome

Report on alcohol consumption among women who are pregnant or who might become pregnant

Curricula Available

Contact Info

Fetal Alcohol Syndrome
NCBDDD, CDC
Mail-Stop E-86
1600 Clifton Road
Atlanta, GA 30333
1-800-CDC-INFO (232-4636)

Fetal Alcohol Syndrome

Last Christmas I talked with a pregnant woman drinking a cup of spiked eggnog.

"I've heard of fetal alcohol syndrome," she said. "You have to be an alcoholic and pregnant for your baby to be born with it. Besides, my Ob/Gyn told me it is safe to drink alcohol during my pregnancy to relax, as long as I only drink occasionally."

Her comment startled me. I realized how little many women know about the dangers of drinking alcohol when pregnant. Indeed, one study found that although nearly two-thirds of women had heard of fetal alcohol syndrome, 70 percent of them thought it meant an infant was born addicted to alcohol.

Fetal alcohol syndrome (FAS) is the most clinically recognizable form of a larger group of problems caused by prenatal alcohol consumption, termed fetal alcohol spectrum disorders (FASD), which also includes the more diagnostically elusive alcohol-related neurodevelopmental disorder (ARND). Children with FAS have some tell-tale facial anomalies, growth deficiencies and various levels of brain damage; behavioral and learning problems result, and the consequences are generally lifelong. ARND describes a similar behavioral and cognitive syndrome without the characteristic facial abnormalities or growth deficiencies of FAS. With fewer physical clues, diagnosis of ARND is more complicated; only a doctor who is an expert in ARND can determine whether a child's behaviors or disabilities are alcohol-related.

Each year, as many as 40,000 babies in the U.S. are born with FASD—as many as one out of every 100 births—costing the nation about four billion dollars. Neurological and learning challenges range from severe to mild, and symptoms often resemble those for attention deficit hyperactivity disorder (ADHD). Children with FASD also have lower IQ—although only 25 percent of children who have FAS have mental retardation (IQ of 69 or under). A recent Michigan study focused on the IQ of 300 children who were followed from before birth to more than seven and a half years of age. For every two additional drinks per day consumed by a mother while pregnant, the child's IQ dropped an average of three points. Children of mothers over the age of 30 who drank were most at risk of having a child with a lower IQ.

How Much Alcohol Is Safe to Drink When Pregnant?

While the medical literature has been clear for some time that there is no safe amount or period for alcohol consumption during pregnancy, some doctors have continued to suggest that limited use during later stages may not be harmful. Nevertheless, studies suggest even a single episode of consuming as little as two drinks may lead to loss of fetal brain cells (one drink = 12 ounces of beer, 5 ounces of wine or 1.5 ounces of hard liquor).

Recently, Surgeon General Richard Carmona urged national attention to the importance of complete abstinence during pregnancy. Said Dr. Carmona, "We must prevent all injury and illness that is preventable in society, and alcohol-related birth defects are completely preventable. We do not know what, if any, amount of alcohol is safe. When a pregnant woman drinks alcohol, so does her baby. Therefore, it's in the best interest for a pregnant woman to simply not drink alcohol." The Surgeon General also noted that despite public health advisories, significant numbers of women continue to drink during pregnancy. In a survey by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, 10 percent of woman aged 18 to 44 reported drinking during pregnancy, and two percent reported drinking in a binge fashion, with more than five drinks per episode.

The FASD syndromes are not hereditary; neuron damage and cell loss in the fetal brain occurs through the direct effects of alcohol as a toxin. Nevertheless, there seems to be a genetic predisposition to problem drinking, and how rapidly and completely a woman's body breaks down alcohol depends to some extent on genetics. Whether from genetic or other factors, the risks for FASD are increased in women older than 30 years and woman with low socioeconomic status. How Can Parents and Teachers Help?

FASD cannot be cured, but early intervention helps improve children's learning and medical outcomes. Ideally children diagnosed or suspected of having FAS or ARND are referred to a multidisciplinary team including specialists such as a clinical geneticist, a developmental pediatrician, mental health professionals, social workers and educational specialists.

Treatment involves coordination of multiple community services. Social services can ensure a safe home environment and help parents learn what problems to expect and how to constructively respond to them, and special educational techniques may help children overcome learning problems.

Parents and teachers often struggle to understand the challenging or maladaptive behavior of children with FASD, and they need help learning effective management techniques for learning and behavior problems. The FAS Diagnostic and Prevention Network is currently evaluating an intervention model based on two complementary elements: 1) individualized, supportive behavioral consultation for parents and school staff of children with FAS/ARND and 2) a school-based social communication intervention provided directly to children with FAS/ARND that targets critical deficits in social communication and peer relations.

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Many children with FASD also experience sensory, developmental and medical problems. As an infant and toddler, Kate, who was later diagnosed with ARND, could not tolerate loud noises, bright lights or crowds. Her mother had to avoid these triggers so her daughter would not go into sensory overload. Kate could not even go to a grocery store without screaming. She also had developmental problems, such as delayed speech and difficulty learning how to roll over, crawl and walk. Learning the alphabet was a major hurdle, and she was never able to learn multiplication or cursive writing. But in terms of health, Kate was fortunate. Although she has a heart murmur and slight scoliosis, Kate had few medical problems beyond frequent earaches. (Ear infections are common in people who have FASD because the Eustachian tubes are poorly formed and the fluid does not drain out, leaving a perfect environment for infection.)

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Now [illegible], Kate is the mother of two children who have FAS. Despite the knowledge that alcohol was the cause of many of her own problems, she lacked the judgment or ability to abstain from alcohol during her pregnancies. After numerous parenting difficulties, Kate moved with her two daughters into her mother's home.

Kate has held numerous jobs, but she has never lasted more than three months in a work situation. Her mother could not afford to support all of them, so she sought to get Social Security for Kate and the children. The process was complicated. Kate was applying for disability for mental health reasons, but FAS [illegible]. Because neither FAS nor ARND is listed separately in the DSM-IV (the Diagnostic and Statistical Manual, Fourth Edition, the comprehensive guide [illegible] psychiatric problems), Kate's mother had to use her daughter's ADHD diagnosis to help her qualify for Social Security. "If you don't have a code in the DSM, you don't exist," she explained.

Fetal Alcohol Spectrum Disorders

Fetal alcohol spectrum disorders (FASDs) can cause serious disabilities that last a lifetime. They can affect how a person looks, grows, learns, and acts. But, FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

- FASD is a term that describes the range of effects that can occur in a person whose mother drank alcohol while pregnant. These effects can include physical and mental disabilities and problems with behavior or learning. Often, a person has a mix of these problems. The term FASD is not intended for use as a clinical diagnosis.

- People with an FASD often have problems with learning, memory, attention span, problem solving, speech, and hearing. They are at very high risk for trouble in school, trouble with the law, alcohol and drug abuse, and mental health disorders.

- FASDs include fetal alcohol syndrome (FAS), which causes growth problems, abnormal facial features, and central nervous system problems. Children who do not have all of the symptoms of FAS can have another FASD. These children can have problems that are just as severe as those of children with FAS.

- It is not known exactly how many people have an FASD. Studies by the Centers for Disease Control and Prevention (CDC) have shown that 0.2 to 1.5 cases of FAS occur for every 1,000 live births in the United States. Other studies using different methods have estimated the rate of FAS at 0.5 to 2.0 cases per 1,000 live births. Scientists believe that there are at least four times as many cases of FASDs as FAS.

There is no known amount of alcohol use that is safe during pregnancy. There is no known time during pregnancy when alcohol use is safe.

- All drinks with alcohol can hurt an unborn baby. A 12-ounce can of beer has as much alcohol as a 4-ounce glass of wine or a 1-ounce shot of liquor. Some drinks, like malt beverages, wine coolers, and mixed drinks, have more alcohol than a 12-ounce can of beer.

- A woman should not drink any alcohol if she is pregnant or planning to get pregnant. If a woman could become pregnant, she should talk to her doctor and take steps to lower the chance of exposing her baby to alcohol.

- FASDs last a lifetime—there is no cure. But if children with an FASD are identified early, they can receive services to help increase their well-being.

- FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

LEGISLATIVE RESEARCH REPORT

FEBRUARY 21, 2008

REPORT NUMBER 08.165

EARLY DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER

PREPARED FOR SENATOR BETTYE DAVIS

BY TIM SPENGLER, LEGISLATIVE ANALYST

You asked for information about Fetal Alcohol Spectrum Disorder (FASD). Specifically, you wished to know whether early diagnosis of FASD was important. Briefly, all our sources believe that early diagnosis is a key factor in enhancing the quality of the life of any child so affected.

Prenatal exposure to alcohol can cause a range of disorders collectively known as fetal alcohol spectrum disorder (FASD).[1] The term FASD is not a clinical diagnoses but rather an umbrella term describing the range of effects that can occur to a child whose mother consumed alcohol during pregnancy. These effects can be physical, mental, or behavioral and have lifelong implications. The term "spectrum" is used because each individual with FASD may have some or all of the aforementioned effects with varying degrees of severity.

Fetal alcohol syndrome (FAS) is the most well know diagnosis—and the most severe—within FASD. To be diagnosed with FAS, a wide range of testing is required including physical, psychological, speech and language tests. Symptoms and the extent of damage caused vary depending on factors such as the amount and kind of alcohol the mother drank, when the alcohol was consumed in the gestational period, and the genetic makeup of both mother and fetus. Fetal Alcohol Syndrome is characterized by abnormal facial features, growth deficiencies, and central nervous system problems. Other conditions that fall under FASD include fetal alcohol- effects (FAE), alcohol related neurodevelopment disorder (ARND) and alcohol-related birth defects (AEBD). All of these conditions are permanent and have no cure. However, all FASDs are also 100% preventable—if a woman does not drink alcohol during pregnancy.

Experts agree that early diagnosis of FASD is important for a variety of reasons. While the conditions are incurable, a child who is identified early can receive services and accommodations that can help him or her lead a more productive and rewarding life. All of the literature we surveyed and the professionals with whom we spoke stress that the earlier intervention occurs, the better the outcome. Diagnosis at birth is ideal but only occurs in cases where the mother acknowledges drinking during pregnancy or the child has extreme FAS facial features. According

[1] Much of the information we gathered for this report came from the Center for Disease Control *www.cdc.gov/ncbddd/fas* and the Substance Abuse and Mental Health Services Administration *www.samhsa.gov*, as well as conversations with experts in the field and other literature.

to our sources, children are often not initially diagnosed until they start school. Many children, however, especially those without distorted facial features, are never diagnosed with having FASD.

Dan Dubovsky, FASD Specialist for the federal Substance Abuse and Mental Health Services Administration (SAMHSA), emphasizes that FASDs, which often appear as oppositional or anti-social behavioral choices, are actually the result of brain damage.[2] As a result, children are negatively pigeon-holed as disruptive or lacking in intelligence. He stresses that being **misdiagnosed** is extremely counterproductive to the child, his or her family, and to their community. For parents, knowing their child (in many cases their adoptive or foster child) is affected by FASD can be of immeasurable importance. Although the challenges of raising a child with special needs remain, knowing that the behavior issues are due to a disorder—and not willful disobedience—is of obvious importance. When a child is accurately identified as having FASD, educational plans and services can be set in place appropriate for his or her needs.

Mr. Dubovsky was emphatic that early diagnosis is crucial—especially as a way to minimize the occurrence of **secondary disabilities**. Secondary disabilities include mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual acting out, and substance abuse problems. He pointed us to a "groundbreaking" Center for Disease Control/ University of Washington study headed by Dr. Ann Streissguth that examines how individuals with FASD whose needs go unmet frequently develop one or more of these secondary conditions. One of the findings highlighted in the study is the importance of being diagnosed before the age of six. We include Dr. Steissguth's report as well as two brief overviews regarding the findings of her study as Attachment A.[3]

A SAMHSA publication, *Fetal Alcohol Spectrum Disorders, The Basics*, includes the following as some of the benefits of identification and treatment of FASD[4]

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful;
- Helps people with an FASD succeed by focusing on why they have trouble in certain programs; and
- Helps improve outcomes and helps prevent future births of children with alcohol related disorders.[5]

---

[2] Dan Dubovsky can be reached at (866) 786-7327.

[3] The document *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects* is in less than stellar condition. We contacted the University of Washington and, while they do not have the report in an electronic format, they will send a hard copy which we will scan and make available. The Center for Disease Control's *Protective Factors for Children* with FAS is available at *www.cdc.gov/ncbddd/fas/protective.htm*. *Secondary Disabilities* from Alaska's FAS office is located at *www.state.ak.us/fas/info/secondaryDisablities.htm*.

[4] We include *Fetal Alcohol Spectrum Disorders, The Basics* as Attachment B.

[5] Dan Dubovsky stresses that a mother who remains unaware of her child's condition may drink during subsequent pregnancies possibly resulting in the birth of additional children afflicted with alcohol related disorders. However, if a diagnosis is made early, and the family educated about FASD, the mother may adjust her behavior and abstain from consuming alcohol during these pregnancies. Therefore early diagnosis can potentially lessen future FASD occurrences.

Dr. Eugene Hoyme, who spent years studying the effects of fetal alcohol syndrome at Stanford University, helped develop a diagnostic spectrum used with alcohol-exposed children. It looks at the whole child, from physical features to cognitive thinking and motor skills. Dr. Hoyme is currently studying ways to diagnose children at birth. He emphasizes that the earlier a child is identified with FASD, and the sooner he or she can receive help, the better the chance for a successful outcome.[6] Often FASD diagnoses are conducted as a team approach with physicians, speech and physical therapists, psychologists, and audiologists participating. Obviously, in some geographic areas, such teams are not available. In these cases, physicians, and other health professionals with proper training, are able to make a diagnosis on their own.

We spoke with Juneau pediatricians Joy Neyhart and Amy Dressel as well as Alaska's FAS program manager Diane Casto and Ric Iannolino, FASD Diagnostic Team Coordinator with Central Council Tlingit Haida Indian Tribes.[7] All these experts concur that early diagnosis of FASD is of paramount importance for children, families and providers. Additionally, Diane Casto points out that many children with FASD are not being raised by their birth mothers but reside with relatives, or in adoptive or foster homes. She asserts that it is vital that these caregivers have all information possible to best assist, and advocate for, the children relying on them. Dr. Neyhart notes that FASD children often have multiple placements within the foster care system as they can be very difficult to manage. This phenomenon is exacerbated when their condition is undiagnosed.

As mentioned, there is a continuum of multiple issues that children with FASD—and their families and providers—face. Interventions for children with FAS/FASD are sometimes non-specific, unsystematic and often lack scientific evaluation. In an effort to remedy this situation, The Center for Disease Control currently has a number of grantees working through a collaborative effort to identify, develop, and evaluate effective strategies for working with children with FASD and their families.[8] While there is no "one size fits all" strategy for helping these unfortunate children, all our sources agree that the earlier a child is accurately diagnosed, the better chance he or she has to lead the fullest life possible. As the State of Alaska's FAS website notes,

> With the right diagnosis, support and understanding, many individuals with FASD are living happy and full lives.

I hope you find this information to be useful. Please do not hesitate to contact us if you have questions or need additional information.

---

[6] *Diagnosing FASD is Tricky*, Minnesota Public Radio, *minnesota.publicradio.org/display/web/2007/09/05/fasd2*.

[7] Dr. Neyhart can be reached at (907) 463-1210, Dr Dressel at (907) 586-1542, Diane Casto at (907) 465-1188, and Ric Iannolino at (907) 463-7373.

[8] For information on the CDC's development of strategies program see *www.cdc.gov/ncbdd/fas/intervening*.

Don Burnell

From: Marilyn Dodd [akafp@gci.net]
Sent: Friday, February 29, 2008 2:44 PM
To: Sen. Bettye Davis
Subject: sb267

Attachments: ATT00001.htm; sb267.doc

ATT00001.htm (4 KB) sb267.doc (31 KB)

Maryann Foland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

We believe this bill is unnecessary and has unintended legal consequences. Practitioners already have a statutory and ethical duty to report suspected alcohol or drug abuse affecting a child. The Medical Practice Act requires all pertinent information to be entered into a medical record. Furthermore, to restrict use of any information only for the purpose of providing medical diagnosis or treatment limits its use in any potential legal case. Since this would affect how evidence may be used, it may require a more wide-reaching change in court rules.

The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Foland, M.D.
President Elect, AKAFP

Alaska Academy of Family Physicians

35555 Spur Highway #266, Soldotna, AK 99669 akafp@gci.net www.alaskaafp.org 907 258-2255 office 530 326-5612 fax

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Alaska State Medical Association

4107 Laurel Street • Anchorage, Alaska 99508 • (907) 562-0304 • (907) 561-2083 (fax)

March 3, 2008

Honorable Bettye Davis
State Senate
Chair, Senate Health, Education, and Social Services Committee
State Capitol, Room 30
Juneau, AK 99801-1182

Transmitted by email: Senator_Bettye_Davis@legis.ak.state.us

RE: SB 267 - Documentation of an Infant's Pre-natal Exposure to Alcohol

Dear Senator Davis:

The Alaska State Medical Association (ASMA) represents physicians statewide and is primarily concerned with the health of all Alaskans.

Notwithstanding your laudable intent to "assist with early FASD diagnosis's when applicable", ASMA feels that this bill, if passed as is, provides for unintended consequences that puts physicians in situations where they may violate other laws, put themselves at unwarranted risk in civil litigation, and impair their ability to be paid by health insurance companies. ASMA can not support SB267.

This statement is based on the comments and advice provided to ASMA by its legal counsel, Mr. Roger Holmes. Those comments are attached to the written testimony.

I am an internal medicine specialist who specializes in the treatment of diabetes and lipids. I do not specialize in the treatment of FASD. However, it is good medicine to include everything in the patient's medical chart that is relevant to the delivery of good medical care to the patient.

From a medical standpoint, it makes no sense to dictate what a physician might include in her or his medical record for an infant based on the consent of a mother who may indeed be impaired by alcohol abuse and/or addiction.

ASMA suggests that Alaska would be better served through legislation that furthers research and education to prevent, identify, and treat FASD.

ASMA urges you not to support SB267.

Sincerely,

By: J. Ross Tanner, DO, President
For: Alaska State Medical Association

cc: Senate Health, Education, and Social Services Committee members

BISS AND HOLMES
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BURTON C. BISS, RETIRED
ROGER F. HOLMES

E-Mail roger.bh@gci.net

February 29, 2008

James J. Jordan
Executive Director
Alaska State Medical Association
4107 Laurel Street
Anchorage, Alaska 99508

Re: SB 267

Dear Mr. Jordan:

You have asked me to comment on the proposed language in AS 08.64.364 which states:

> (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, *if the mother provides her consent to the inclusion of the information in the infant's medical file.*
>
> (b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care.

The Sponsor's Statement indicates that the purpose of this statute is to mandate the inclusion of this information in an infant's chart to encourage early detection of FASD. However, the way the bill is written, it appears physicians *may not* include this information in the patient's chart unless the mother gives her consent. Were this to be the result of this bill, it would turn medicine upside down. The infant is the patient. The doctor has a moral, legal and ethical obligation to include anything and everything in the patient's medical chart which the physician feels is relevant regardless of receiving the permission of the patient or the patient's mother.

It is below the standard of care for a physician to fail to record in the chart all of the information pertinent to diagnosis and treatment. The failure to record something the physician feels is relevant subjects the physician to a claim of malpractice.[1] It also subjects the physician to discipline

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[1] Sweet v. Sisters of Providence in Washington, 881 P.2d 304, 311 (Alaska, 1994) "In Patrick v. Sedwick, 391 P.2d 453, 457 (Alaska 1964), for example, the Alaska Supreme Court noted that "it was incumbent upon the appellee surgeon to have described accurately and fully in his report of the operation everything of consequence that he did and which his trained eye observed during the

including a possible loss of license as it is unprofessional conduct for a physician fail "to prepare and maintain accurate, complete, and legible records in accordance with generally accepted standards of practice for each patient..."[2] No physician could ethically or legally fail to include this information in an infant's chart regardless of the feelings of the mother.

Subsection (b) limits the use of FASD information in the chart to diagnosis, treatment and care of the patient. This too has unintended, impermissible and, most likely, unconstitutional consequences. It appears the information could not be used by the patient in a law suit against a school district, health care provider or other third party. Nor could the health care provider use that information in defense of a suit. Actually, as written, the health care provider could not even submit the record to Blue Cross in connection with getting paid for the care provided. Nor, if this record were made in a hospital emergency room, could it used as part of a peer review process.

There is a companion bill in the House - HB300. The House sponsor's statement says:

> The bill specifies that information related to a mother's use of alcohol can only be used for diagnostic and medical purposes, not as evidence against the woman's fitness or in an attempt to remove her custodial rights.

Since this bill purports to limit the evidence which can be used in a Court proceeding, it may need a two-thirds majority.[3]

Please call me if you have any questions.

Very truly yours,

BISS & HOLMES

Roger F. Holmes

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operation.... If these requirements had been met the report would ... more likely ... have supplied sufficient facts to have permitted expert witnesses to testify on the question of negligence.'"

[2] 12 AAC 40. 967(9).

[3] I have not looked at the issue of the constitutionality of depriving a spouse or a child's guardian ad litem of the use of relevant information in a child custody dispute.

March 3, 2008

Senate Bill 267

Talking Points

- If medical providers were reporting prenatal alcohol exposure routinely we would not need this bill

- It is not illegal for women to drink during pregnancy in Alaska and children exposed to alcohol during pregnancy cannot be diagnosed for several years from the time of their birth.

- Witn respect to mandatory reporting of suspected alcohol abuse affecting a child by medical professionals per Title 47 Child Protection. It is our contention that this practice is reactive and counter to the intent of this piece of legislation. Senate Bill 267 provides a non-punitive, pro-active means for mothers to self report their prenatal alcohol use.

- As a coordinator of one of Alaska's diagnostic clinic my experience is that some mother have died or have lost custody of their children, relative may not be aware of their alcohol use during the specific nine months of a mother's pregnancy the result is many children and their families can not obtain a diagnosis.

- Children are diagnosed at the earliest in our clinic at 2 years of age children must be identified much early in order to mitigate some of the behavior and cognitive deficits long past the post natal reporting period that this bill provides for.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM March 3, 2008

SUBJECT: Legal and practical issues relating to the requested CSSB 267(HES) (Work Order No. 25-LS1471\C)

TO: Senator Bettye Davis
Chair of the HESS Committee
Attn: Thomas Obermeyer

FROM: Alpheus Bullard TGB
Legislative Counsel

You requested a committee substitute for SB 267 based on an amendment prepared by Jan Ruthdale of the Department of Law. I have several comments.

1. The requested committee substitute directed a person making a postnatal examination of a mother and infant to document "*observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file.*" This is unclear. Whose "observations," whose "medical history," and what is "available information"? I redrafted this to read, "the person's observations," the mother's pertinent medical history" and other "information relevant" to the infant's prenatal exposure to alcohol.

2. The language you requested provides that *"[i]nformation described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024."* The committee substitute you requested makes changes to a provision that directs that certain information be recorded in an infant's medical file. This means that the mother's information is released to the infant's medical record. Any future provider of medical services to the infant will encounter the information provided by the mother in the infant's file. If the information obtained from the mother by a medical provider is not confidential, this is something of which she should be made aware. I'm not sure what the sense of "release" is supposed to be, but it does not seem to make sense in the context of what the bill requires.

Note too, that the concept of doctor-patient confidentiality would not apply just to "*confidential medical information of the mother*" but all noncriminal information shared by the mother in seeking the advice, care, and/or treatment of a physician for herself or her child. It is a generally accepted principle that individuals seeking medical help or

advice should not be inhibited by any fear that their medical concerns or conditions will be disclosed to others. Patients entrust personal knowledge of themselves to their physicians, which creates an uneven relationship in that the vulnerability is one-sided. There is usually an expectation that physicians will hold that special knowledge in confidence and use it exclusively for the benefit of the patient. See Alaska Rule of Evidence 504(b) which provides:

> **General Rule of Privilege.** A patient has a privilege to refuse to disclose and to prevent any other person from disclosing confidential communications made for the purpose of diagnosis or treatment of the patient's physical, mental or emotional conditions, including alcohol or drug addiction, between or among the patient, the patient's physician or psychotherapist, or persons who are participating in the diagnosis or treatment under the direction of the physician or psychotherapist, including members of the patient's family.

The committee substitute would have such information recorded in the infant's medical file, but not *"released without the consent of the mother, except for court order, or as required by AS 47.17.024."* I don't know how a court would interpret this language, but I believe that it is certainly possible that the changes affected by the committee substitute could be interpreted as an unconstitutional violation of a mother's right to privacy.

3. Senate Bill 267 requires a person licensed under AS 08.64 to document "*an infant's prenatal exposure to alcohol*" in the infant's medical file, and that the information "*may not be used except for the purposes of providing medical diagnosis, treatment, or care.*" AS 47.17.024 imposes a duty on practitioners of the healing arts to notify the Department of Health, Education and Social Services of an infant's condition that the practitioner has determined has been adversely affected by, or is withdrawing from exposure to, a controlled substance or alcohol. The duty imposed by AS 47.17.024 is a different duty than that created under the bill. SB 267 deals <u>only</u> with the documentation of information in an infant's medical file relating to a mother's consumption of alcohol, <u>not</u> a practitioner's determination that an infant has been adversely affected by alcohol. These are legally and practically distinct actions and responsibilities.

If you have any questions, please do not hesitate to contact me.

ALB:lmb
08-051.lmb

Enclosure

February 25, 2008

Representative Doll
Senator Davis
Capitol Building
Juneau Alaska 99801

Greetings,

I would like to thank you both for sponsoring bills to increase the access to support services for people experiencing brain damage caused by fetal alcohol spectrum. This bill will remove one of the major barriers to effective diagnosis, by increasing the knowledge of one of the key indicators. I believe this bill still maintains the relationships between medical provider and parents.

I worked closely for a number of years with a young person experiencing FASD. I witnessed the frustration of fellow staff members and community members, and the negative attitudes toward this individual.

Once it was determined that the person's behaviors were a result of FASD, there was a dramatic change in treatment of this individual. People working with her experienced much less frustration, and were much more effective in working with her. This resulted in a higher quality of life, work, and relationships for the individual.

This bill is a win-win for people with FASD, the people that care for them, and the State of Alaska in general. Thank you for sponsoring this legislation.

Joy Lyon
570 Seater
Juneau AK 99801

25-LS1471\C
Bullard
3/3/08

CS FOR SENATE BILL NO. 267(HES)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR DAVIS

A BILL

FOR AN ACT ENTITLED

"An Act relating to requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the person's observations, the mother's pertinent medical history, and other information relevant to the infant's prenatal exposure to alcohol in the infant's medical file. Information described in this section that was obtained from statements of the mother made during the postnatal examination that is confidential medical information of the mother may not be released without the consent of the mother, except by court order, or as required by AS 47.17.024. The documentation must be in the form or format required by the

department.

(b) Except as provided in AS 47.17.024, information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care of the infant.

(c) In this section, "infant" means a child who is less than 12 months of age.

Resources

- SAMHSA FASD Center for Excellence: fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- National Clearinghouse for Alcohol and Drug Information: ncadi.samhsa.gov
- These sites link to many other Web sites.

Paradigm Shift

"We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed."

—Dubovsky, 2000

Strengths of Persons With an FASD

- Build on strengths of persons with an FASD, such as giving them opportunities to help in the classroom.

Photo courtesy of Microsoft

- Use teaching strategies that focus on strengths.

- Find jobs that use the person's strengths.

Strengths of Persons With an FASD

- Highly verbal

- Highly moral—deep sense of fairness

- Kind with younger children and animals

Photo courtesy of Microsoft.

- Able to participate in problem solving with appropriate support

Strengths of Persons With an FASD

- Cuddly and cheerful

- Happy in an accepting and supportive environment
- Loving, caring, kind, sensitive, loyal, and compassionate
- Energetic and hard working
- Fair and cooperative
- Spontaneous, curious, and involved

Permission to use photos on file.

Strengths of Persons With an FASD

- Friendly
- Likable
- Desire to be liked
- Helpful

- Determined
- Have points of insight
- Not malicious

Dubovsky, Drexel University College of Medicine (1999)

Strategies To Improve Outcomes for Individuals With an FASD

Self-Esteem and Personal Issues

- Use person-first language (e.g., "child with FAS," not "FAS kid").
- Do not isolate the person.

- Address issues of loss and grief.
- Do not blame people for what they cannot do.
- Set the person up to succeed.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Executive Function Deficits

- Use short-term consequences specifically related to the behavior.
- Establish achievable goals.
- Provide skills training and use a lot of role playing.

Photo property of SAMHSA.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Information Processing Problems

- Check for understanding.

- Use literal language.

- Teach the use of calculators and computers.

- Look for misinterpretations of words or actions and discuss them when they occur.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Memory Problems

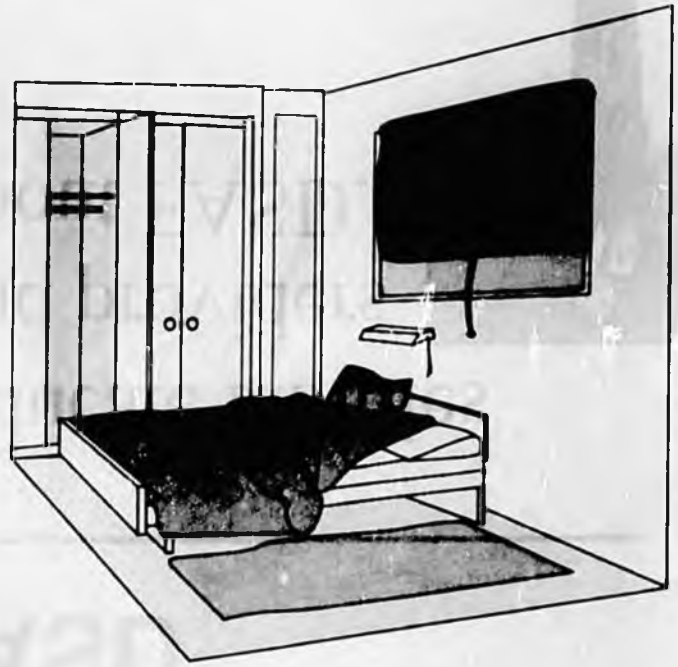
- Provide one direction or rule at a time and review rules regularly.

- Use a lot of repetition.

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Sensory Integration Issues

- Simplify the individual's environment.



- Provide a lot of one-to-one physical presence.
- Take steps to avoid sensory triggers.

Strategies To Improve Outcomes for Individuals With an FASD

- Ask about possible prenatal alcohol exposure at intake.

- Educate families and providers about FASD.

- Ask about substance use during medical appointments.

- Have a thorough diagnostic workup.

Dubovsky, Drexel University College of Medicine (1999)

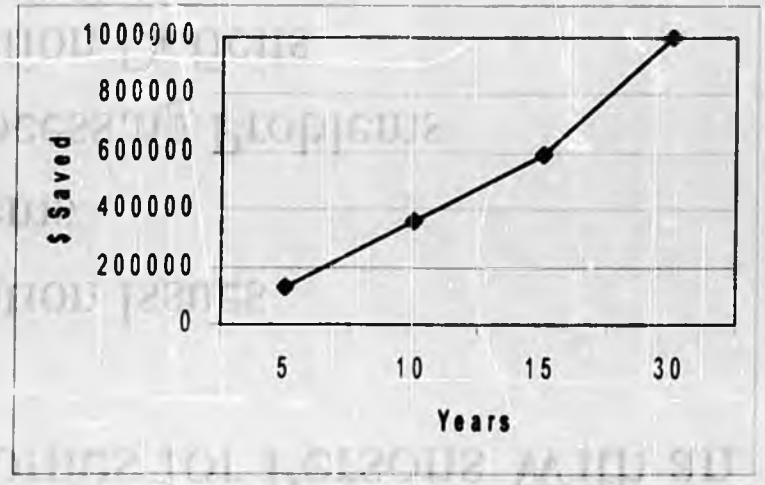
Outcomes

This section includes:

- Strategies To Improve Outcomes for Persons With an FASD
  - Strategies for Sensory Integration Issues
  - Strategies for Memory Problems
  - Strategies for Information Processing Problems
  - Strategies for Executive Function Deficits
  - Strategies for Self-Esteem and Personal Issues
- Strengths of Persons With an FASD
- Paradigm Shift

Economic Costs of FAS

- One prevented case of FAS saves:
  - $130,000 in the first 5 years
  - $360,000 in 10 years
  - $587,000 in 15 years
  - More than $1 million in 30 years



Increased savings through prevention

Lupton, Burd, and Harwood (2004)

Economic Costs of FAS

- FAS alone cost the United States more than $4 billion in 1998.
- The average lifetime cost for each child with FAS is $2 million.
  - $1.6 million for medical care services
  - $0.4 million for loss of productivity

Lupton, Burd, and Harwood (2004)

Systems of Care

Many Doors, No Master Key: Resources Needed for Brandan, Age 1-2 Years

Health

- Pediatrician
- Neurologists (2)
- Pediatric Ophthalmologist
- Audiologist
- Otolaryngologist
- Pharmacy
- Medical Supply Providers
- Gastroenterologist
- Feeding Specialist
- Nutritionist
- High-Risk Infant Clinic
- FAS Diagnostic Clinic
- Lab and X-Ray Services
- Surgeons
- Pulmonologist
- Respiratory Therapist

Education

- Physical Therapist
- Speech/Language Pathologist
- Infant Educator
- Cultural Recreational Therapy (e.g., drumming)
- Birth-3 Program: Occupational Therapist, Speech/Language Pathologist, Teacher, Aide, Play Therapist

Social and Community Services

- Local Indian Child Welfare Advisory Committee
- Tribal Social Worker
- Child Welfare/ Case Worker
- Tribal Council
- Respite Providers
- Foster Care System
- Daycare
- Div. of Dev. Disabilities/Case Worker and Family Resource Coordinator
- Substance Abuse Treatment (birth mother)
- Mental Health Counseling (birth mother)
- Parenting Education (birth mother)

Legal and Financial Services

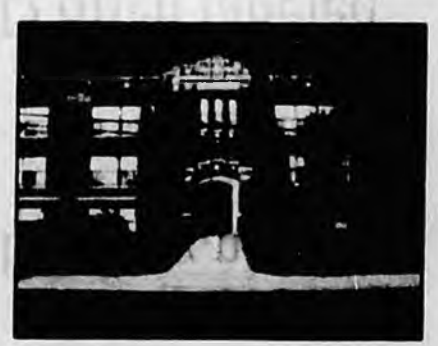
- SSI
- Medicaid
- Guardian Ad Litem
- Judge-Foster Care Issues
- Attorneys for Birth Parents

~ About 40 service providers

Systems of Care for Persons With an FASD

- Health

- Education



- Social and community services
- Legal and financial services

Intervention Issues

- Failure in traditional mental health treatment programs
  - People with an FASD may know what they need to do but cannot follow through
  - Caregivers with unrecognized FASD often labeled neglectful, uncooperative, or sabotaging treatment because they do not follow instructions
- Limited FASD-specific treatment services

General Issues With FASD

- Often undiagnosed among persons without FAS facial features
- More difficulties seen in those without FAS facial features and with higher IQs
- Adaptive functioning more impaired than intelligence

Treatment

This section includes:

- General Issues With FASD
- Intervention Issues
- Systems of Care for Persons With an FASD
- Economic Costs of FAS

Benefits of Identification and Treatment

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful

- Helps people with an FASD succeed by focusing on why they have trouble in certain programs

- Helps improve outcomes

- Helps prevent future births of children with an FASD

Risks to an Adult of Not Accurately Identifying and Treating FASD

- Unemployment
- Loss of family
- Homelessness
- Jail
- Premature death
- Increased substance abuse

Risks to a Child of Not Accurately Identifying and Treating FASD

- Loss of family
- Increased substance use
- Premature death

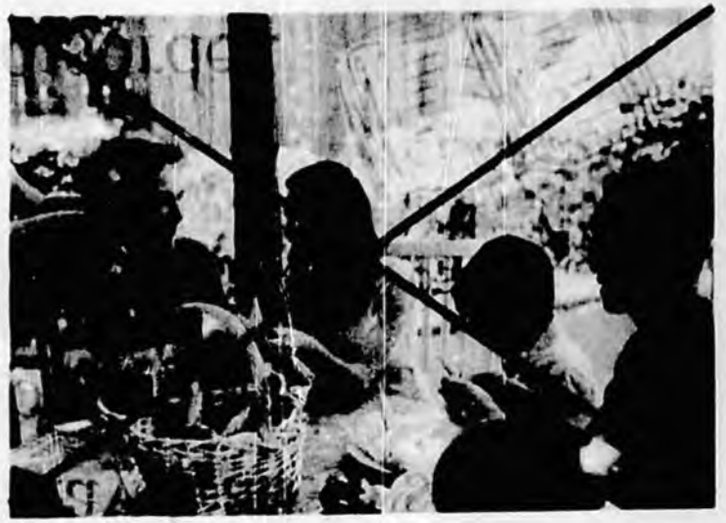


Photo courtesy of Microsoft.

FASD and Mental Health Disorders

- Prenatal alcohol exposure may lead to severe behavioral, cognitive, and psychiatric problems.

DSM-IV

- FASD is not a psychiatric disorder.

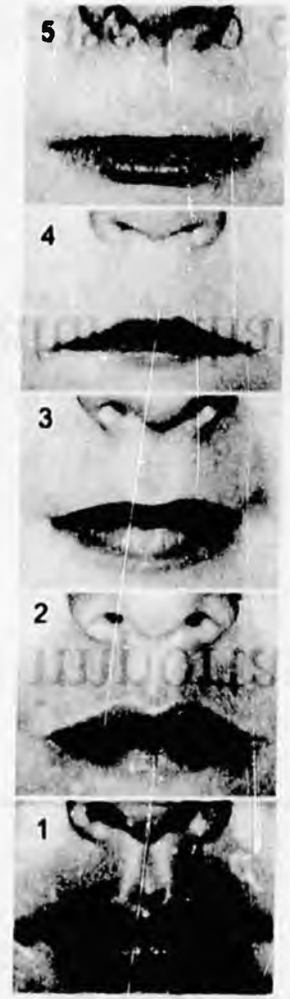
- FASD can co-occur with a mental health or substance abuse disorder.

Differential Diagnosis of Features of FAS

- Differential diagnosis is very important because:
  - Many syndromes can cause features that look like FAS.
  - Facial features alone cannot be used to diagnose FAS.

Diagnosing Fetal Alcohol Syndrome

- Prenatal maternal alcohol use
- Growth deficiency
- Central nervous system abnormalities
- Dysmorphic features
  - Short palpebral fissures
  - Indistinct philtrum
  - Thin upper lip



Lip-Philtrum Guide 1

Caucasian

Lip-Philtrum Guide 2

African American

Source: Astley, S.J. 2004. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition*. Seattle: University of Washington Publication Services, p. 114.

Diagnosis

This section includes:

- Diagnosing Fetal Alcohol Syndrome
- Differential Diagnosis of Features of FAS
- FASD and Mental Health Disorders
- Risks to a Child of Not Accurately Identifying and Treating FASD
- Risks to an Adult of Not Accurately Identifying and Treating FASD
- Benefits of Identification and Treatment

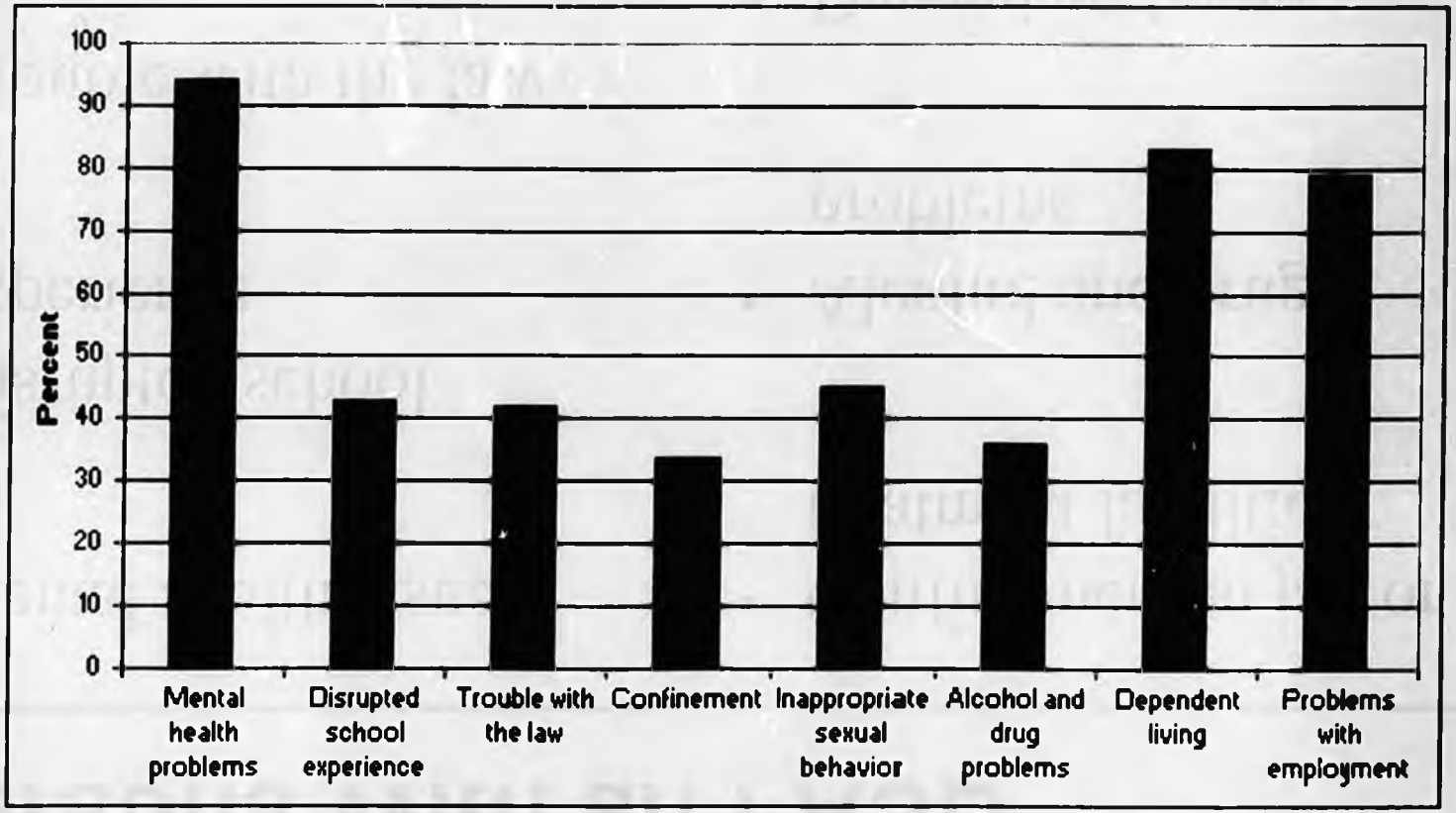
Factors Associated With Reduced Secondary Disabilities

- 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:

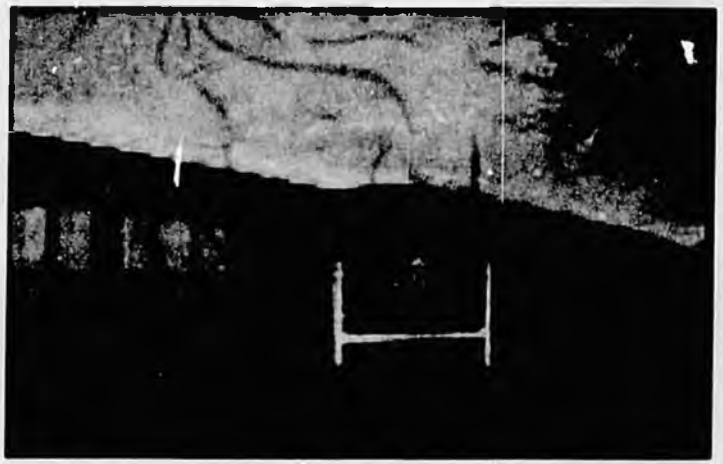
- Overall Difficulties for Persons With an FASD
- Primary Disabilities of Persons With an FASD
- Typical Difficulties for Persons With an FASD
- Secondary Disabilities of Persons With an FASD
- Factors Associated With Reduced Secondary Disabilities

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

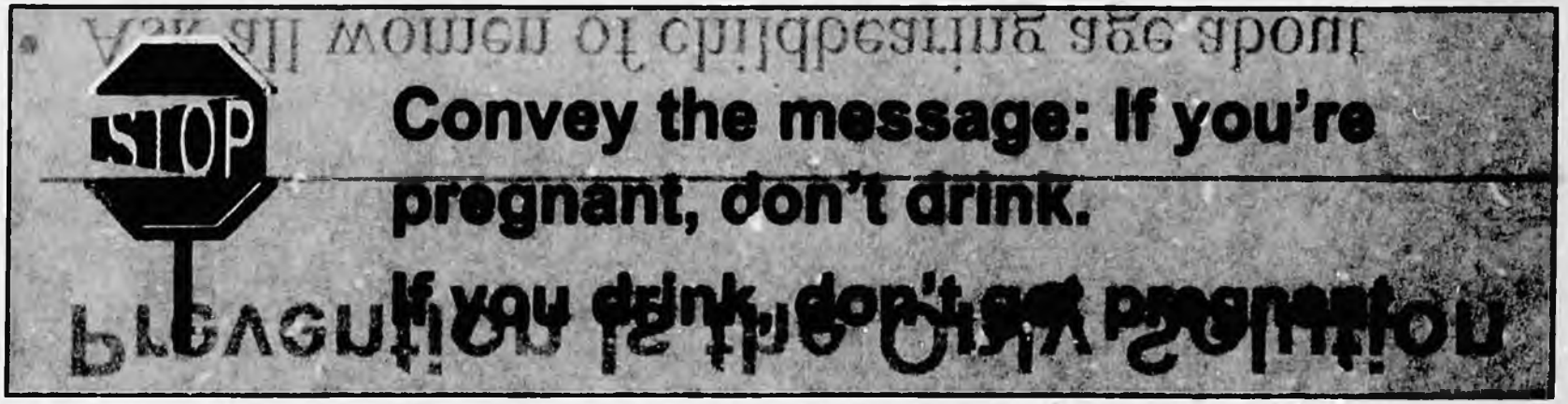
- Women of childbearing age?
- Women who have a history of alcohol or other drug use?
- Women who are at risk?
- Teenagers?
- Men?
- EVERYONE!

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.

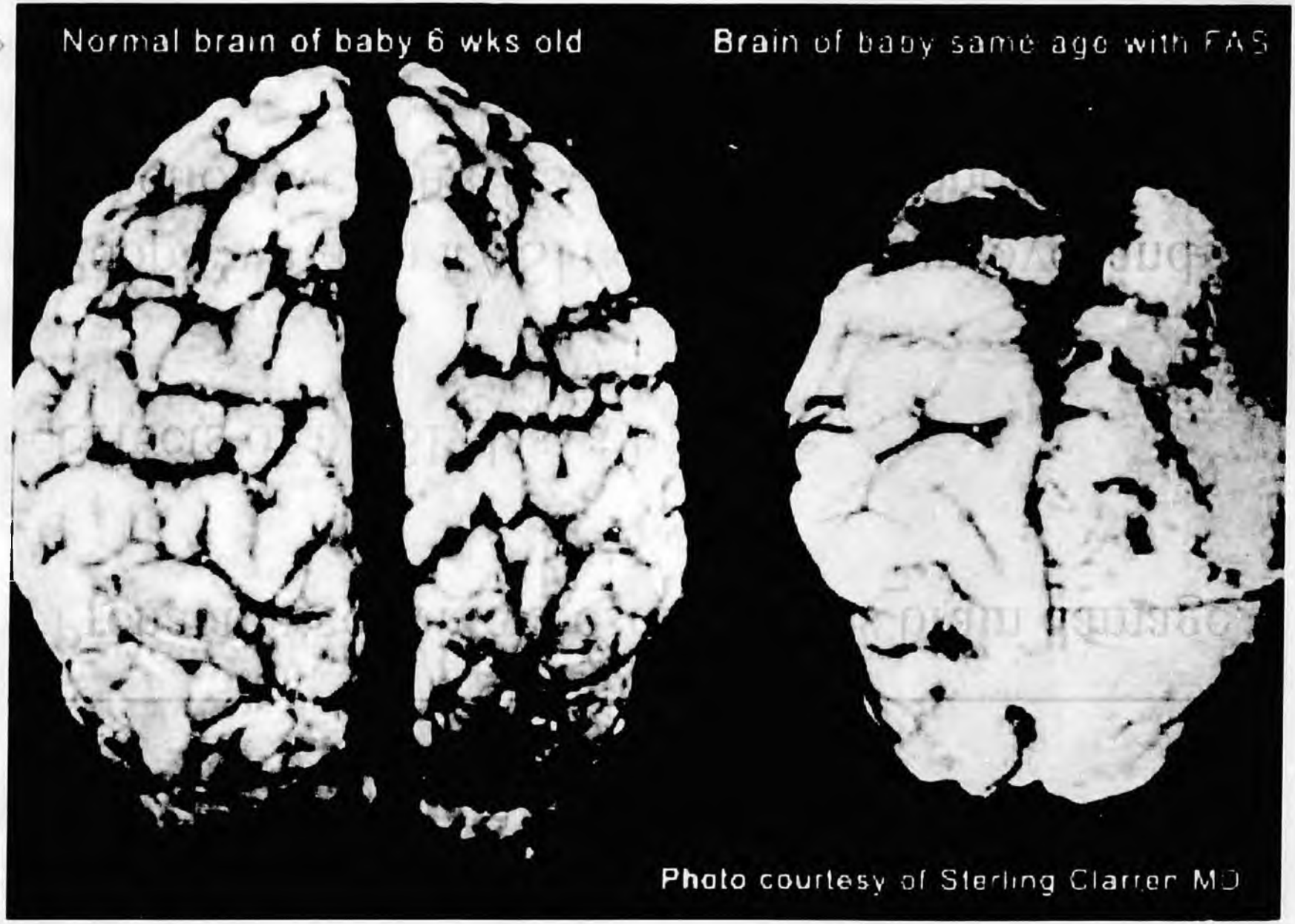
FAS and the Brain

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

Permission to use photo on file.



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

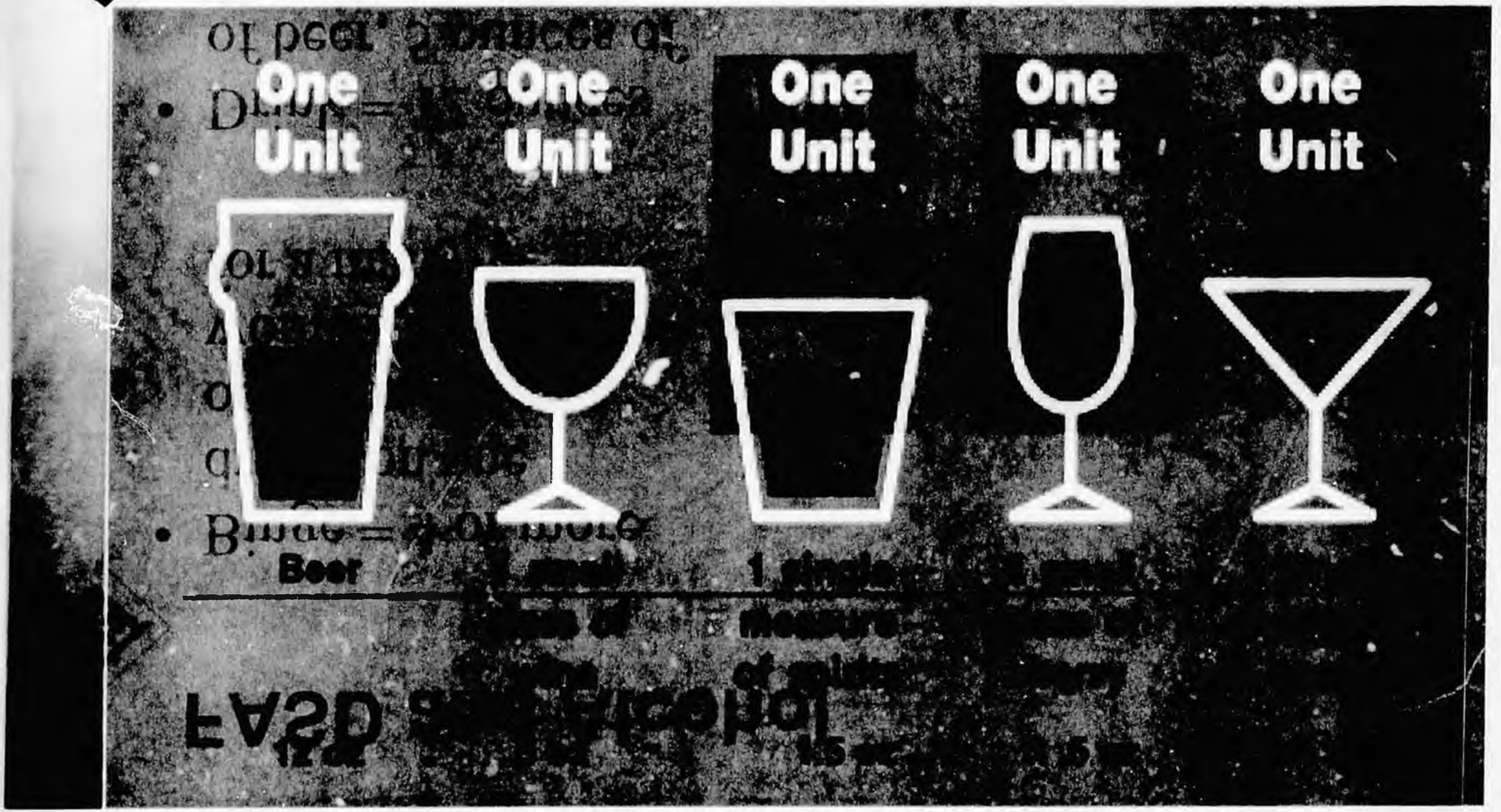
Size Matters

12 oz.

VS.

16 oz.

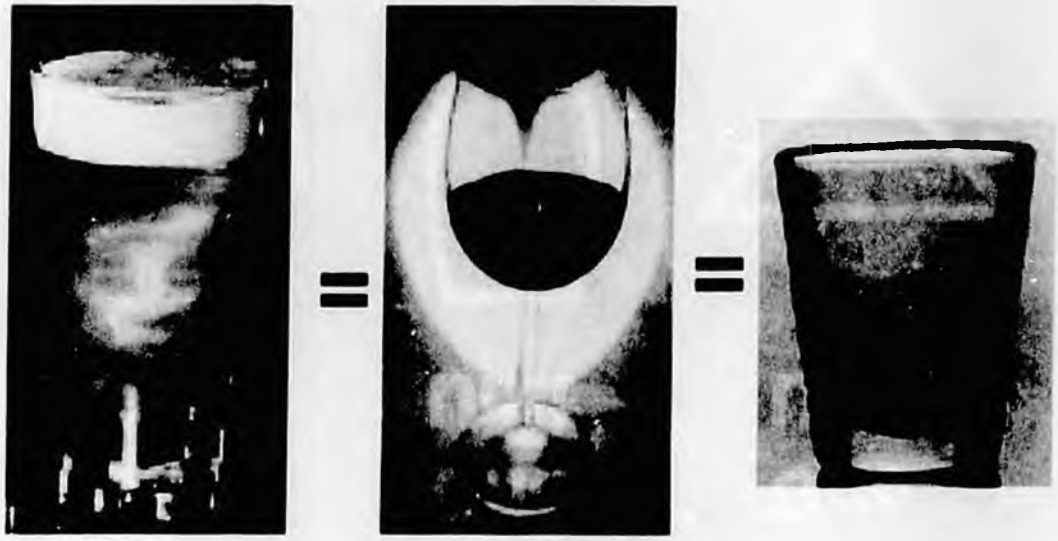
Size Matters



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.

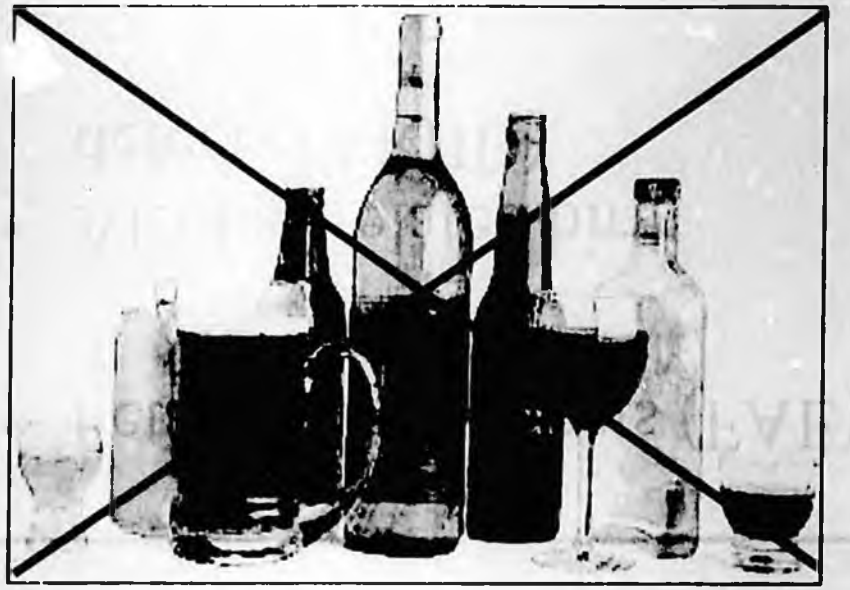
- Alcohol is a teratogen.

"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

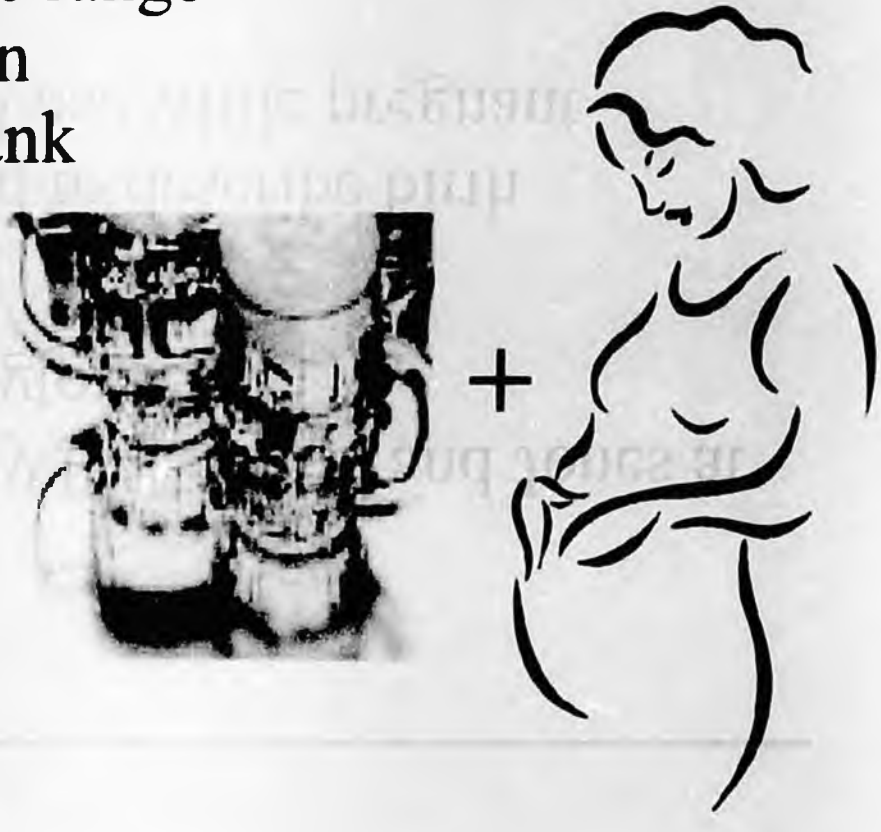
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)

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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Fred L. Bookstein, Ph.D.

Final Report

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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

(DDD) is also a strong protective factor for most secondary disabilities. The services provided by DDD would appear to be both useful and necessary for many clients with FAS/FAE who do not now qualify.

7. Violence against individuals with FAS/FAE occurred at an alarming rate: 72% had experienced physical or sexual abuse, or domestic violence. Being a victim of violence was a strong risk factor for Inappropriate Sexual Behavior, increasing the odds fourfold. Children and adults disabled by FAS/FAE must have better protection and their families may need special training and guidance about Inappropriate Sexual Behavior.

8. Thirty females with FAS/FAE had given birth to a child. Of these, 57% no longer had the child in their care, 40% were drinking during pregnancy; 17% had children diagnosed FAS or FAE; and an additional 13% had children who were suspected by the informants of having FAS/FAE. Special advocacy services for these high risk mothers who themselves have FAS/FAE and special attention to their birth control needs and child care needs should be a top priority.

Recommendations Deriving from the Findings

1. Develop statewide networks of local FAS/FAE Diagnostic Clinics coordinated with local community service providers, to facilitate early diagnosis. This could reduce disrupted schooling, trouble with the law, inappropriate sexual behavior, confinement, alcohol and drug problems, dependent living, and problems with employment, because the organic problems of the child will be recognized from an early age.

2. Develop a coordinated system of parent and citizen education centers, and a system for ongoing in-service training programs for all relevant service providers. These should focus on strategies for improving the quality of life, increasing the duration of stay in each placement, and providing the appropriate life skills and job skills training. This could decrease all secondary disabilities.

3. Develop a state inter-agency network specifically on FAS/FAE including representatives from key state and private agencies and parents groups, to identify an "FAS/FAE Coordinator" within each agency, and to develop methods for detecting, diagnosing, and serving this population. Multiple state agencies, including mental health, schools and special education, the juvenile and criminal justice system, alcohol and drug abuse treatment, and the health department must be involved in this effort. No single agency can be responsive to all the broad based needs of people with FAS/FAE and their families.

4. Fund research on methods to quantify the Central Nervous System impairments associated with FAS/FAE in order to develop clinically-useful diagnostic tools for the neurobehavioral effects of prenatal alcohol exposure. This should facilitate diagnosis of alcohol-affected individuals without the facial dysmorphology and growth deficiency, and permit a speedier response to their service needs before the onset of secondary disabilities.

5. Develop and test new methods (such as those identified in this report) that could be utilized for modifying the eligibility criteria for services from the Division of Developmental Disabilities. Enhancing eligibility for case management, job coaching, and supervised housing should reduce the level of costly secondary disabilities among individuals with FAS/FAE who are unable to live and work independently, but are now unable to get appropriate services because they may not have an IQ below 70 or a full FAS diagnosis.

6. Fund a model long-term residential/job training program for youth and adults with FAS/FAE, and then implement this statewide and nationwide.

7. Mandate the full disclosure of medical/mental health/background history when placing a child in foster or adoptive placements, and provide education and training on FAS/FAE and appropriate support services to families raising such children, including biological families.

8. Prevent future children from being born with FAS/FAE: (1) Expand alcohol/drug inpatient treatment programs for women and their children; (2) Fund a statewide network of Birth to 3 Advocacy programs

for working with the highest risk mothers abusing alcohol/drugs during pregnancy; and (3) Provide advocacy and free long-term birth control options to women with FAS/FAE.

Conclusions

1. People with FAS and FAE have an unacceptable level of secondary disabilities that severely impairs their quality of life and is extremely costly to society.

2. The low level of societal protection and support given to people with FAS and FAE and their families is unacceptable and further compromises their lives. They should be given an appropriate level of societal protection and support. To do this, their primary disabilities must be better understood by families, service providers, and by society at large.

3. The permanent, organic brain damage of people with FAS and FAE is often "hidden" in that it often does not conform to current system guidelines for providing services, such as: a low IQ score, a debilitating physical handicap, serious mental illness, or even an FAS face (and diagnosis).

4. By understanding the devastating secondary disabilities that characterize most individuals with FAS/FAE, and by understanding the intrinsic and extrinsic risk and protective factors that exacerbate or ameliorate these disabilities, we should be able to improve the quality of life for people with FAS and FAE and their families, and to reduce costs to society.

5. The magnitude and cost of these secondary disabilities is huge—when calculated against the estimated figure of 1 to 3 FAS per 1000 births (NIAAA, 1987) and several fold this figure for FAE.

2 Introduction

It is fitting that the International Conference on Overcoming and Preventing Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects is being held at the University of Washington School of Medicine, September 4-6, 1996. This University has been an important site for fetal alcohol studies for the past 23 years.

In 1973, Kenneth Lyons Jones and David W. Smith, dysmorphologists at the University of Washington Medical School, Department of Pediatrics, identified a "similar pattern of craniofacial, limb, and cardiovascular defects associated with prenatal onset growth deficiency and development" in eight unrelated children of three ethnic groups, all born to chronic alcoholic mothers (Jones, Smith, Ulleland, & Streissguth, 1973). The distinctive pattern of malformations indicated that the damage was of prenatal origin. In a second report, three more infants were identified, and the first necropsy on such a patient "disclosed serious dysmorphogenesis of the brain," which the authors thought might be responsible for some of the functional abnormalities and joint malpositions seen in the syndrome. The naming of this syndrome as Fetal Alcohol Syndrome (FAS) put the emphasis squarely on the presumed etiology and brought international attention to this phenomenon (Jones & Smith, 1973). Among the letters that came to David Smith, was one from Paul Lemoine of Nantes, France, who had published a large study of children born to alcoholic mothers who had similar features and behaviors. Lemoine and colleagues had published their findings in 1968 in a local pediatric journal, but the article had not been translated into English, nor had it appeared in the international medical literature.

From the start, both groups of investigators were fascinated with the unusual behaviors of these children who looked alike (although they were not related) and behaved in a hyperactive and unfocused manner. Through utilization of records from the National Perinatal Collaborative Project (NPCP), Jones and colleagues (1974) were able to demonstrate that 44% of the children of chronic alcoholic mothers identified during pregnancy had "borderline to moderate mental retardation" (defined as an IQ of 79 or below) when examined at 7 years of age. Thirty two percent had enough abnormal features from the physical examination alone to suggest the Fetal Alcohol Syndrome. In a carefully matched comparison group selected from over 50,000 other women and children in the NPCP study, fewer than 10% of the other children had IQ scores below 79, and none had the physical features of FAS.

Clarren and colleagues (1978) presented additional evidence of Central Nervous System (CNS) damage in patients with FAS, "neuropathologic findings on four human neonates exposed to large amounts of ethanol at frequent intervals during gestation...All four brains showed similar malformations stemming from errors in migration of neuronal and glial elements." Two had hydrocephalus and only two of the four were diagnosed as having the Fetal Alcohol Syndrome from external criteria. They concluded: "...the brain alterations may be the only distinct abnormality produced by in utero ethanol exposure." Since 1978 children who had some but not all the features of FAS have been referred to as having Fetal Alcohol Effects (FAE) (Hanson et al., 1978) or Possible Fetal Alcohol Effects (PFAE) (Clarren & Smith, 1978). Recently there have been suggestions that the terminology should be reconsidered (Aase et al., 1995; IOM, 1996).

Within 4 years of the naming of Fetal Alcohol Syndrome, experimental studies of laboratory animals were published demonstrating that alcohol is teratogenic and can produce malformations from prenatal exposure (e.g., Chernoff, 1977; Randall et al., 1977). By 1978, 245 clients with Fetal Alcohol Syndrome had been reported in the medical literature, and FAS was described as the "most frequent known teratogenic cause of mental deficiency in the western world" (Clarren & Smith, 1978). It also was recognized by this time that prenatal alcohol exposure produces a whole spectrum of effects, of which FAS is the most clearly definable.

By the mid 1980's, it was apparent that the physical features of FAS were less unique and characteristic after the onset of adolescence. Clients with this disorder whom we had watched grow up in Seattle had far more life problems than would be expected solely on the basis of their mental retardation or delayed development. Furthermore, as more clients were evaluated, it was clear that there were many children with the full features of FAS who did not technically qualify as mentally retarded, and in many instances, had trouble obtaining appropriate services (Streissguth et al., 1985). It also was clear that many children without the physical manifestations of FAS were also born to alcohol abusing mothers, and that these too had cognitive and adaptive behavior problems similar to children with FAS (Streissguth et al., 1991a).

Efforts to prevent FAS began almost as soon as alcohol was clearly identified as a teratogen, and several public policy decisions were made to enhance efforts to prevent the prenatal effects of alcohol. The Surgeon General of the U.S. (1981) recommended that women not drink alcoholic beverages during pregnancy or when planning a pregnancy. Congress passed legislation in 1989 to mandate warning labels on all alcohol beverage containers sold in the U.S. that included a warning against drinking alcohol during pregnancy.

Understanding the long-term impacts of FAS and FAE on society has taken more time. Understanding the life problems that characterize people with FAS and FAE as they grow and mature is essential to: developing effective interventions, estimating the costs to society, and mandating appropriate public policies.

FAS and FAE have been recognized for the past 20 years as major known causes of developmental disability. Yet, it is only in the past 10 years that the lifelong implications of these disabilities have been recognized. Follow-up studies in four countries have demonstrated the continuing adverse effects of prenatal alcohol exposure into adolescence and adulthood (Aronson, Olegard et al., 1987; Lemoine & Lemoine, 1992; Majewski, 1993, Spohr et al., 1993; 1994; Steinhausen et al., 1993; 1994; Streissguth et al., 1985; 1991).

In 1992, in recognition of this problem, the Centers for Disease Control and Prevention (CDC) through the National Center for Environmental Health, Disabilities Prevention Program, issued a request for proposals. The present research project was undertaken in response to that request. The aim of this project has been to build a prevention information base fundamental to the amelioration of secondary disabilities in clients with FAS and FAE.

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.

The study has three main goals:

1. To document the occurrence and range of secondary disabilities that are associated with FAS and FAE.
2. To determine the risk factors associated with these secondary disabilities in order to make recommendations for preventive strategies.
3. To develop a brief Fetal Alcohol Behavior Scale (FABS) so that state/community agencies may identify clients with probable FAS/FAE who may be in need of special services to prevent additional secondary disabilities.

This document is the Final Report of that project.

3 Methods

3.1 Diagnostic Criteria

Fetal Alcohol Syndrome (FAS) is diagnosed when three primary characteristics occur together: growth deficiency, a characteristic pattern of abnormalities primarily observable in the face, and some manifestations of Central Nervous System (CNS) dysfunction. The definition of CNS criteria used here is in keeping with that originally used by Clarren and Smith (1978) and is *not* wholly consistent with the modification suggested by the recent IOM (1996) report for diagnosing FAS. Over the years, a small number of children had been diagnosed PFAS (possible or probable FAS). This term was applied to borderline cases: either the CNS and facial features were classic but the growth was marginal, or the CNS and growth deficiency were classic and the face was "almost" classic. For this report, PFAS and FAS were combined. Fetal Alcohol Effects (FAE) and PFAE (possible or probable FAE) are terms that have been used clinically to apply to individuals who manifest some, but not all of the characteristics of FAS, but were exposed prenatally to significant levels of alcohol. The terms FAE and PFAE, as they have been used by Seattle dysmorphologists since 1974, *are* consistent with the new diagnostic category of ARND (Alcohol Related Neurodevelopmental Disabilities) suggested by the IOM (1996). For this report, FAE and PFAE were combined.

In the present study, a diagnosis of FAS was assigned to clients who had: (1) a clear history of prenatal alcohol exposure; (2) dysmorphic features (primarily observed in the face, such as short palpebral fissures, a pattern of flattened midface, smooth and/or long philtrum, and thin upper lip); (3) growth retardation for height and/or weight below the 10th percentile; and (4) CNS dysfunction (as manifested by microcephaly, developmental delay, hyperactivity, attention and/or memory deficits, learning difficulties, intellectual deficits, motor problems, neurologic signs, and/or seizures). A diagnosis of FAE or PFAE was attributed to those who had a clear history of prenatal alcohol exposure and CNS dysfunction, but did not manifest all of the physical features of FAS. All diagnostic evaluations were performed by physicians trained in dysmorphology and genetics.

3.2 Ascertainment

The 661 clients in this study represent a gradually accrued group that began with the first patients diagnosed FAS in 1973 by Jones and Smith and ended with those who came to the University of Washington, FAS Diagnostic Clinic between 1993 and 1995. The clients were largely ascertained through clinical referral across a 22-year period, and diagnosed by a small homogeneous group of dysmorphologists who were trained by David W. Smith at the University of Washington Dysmorphology Unit. The sample includes, but is not limited to all those available from the following published studies: 11 clients from the two 1973 Lancet papers describing FAS (Jones et al., 1973; Jones & Smith, 1973); 20 and 17 clients respectively, from the first two FAS follow-up studies (Streissguth, Herman, & Smith, 1978a and b); 8 clients from the 10-year follow up study of the first 11 clients diagnosed with FAS (Streissguth et al., 1985); Northwest sample only (n=51) of the first FAS follow-up study of adolescents and adults (Streissguth et al., 1991a); 10 clients in the test-retest IQ study of adolescents and adults (Streissguth, Randels, & Smith, 1991b); and 24 clients participating in the FAS genotype study (Faustman et al., 1992). The published groups are overlapping, but data for each client are counted only once in the report that follows.

Ascertainment of the 661 clients was through clinical referral for an FAS diagnostic evaluation or through participation in ongoing FAS research projects conducted by the Fetal Alcohol and Drug Unit. Sterling Clarren was the primary diagnostician, diagnosing two-thirds of the clients; David W. Smith, Kenneth L. Jones, and Smith's other dysmorphology fellows diagnosed 7% of the sample. Twenty four percent of the sample were diagnosed during or before 1990, 15% were diagnosed 1991-1992, and 61% were diagnosed in 1993 or later at the University of Washington FAS Diagnostic Clinic, directed by Sterling Clarren. The clients were primarily from the Pacific Northwest.

The University of Washington FAS Diagnostic Clinic was established with primary funding from CDC in January 1993. Patients are referred to the FAS clinic by physicians, parents, teachers, caseworkers and other concerned caregivers. Patients are typically referred for cognitive and behavioral problems, and must have a confirmed or suspected history of prenatal alcohol exposure. Only a small number of patients are referred to the clinic based on there being a history

or prenatal alcohol exposure, without major concern for behavioral or cognitive delays. The clinic meets one day per week and can accommodate 4 or 5 patients per day. As many more clients apply than can be seen, priority is given to those whose biologic mothers are living and known to be in the area, in keeping with the goals of the CDC grant that provides basic funding for the FAS clinic (Clarren & Astley, 1997).

3.3 Recruitment

Patients were referred from the FAS Diagnostic Clinic for our Secondary Disabilities Study. Those clients who met diagnostic criteria and who, along with their caregivers, consented to participate were enrolled in the study. The study, which was approved by the University of Washington Human Subjects Review Committee, was explained to the families by our client advocate. Additionally, a Confidentiality Certificate was obtained from the Public Health Service to further protect the clients and their families. Three kinds of consents were obtained: (1) for participation in the study, (2) for photographs, and (3) for release of information from schools, hospitals, etc. Clients in our other FAS research projects who met the diagnostic criteria were also notified about the new study and asked to participate. Caregivers were contacted over a four-year period to gather and update information on past and current client status, Secondary Disabilities, and Risk and Protective Factors. Reports of psychological evaluations conducted for research purposes were provided upon request to the clients or their caregivers. In case of a crisis call, clients were referred to appropriate community agencies and professional local services.

3.4 Samples

This final report utilizes two overlapping samples from the 661 clients in this study, one sample for describing the Primary Disabilities (n=473) and one for describing the Secondary Disabilities (LHI Sample, n=415—see Table 3.1). All clients were diagnosed either FAS, FAE, PFAS, PFAE, or ARND as described above. Clients from southwest Indian reservations who were included in earlier reports (Streissguth et al., 1988 Manual; Streissguth et al., 1991a; LaDue, Streissguth, & Randels, 1992) are not included in the current report because their recruitment and follow-up were not comparable to those clients in the Northwest. The Primary Disabilities sample includes clients from three years of age and up, the Secondary Disabilities sample includes those 6 years and older. Although the two samples are not entirely nested, the referral source, the diagnosing physician, and the age and date of diagnosis were comparable for the two samples.

Table 3.1 Secondary Disabilities Sample (LHI): enrollment and interview status

Interview status	(n)
Enrolled patients	661
Not eligible for LHI:	
too young (< 6 years old)	82
SW reservation clients	64
enrolled too late, data not processed in time	9
Eligible interviews not obtained:	
family could not be found	52
caretaker refused interview	22
caretaker not available for interview	16
invalid interview	1
Total valid interviews conducted	415

The 91 eligible clients for whom LHI's were not obtained do not differ from the 415 for whom LHI's were obtained in terms of alcohol-related diagnosis, age at diagnosis, frequency of diagnosis prior to 1980, ethnicity, or sex. The loss of these 91 does not seem to present a bias in extent of Primary Disability in that they do not differ significantly from the 415 valid interviews in: IQ (as measured either by mean IQ score or by number of IQ scores at or below 70); achievement (WRAT reading, spelling, arithmetic scaled scores); or adaptive behavior (VABS, Communications, Daily Living Skills, socialization, and Adaptive Behavior Composite). The interviewed sample appears to be fairly representative of the full set of eligible clients accumulated in this database.

3.5 Primary Disabilities Sample (IQ): Tests Administered

Clients were administered an age-appropriate Wechsler IQ Test: Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R); Wechsler Intelligence Scale for Children-Revised (WISC-R); and the Wechsler Adult Intelligence Scale-Revised (WAIS-R) (Wechsler, 1967, 1974, 1981). The Wide Range Achievement Test-Revised (WRAT-R) (Jastak & Wilkinson, 1984) was also administered individually to each client, and the Vineland Adaptive Behavior Scale (VABS) (Sparrow et al., 1984) was administered to a caretaker or person who knew the client well, usually at the time the IQ and achievement tests were administered. Testing was carried out primarily at the Fetal Alcohol and Drug Unit (FADU) or in clients' homes or schools.

Every effort was made to schedule testing at a time and location convenient for the client and caregiver, including evenings and road trips to the client's school or home. If clients were unable to be seen for psychological testing, scores from previous IQ and achievement evaluations were used for analysis when available. Reports of psychological evaluations were systematically requested from the schools. All applicable scores were entered into the database and used in analysis. The clients were not asked to come in for psychological evaluations if they had been administered IQ tests within the past year and achievement tests within the past 6 months.

The following psychological test scores were used in the present analyses: From the WPPSI, WISC-R, and WAIS-R: the full scale IQ score, the Verbal Scale IQ score (VIQ), the Performance Scale IQ score (PIQ), and the 11 Subtest Scores were used. WISC-III IQ scores, corrected for comparability with the WISC-R, were used for 11 clients who either could not be seen at our lab for testing or who had been tested at their schools on the WISC-III within the prior year, so were not eligible for retesting. From the WRAT-R: the Standard Scores (SS) for Reading, Spelling, and Arithmetic were used. From the VABS: the Standard Scores from the Adaptive Behavior Composite (ABC) and the Standard Scores for Socialization, Communication, and Daily Living Skills were used.

3.6 Secondary Disabilities Sample: Life History Interview (LHI)

The Life History Interview (LHI) was developed in the third year of the project to evaluate clients of any age and any degree of disability in order to attain maximum coverage of the sample. The focus of the LHI was on the kinds of Secondary Disabilities and Risk and Protective Factors that characterize these clients. The interview was administered by telephone to caretakers/informants of the clients.

The LHI grew out of our experience with deriving secondary disability data from the clinical database that has been accruing during the many years we have been following these clients. Some preliminary secondary disabilities data, coded directly from our clinical records, were presented previously (Streissguth, Kopera-Frye, & Barr, 1994). Higher rates of Secondary Disabilities were obtained from the LHI than from abstracting our clinical database.

The LHI is a comprehensive structured evaluation of ten major areas of possible long-term functional covariates or consequences characteristic of clients diagnosed with FAS/FAE: (1) household and family environment; (2) independent living and financial management; (3) education; (4) employment; (5) physical abuse, sexual abuse and domestic violence; (6) physical, social and sexual development; (7) behavior management and mental health issues; (8) alcohol and drug use; (9) legal status and criminal justice involvement; and (10) companionship and parenting. These areas of concern were explored in terms of past and current client status, secondary disabilities, and possible risk and protective factors.

Interviewers phoned ahead of time to schedule a convenient time for the interviewee and asked to interview the person who knew the client best. Adoptive mothers were the most frequent informants, 33%; followed by biologic mothers, 17%; foster mothers, 12%; stepmothers, 6%; fathers (all types), 7%; legal guardians, 7%; grandmothers, 4%; other relatives, 1%; caseworkers, 6%; spouses or partners, 1%; residential caretakers, 1%; and by others, 2%. A small proportion of the clients, 2%, had no one available who knew them well, so were interviewed themselves for the LHI. Self report data were only used when they appeared valid in terms of existing data in the clinical database. A total of 415 valid interviews were obtained and coded during a 14-month interval in 1995.

The 37 page LHI contains over 450 separate questions organized to provide the interviewer with clear visual guides for accurate coding. Most questions required the interviewer to code a choice according to a prespecified list of responses. Other questions permitted open-ended responses which were written in verbatim and coded later. Validity ratings by the interviewer follow each section of the LHI. A section was coded "valid" when the responses appeared to be genuine and focused on the questions being posed. A section was coded "questionable" if the informant did not know the client well, seemed guarded, seemed confused and/or contradicted himself/herself, seemed to be biased, seemed hostile, did not understand or speak English very well, or seemed mentally handicapped. All sections with questionable validity codes were reviewed prior to data analysis.

Seven interviewers were trained in administration and coding procedures by the project director, who was regularly available to address queries. Each completed interview was reviewed by the team of interviewers, and coding consensus was reached for any items under contention. Finally, all coded interviews were reviewed by the project director before they were submitted for data entry.

The LHI took, on average, 70 minutes to administer (range, 18 minutes to 3½ hours). Interviews took longer to administer when they involved older clients or those with a greater number of Secondary Disabilities. Interview length was not related to sex, race, or fetal alcohol-related diagnosis of the client.

Most caregivers felt that the LHI covered major areas of the client's functioning, in terms of prevalent problems, possible environmental buffers, and assessment of service needs. Many caregivers stated they felt that the data generated from this interview, once disseminated to the service agencies and community advocates, would help them provide better care for their children with FAS/FAE.

3.7 Quantifying Data Across the Life Span

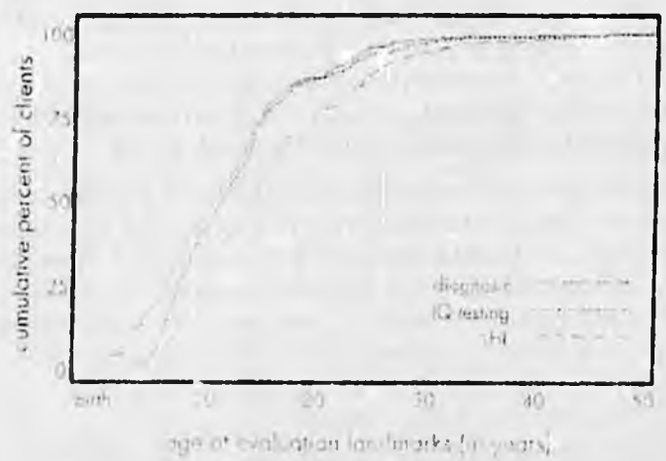
Data presented in the following chapters were collected across the life span of each client. A given client may have been diagnosed FAS (or FAE) at age 3 years, given an IQ test at age 5 years, and had a caretaker provide information for the LHI when the client was 16 years old. In addition, questions on the LHI assess the onset for many outcomes (age of onset of alcohol/drug problems, age of onset of problems in school). Thus, a given client may contribute data to any of several age groups depending on the topic at hand.

Figure 3.1 presents the cumulative age distributions for ages at which three key evaluation landmarks were made: diagnosis, IQ testing, and LHI. One at a time, follow the dotted horizontal line (at 50%, or median) to each of the three curves and drop a vertical line to the "age" axis. It is seen that the median ages at diagnosis, IQ testing, and LHI are approximately 10, 11, and 14 years, respectively. The dashed line for LHI is to the right of the other lines indicating that this was generally the most recent data collected.

The eight Secondary Disabilities are defined by any history of the secondary disability since birth. Thus, a comment that 59% of clients 21 years and older were reported as having a history of Disrupted School Experience does not mean that problems in school happened after age 21 years; the disruptions may have occurred at much younger ages. Ages at interview correspond to age covered by the history of secondary disability as follows:

- History of secondary disability for clients 21-51 years old at interview covers ages: birth-age at LHI (birth to 51 years)
- History of secondary disability for clients 12-20 years old at interview covers ages: birth-age at LHI (birth to 20 years)
- History of secondary disability for clients 6-11 years old at interview covers ages: birth-age at LHI (birth to 11 years).

3.1 Client ages at evaluation landmarks (LHI sample, n=415)



3.8 Strengths and Limitations of Study Design and Analysis

The strengths of this study design are: It attempts complete coverage of a large and established roster of clients, recruited in a similar manner and examined in a uniform setting. There is no apparent bias in data collection or cooperation. The clients span a broad spectrum of ages, socio-economic backgrounds, and rearing conditions. The instrument (the Life History Interview—LHI), in the hands of a skilled interviewer, seems robust over a huge range of informants and across the full age range of clients, 6 through 51 years, providing extensive coverage of life experience. The LHI has a rich and redundant coding scheme covering many different kinds of behaviors and difficulties.

The limitations of the study design are: It does not involve a representative sample of any defined population. It contains no measures of dose except that all clients were born to mothers who abused alcohol. The diagnostic categorization, although carried out by a small number of dysmorphologists with the same training, is subject to temporal changes in interpretation and referral patterns. Effective utilization of the LHI requires gifted interviewers, trained by those with extensive experience with FAS across the lifespan, and the prior establishment of trust and rapport with families. Nevertheless, the LHI data are only as valid as the knowledge and capabilities of the informants. Obviously there was no random assignment of clients, caretakers, or interventions.

The strengths of the data analysis are: It represents an effective distillation of the vicissitudes of hundreds of lives into a small number of major channels of secondary disability. The sample is large enough to subset informatively in many different and interesting ways. Statistical analysis easily translates into English sentences. Findings are strong and plausible in respect of aspects of the client and also of the client's environment. Many risk/protective factors common to most secondary disabilities have been detected. The statistics are quite simple; the graphics are powerful. The findings lead easily to policy implications and recommendations.

The limitations of the data analysis are: There is no real possibility of assessing causation. The secondary disabilities are intercorrelated as are the risk/protective factors. There is no apparent concern for hypothesis-testing of the academic flavor. The absence of intervention research on this population precludes assessment of the causal role of interventions.

4 Client Characteristics

Two samples are described in this report: The Primary Disabilities Sample (determined by the 473 clients on which a valid IQ test was obtained) and the Secondary Disabilities Sample (determined by the 415 clients on whom a Life History Interview (LHI) was obtained). The two samples are comparable demographically with respect to sex, ethnicity, and diagnosis. Each sample is approximately one-third FAS and two-thirds FAE. The Secondary Disabilities Sample excludes clients below age 6, but includes more clients who are over 21 years.

The two samples have 378 clients in common. Thirty-seven individuals have an LHI but no IQ exam, and 95 have an IQ exam but no LHI. As IQ data from past examinations on our unit had to be used for old clients who could not be brought in for examination, 73 of the 473 IQ scores are evaluations conducted when the clients were 3-6 years of age.

Table 4.1 presents demographic characteristics of the Secondary Disabilities Sample.

Table 4.1. Demographic Characteristics of the Secondary Disabilities (LHI) Sample (N=415).

Demographic Characteristics	N	(%)
SEX		
Male	236	(57%)
Female	179	(43%)
ETHNICITY		
White	248	(60%)
Native American	103	(25%)
Black	30	(7%)
Hispanic	27	(6%)
Asian	5	(1%)
Other	2	(<1%)
PATIENT AGE AT TIME OF INTERVIEW		
6-11 Years	162	(39%)
12-20 Years	163	(39%)
Over 21 Years	90	(22%)

The 415 clients in the Secondary Disabilities Sample ranged in age from 6 to 51 years at the time the interview was administered to their caretakers or informants. Overall, their median age was 14.2 years. The data in this report are divided into three age groups as shown below. Table 4.2 shows the breakdown of these age groups by sex and diagnosis, Table 4.3 by age at diagnosis and year of diagnosis.

Table 4.2 The Secondary Disabilities (LHI) Sample (n=415) by sex, diagnosis, and age at interview

	6-11 years		12-20 years		21-51 years		Total	
Median age	8.7 years		15.8 years		25.7 years		14.2 years	
(n)=	(162)		(163)		(90)		(415)	
Diagnosis	Male	Female	Male	Female	Male	Female	Male	Female
FAS	24	22	34	22	26	27	84	71
FAE	67	49	68	39	17	20	152	108
Total	91	71	102	61	43	47	236	179

Table 4.3. The Secondary Disabilities (LHI) Sample by age of diagnosis, year of diagnosis, and age at interview

Age at LHI	(n)	6-11 years N=162	12-20 years N=163	21-51 years N=90
Age at Diagnosis				
Birth to 5	(94)	65 (40%)	12 (7%)	17 (19%)
6-11	(145)	97 (60%)	44 (27%)	4 (4%)
12-20	(130)	0 (0%)	107 (65%)	23 (26%)
21 and over	(46)	0 (0%)	0 (0%)	46 (51%)
Year of Diagnosis				
1973-1975	(18)	0 (0%)	3 (2%)	15 (17%)
1976-1980	(15)	0 (0%)	5 (3%)	10 (11%)
1981-1985	(18)	2 (1%)	5 (3%)	11 (12%)
1986-1990	(49)	15 (9%)	22 (13%)	12 (13%)
1991-1992	(62)	25 (16%)	27 (17%)	10 (11%)
1993-1995	(253)	120 (74%)	101 (62%)	32 (36%)

Table 4.4 shows the current living situation of these 415 clients by age at interview. About half of these clients lived with biologic or adoptive parents at the time the interview was conducted.

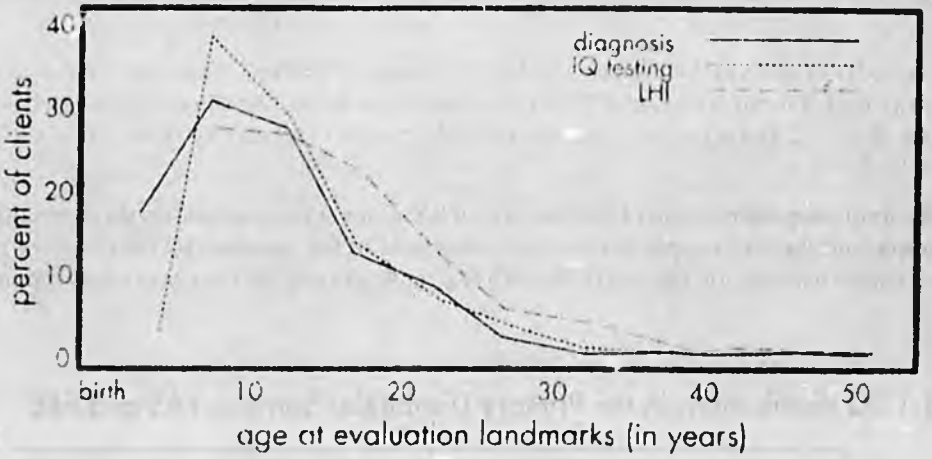
Table 4.4. Current Living Situation of 415 Clients with FAS/FAE at time of interview

Living Situation	Client age at interview:					
		6–11 years		12–20 years		21 years and over
	TOTAL	FAS	FAE	FAS	FAE	FAS	FAE
Biological Parents	9	2	1	1	3	1	1
Biological Mother	51	4	13	6	19	2	7
Biological Father	34	3	14	3	10	3	1
Adoptive Relatives	10	1	4	1	4	0	0
Non-Adoptive Relatives	22	9	4	3	3	0	3
Adoptive Parents	94	12	39	16	20	5	2
Foster Parents	55	8	23	9	12	3	0
Legal Guardian	25	7	11	2	4	1	0
Friends	7	0	0	1	5	0	1
Spouse only	5	0	0	0	0	3	2
Spouse and Children	3	0	0	0	0	2	1
Partner Only	9	0	0	1	3	2	3
Partner and Children	3	0	0	0	1	2	0
Single Parent with Children	5	0	0	0	0	2	3
Live-in Work	1	0	0	0	1	0	0
Armed Forces	2	0	0	1	0	1	0
Alone	19	0	0	0	0	10	9
With or Near Attendant	1	0	0	0	0	1	0
Rent Subsidy Program	1	0	0	0	0	1	0
Assisted Living	2	0	0	0	0	2	0
Shared Living	6	0	0	0	2	3	1
Therapeutic Foster Home	8	0	2	0	5	1	0
Group Home	6	0	2	0	1	3	0
Adult Family Home	4	0	0	1	1	1	1
Residence School	1	0	0	1	0	0	0
Residence Treatment	8	0	2	3	1	1	1
Residence Corrections	0	0	0	1	0	1	0
Juvenile Corrections	4	0	0	3	1	0	0
Unstable or Homeless	8	0	0	2	4	2	0
Don't Know	6	0	1	1	3	0	1

The general level of intellectual functioning for the clients in the LHI sample is in the "borderline" range, their median IQ is 86. The group's average reading and spelling levels are consistent with their intellectual level: median WRAT-R Reading SS, 82; median Spelling SS, 80. But Arithmetic is lower (median WRAT-R Arithmetic SS, 75). The median for the Vineland Adaptive Behavior Scales (VABS) composite score is 62. The averages for the three summary subdomain scores in Communication, Daily Living Skills, and Socialization are 67, 69, and 66 respectively.

Figure 4.1 shows three relevant ages of events for the LHI sample: the ages at which the clients were diagnosed; the ages at which the IQ test used in this report was administered; and the ages of the clients when the interview was conducted with their caretakers.

4.1 Percent of clients getting diagnosed, tested and the LHI within age ranges, n=415



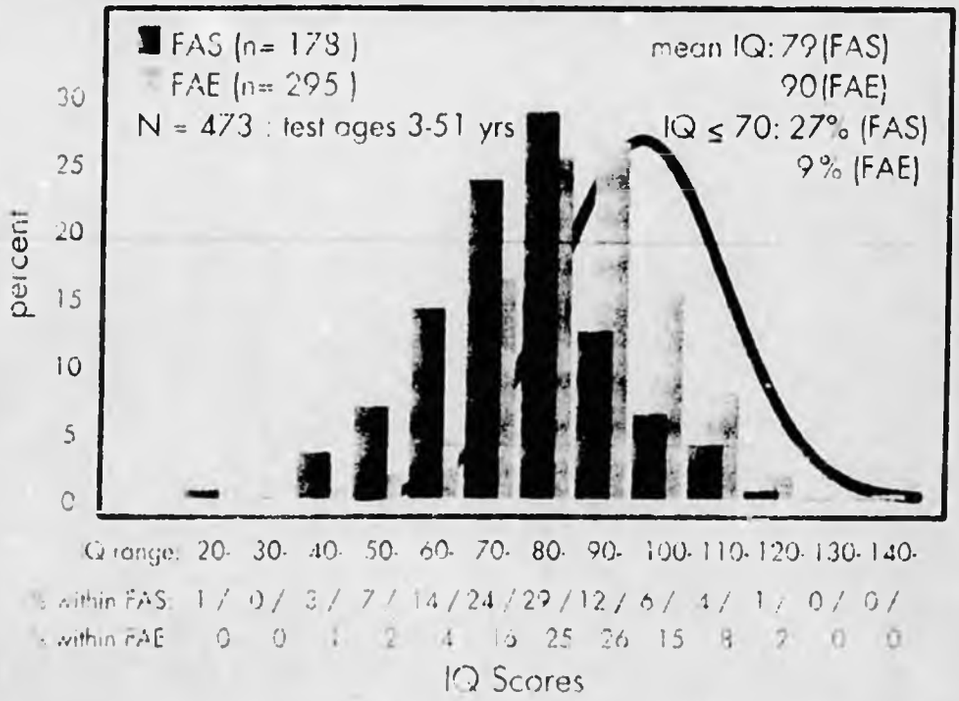
5 Primary Disabilities

General intelligence, mastery of reading, spelling, arithmetic, and general level of adaptive functioning are considered here as measures of "primary disabilities," representing the CNS manifestations of FAS, the birth defect with which these clients were born. Most of these clients have been raised in environments in which they had the opportunities to learn basic academic skills and adaptive behaviors. Rather than trying to "adjust" such data for adverse early environmental circumstances, we evaluate the effects of such circumstances in the section on risk and protective factors.

IQ data were available on 473 clients in the Primary Disabilities Sample. 178 have a diagnosis of FAS and 295 a diagnosis of FAE. Clients with FAS have a mean IQ score of 79, with a range from 29 to 120. Clients with FAE have a mean IQ of 90, with a range from 12 to 142. Twenty-seven percent of the clients with FAS and 9% of the clients with FAE have an IQ of 70 or below.

Figure 5.1 depicts the frequency distribution of the two sets of IQ scores superimposed on the normative bell curve of IQ. Both the FAS sample and the FAE sample deviate to the low side of the standard IQ distribution. The 11-point IQ discrepancy between clients with the full FAS and those with FAE replicates one we have previously reported (Streissguth et al., 1991a).

5.1 IQ distributions in the Primary Disabilities Sample: FAS and FAE



The Wechsler IQ tests contain 11 subtests which are often interpreted clinically as a profile. We "centered" those subtest profiles by subtracting the client's mean subtest score from each of the 11 raw scores, to derive a set of 11 centered scores varying about zero as shown in Figure 5.2.

5.2 Profile of IQ subtests: FAS and FAE

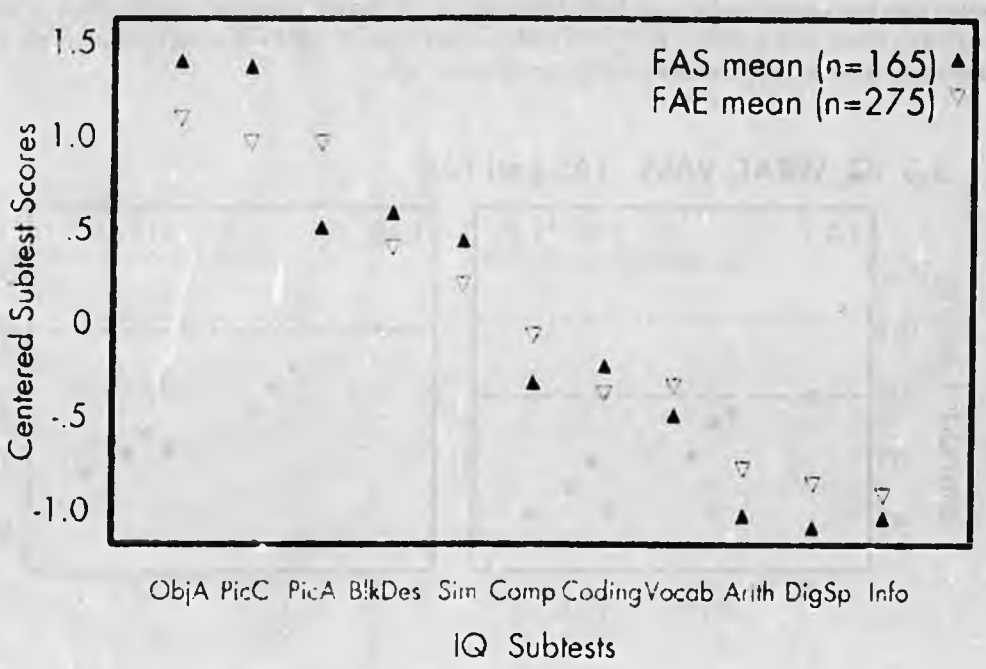


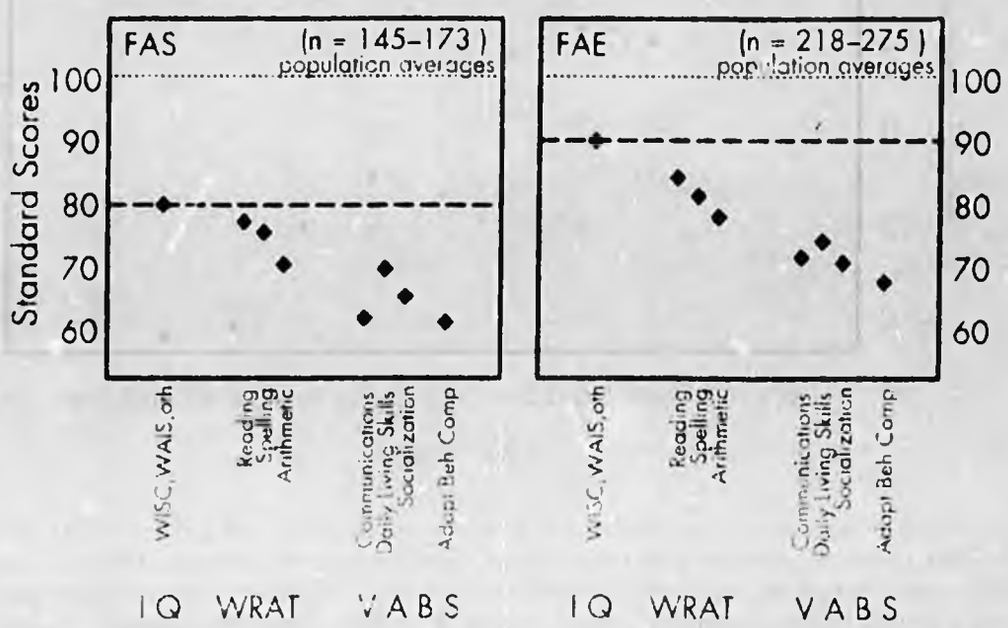
Figure 5.2 shows the group means of the "centered" subtest scores for clients with FAS versus FAE. Three subtests on which the FAS/FAE clients do poorly relative to their other subtest scores are Arithmetic, Digit Span and Information. This is a similar pattern to that seen in learning disabled children whose arithmetic, coding or vocabulary, information, and digit span are often the lowest subtests (Vargo, Grosser, & Spafford, 1995). Two subtests on which the FAS/FAE clients do best relative to their other subtest scores are Object Assembly and Picture Completion. This specific pattern of subtest strengths and weaknesses is similar to that associated with prenatal alcohol exposure in the 500 subjects in the Seattle Longitudinal Prospective Study on Alcohol and Pregnancy (Streissguth et al., 1993, Figure 7.1, page 159).

A "strength of profile" score was calculated for each client which reflects the degree to which an individual's subtest profile parallels the group subtest profile shown in Figure 5.2. This "strength of profile" score appears as item 18 on Table 6.1 of the most important Risk and Protective Factors. A high score equals high congruence; a low score, little congruence. This pattern profile covariance is computed as a weighted sum of 11 centered subtest scores. The weight for each score is the sample mean for that score. The "strength of profile" score is not correlated with IQ or age.

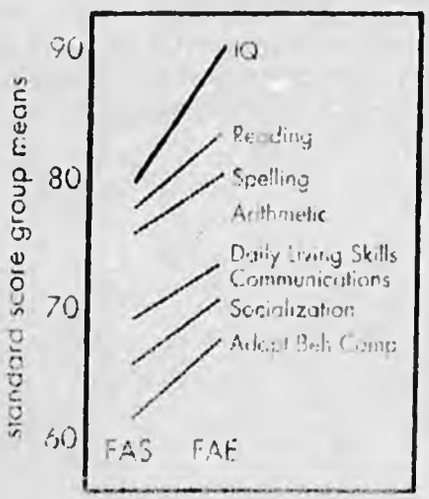
We compared academic achievement to what might be anticipated from overall IQ level. Figure 5.3 shows that clients with FAS are functioning close to their IQ level for Reading and Spelling, but are two-thirds of a standard deviation low in Arithmetic. For FAE, average Arithmetic scores are nearly a full standard deviation lower than would be expected from IQ levels; the other two achievement scores are relatively lower as well. These data replicate the findings of the previous study restricted to adolescents and adults (Streissguth et al., 1991a).

Figure 5.3 shows that both groups of clients have low adaptive behavior scores relative to their respective IQ levels. The relative deficit in these scores, in fact, is considerably greater than shortfalls in achievement, regardless of diagnosis. Figure 5.4 clarifies all these comparisons in a different graphic style.

5.3 IQ, WRAT, VABS: FAS and FAE



5.4 Relationship of achievement and adaptive behavior to IQ, by diagnosis



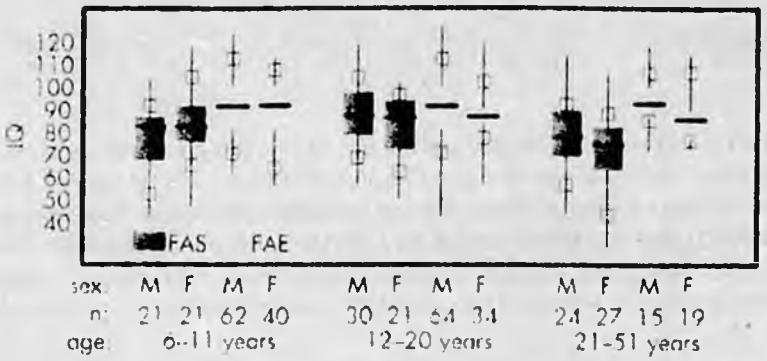
In Figure 5.4, each mean score for the FAS group has been connected by line to the corresponding mean score for the FAE group. The darkest line (at the top) is IQ, which is higher for both FAS and FAE clients than are the Achievement and Adaptive Behavior scores for the same group of clients.

The lines for Arithmetic and Communications are approximately parallel to the IQ line. This indicates that although Arithmetic and Communications are lower than IQ, the discrepancy is about the same for FAS clients as it is for clients with FAE.

The five darker lines (Reading, Spelling, Daily Living Skills, Socialization, and the Adaptive Behavior Composite) are relatively flatter. This indicates that although all 5 mean scores are lower than IQ within their respective samples, the discrepancy appears to be greater for FAE clients than for FAS clients.

Figure 5.5 presents data from only the Secondary Disabilities (LHI) Sample on which IQ was available (n= 378). This figure shows that the IQ scores for the clients at each LHI age grouping were comparable for subgroups defined by sex and diagnosis. The distribution of IQ scores is presented with a boxplot for each of the 12 groups: age (3) by sex (2) by diagnosis (2).

5.5 LHI Sample: IQ distributions by sex, diagnosis, and age at interview



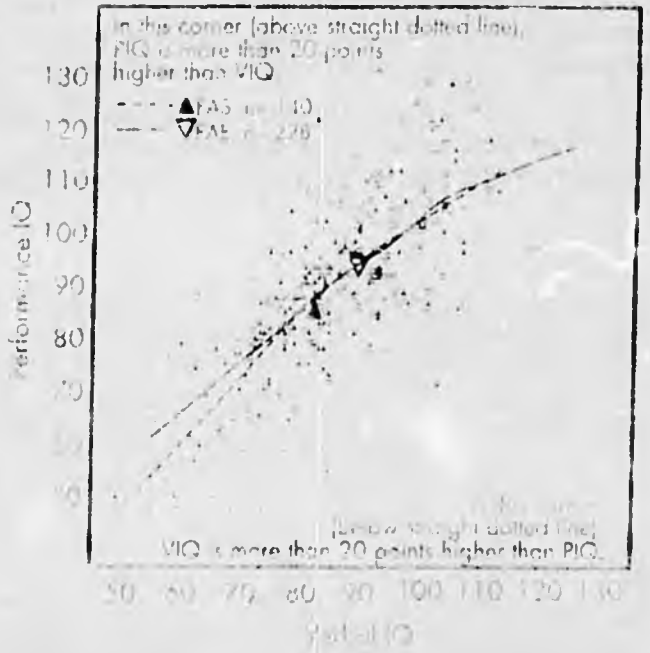
The box in a boxplot spans the middle half of the data from 25th to 75th percentiles; the dark horizontal line within a box indicates the median IQ score; the whiskers extending vertically from each box reach to the lowest and highest IQ; the open boxes on lower and upper whiskers indicate the 10th and 90th IQ percentiles respectively.

Figure 5.6 describes the discrepancies between PIQ (Performance IQ) scores and VIQ (Verbal IQ) scores, and how these discrepancies for the FAS/FAE clients differ from the normal population. Notice that more individuals fall outside the dotted line at the top of the figure compared to the number outside of the lower dotted line. This indicates that more FAS/FAE individuals have a PIQ greater than VIQ by 20 or more points, compared to the converse. Actually 8% of the clients fall above the line compared to 2.4% below the line. According to Sattler (1988), only 5% of a population would be expected to have a PIQ greater than VIQ by this magnitude.

Notice also the two heavy dashed curves illustrating that for individuals with IQs up to about 100, clients were more likely to deviate in the direction of PIQ greater than VIQ rather than the converse.

The large black triangle represents the mean scores of all individuals with FAS. Here we see that the mean PIQ is 84 while the mean VIQ is 79 for an average discrepancy of 5 points. The large white triangle represents the mean scores of all individuals with FAE. There is also a 5 point discrepancy between the mean PIQ of 93 and the mean VIQ of 88.

5.6 The two components of IQ by diagnosis



Risk and Protective Factors: Overview & Definitions

Our main goal in this research project was to study the prevalence in this sample of the deleterious life outcomes we have called Secondary Disabilities. These are examined in Chapters 7 through 17. Of course, risks of these outcomes are not the same for all clients. In this Chapter, we describe our rationale and methodology for quantifying these risks. Table 6.1 contains our final list of 21 Risk and Protective Factors and their definitions; Figure 6.1 depicts the relationship of these 21 Risk and Protective Factors to our six main Secondary Disabilities, and Figure 6.2 displays the 8 by 8 matrix of all eight Secondary Disabilities against each other. Of course, we cannot maintain that these relationships are causal or independent.

Definition of the Risk and Protective Factors

We considered two types of Risk and Protective Factors: Intrinsic and Extrinsic. *Intrinsic* Factors include attributes of the client that directly characterize his/her biology or extent of putative brain damage and include age, sex, diagnosis, IQ, IQ subtest profile, and ABC score. *Extrinsic* Factors represent environmental influences that have the potential of affecting life outcomes; these can be gleaned from the Life History Interview (LHI). Extrinsic Risk and Protective Factors were subjectively evolved from clinical experience, for example: fraction of life in a stable and nurturant home, living in non alcoholic families, not being abused or neglected, receiving special help as needed. Some of the Risk and Protective Factors were available from the test and demographic data in our database, the rest were developed into questions on the LHI, dispersed appropriately within the various sections of the interview. Variables like "fraction of life" came from questions like: "During what ages did client live in a stable and nurturant household?" The quality of "nurturance" is subjective, but the fraction of life is intended as an explicit quantification. Typically the informant would think back over the history of living situations and list for the interviewer the inclusive periods during which the situation was judged "nurturant"; hence, the dates are probably fairly accurate. (Not all Risk and Protective Factors fit under intrinsic or extrinsic, e.g. the FABS is neither.)

After administering 415 LHI's, we developed a scoring system that included two types of scores. Some were median splits, in which the top half of the distribution was compared with the lower half on a given item, such as "fraction of life lived with alcohol and drug abusers"; others were simple thresholds—binary scores that applied only to a proportion of the subjects, such as "violence against client." For some scores like this, with broader coverage, separate components (domestic violence, physical abuse, and sexual abuse) were also examined individually as risk factors. A likely group of 55 such candidates was examined in relation to the Secondary Disabilities discussed in Chapter 7.

After examination of the data, we retained the set of 21 Risk and Protective Factors depicted in Table 6.1, which presents the definition of each, the type of score obtained, distributions for all dichotomies, and the source of the information from which the data derive. For items deriving from the LHI, the specific item numbers are documented in Table 6.1.

Table 6.1. Definitions and derivations of risk/protective factors as reported by the caretaker, physician and psychometrist with distribution for clients 12 years and over.

Definition	Type	Derivation of binary protective/ risk factors**	%	Source of info
1. Stable and nurturant household	E	Median split on fraction of life:		LHI
		P: 72 – 100% of life	49%	
		R: 0 – 71% of life	51%	
2. Age of diagnosis of FAS/FAE	E	Age at diagnosis split at 6 years:		Dysmorphology Exam
		P: under 6 years	11%	
		R: 6 years and over	89%	
3. Violence against client	E	Yes/no if ever in life patient experienced domestic violence, sexual abuse, and/or other physical abuse:		LHI
		P: no violence experienced	28%	
		R: violence was experienced	72%	
4. Average number of years per living situation till age 18	E	Median split on number of years HH:		LHI
		P: 2.8 – 18.0 yrs per household	62%	
		R: <2.8 yrs per household	38%	
5. Quality of home environment during during later childhood (8–12 years)	E	Median split on a count of positive qualities of home:		LHI
		P: 10 – 12 good qualities	65%	
		R: 0 – 9 good qualities	35%	
6. DDD eligibility status	E	Indicator of whether the family both applied for and was eligible for DDD		LHI
		P: applied for and was eligible	56%	
		R: applied for, but was not eligible	44%	
7. Living with alcohol/drug abusers	E	Median split on fraction of life the proband has lived with alcohol/drug abusers:		LHI
		P: 0 – 29% of life	51%	
		R: 30 – 100% of life	49%	
8. Alcohol related diagnosis	E	Indicator of FAS rather than FAE		General Information Form
		P: FAS or PFAS	43%	
		R: FAE, PFAE, ARND	57%	
9. Basic needs are not met	E	Median split on fraction of life that basic needs are not met:		LHI
		P: 0 – 12% of life	49%	
		R: 13 – 100% of life	51%	
10. Fetal Alcohol Behavior Scale (FABS)	[illegible]	Median split on number of fetal alcohol behaviors according to caretaker:		Personal Behavior Checklist
		P: 0 – 20 of 36 behaviors endorsed	[illegible]	
		R: 21 – 36 of 36 behaviors endorsed	[illegible]	
11. Intelligence quotient (IQ)	[illegible]	Full scale IQ		[illegible]
		P: [illegible]	[illegible]	
		R: IQ [illegible]	[illegible]	

Definition	Type	*Derivation of binary protective/ risk factors**	%***	Source of info (LHI items)
Table Continues				
12. Driver's license attainment (≥16 years of age only)	E	Whether or not patient ≥16 years has has a driver's license: P: yes R: no	 31% 69%	LHI
13. Sex	I	Sex: P: female R: male	 43% 57%	General Information Form
14. VABS ABC Standard Score	I	Median split on the Adaptive Behavior Composite Standard Score P: VABS ABCss ≥ 65 R: VABS ABCss < 65	 38% 62%	VABS Interview (FADU)
15. Difference between IQ and ABCs	I	Comparison of IQ & VABS ABCss P: IQ & ABCss are within 15 pts R: more than 15 pts different	 32% 68%	Testing & interviewing (FADU)
16. Has there always been at least one caretaker after age 18 years	E	Yes/No P: never after age 18 years R: sometimes—always	 64% 36%	LHI
17. Difference between performance and verbal IQ	I	Performance IQ (PIQ) minus verbal IQ (VIQ) P: PIQ more than 15 points higher R: PIQ not more than 15 points higher	 17% 83%	FADU testing
18. Similarity of IQ subtest profile to other FAS/FAE patients	I	Median split on the IQ subtest strength of profile score P: weak IQ profile (not similar) R: strong IQ profile (similar)	 49% 51%	FADU testing
19. SSI eligibility status	E	Indicator of whether the patient both applied for and was eligible for SSI P: applied for, but was ineligible R: applied for, and was eligible	 28% 72%	LHI
20. Age of Secondary Disability assessment	E	Status as adult (≥21 years) P: under 21 years old R: 21 years and older	 64% 36%	from dates
21. Always 2 caretakers available before 18 yrs	E	yes/no P: not always 2 caretakers R: always 2 caretakers available	 57% 43%	LHI

* E = Extrinsic, I = Intrinsic

**Item polarities are assigned according to the median plotted in figure 6.1, which pertains *only* to the first six secondary Disabilities. For Risk and Protective Factors for the last two Secondary Disabilities (Dependent Living and Problems with Employment) see Figures 16.2 and 15.2, respectively.

P=protective end; R=risk end

***Percents apply only to clients 12 years and older

Odds Ratios

Through most of this report, we will express effects of Risk and Protective Factors in terms of *odds ratios*. (Some readers may recognize this approach as a series of univariate logistic regressions.) An example will make the computation clear. Suppose we are interested in the role of low IQ (less than or equal to 70) as a predictor of some binary outcome, in this case, "Trouble with the Law," one of the summary Secondary Disability scores introduced in the next chapter. The subsample to which this outcome score seems most pertinent is the set of clients 12 and older. For this subsample, the 2 x 2 table is as follows:

	Trouble	
	no	yes
>70	72	122
IQ		
≤70	20	18

The odds of no Trouble for IQ>70 are 72:122. The odds for IQ≤70 are 20:18. The *odds ratio* for the effect of the IQ dichotomy on this outcome is thus (20/18)/(72/122), or 1.88, about a 2:1 *protective* effect. The clients of lower IQ have *relatively fewer* problems with the law; that is, they do better. For a different cut of "low IQ" at 85, the table is:

	41	88
	51	52

The odds ratio (51/52)/(41/88), or 2.10, stands for just about the same "protective effect." Ratios less than 1 indicate "risk" rather than protection. The method of multiple logistic regression would attempt to "adjust" all such odds ratios for associations among the separate factors. We have no reason to believe that any of the assumptions of these analyses are met, and so we do not pursue this refinement here.

For each Secondary Disability in the subsequent chapters, each risk or protective factor is associated with an odds ratio of this sort. For IQ ≤ 70, for instance, the ratios are: for Mental Health Problems, (2/36)/(9/187) or 1.15 (clearly a problem of small cell counts here); for Disrupted School Experience, (19/17)/(73/122), or 1.87; for Confinement, (22/16)/(95/100), or 1.45; for Inappropriate Sexual Behavior, (17/21)/(99/92), or 0.75 (a slight escalation of risk); for Alcohol/Drug Problems, (28/9)/(123/73), or 1.85.

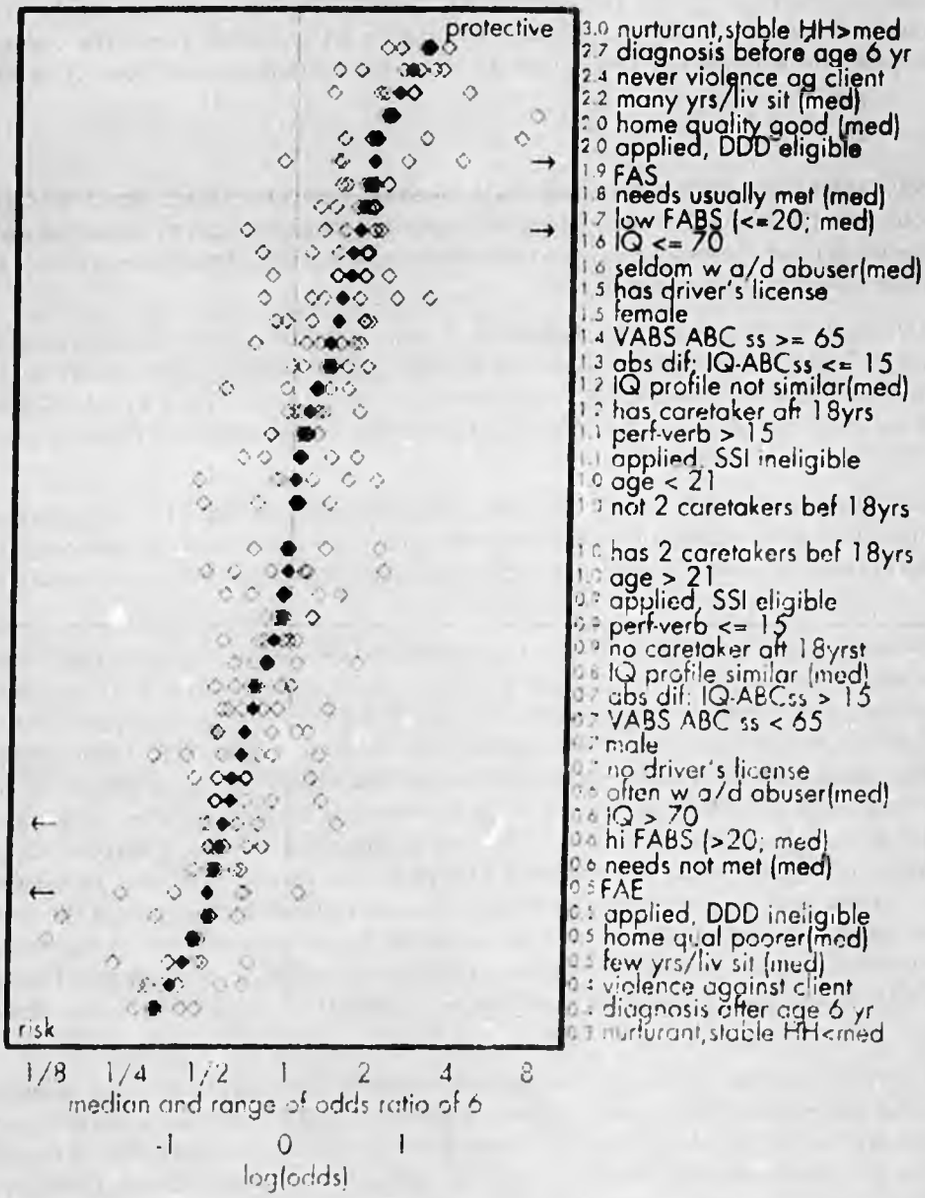
As a sorted list, these odds ratios are (.75, 1.15, 1.45, 1.85, 1.87, 1.88) with median (1.45 + 1.85)/2 = 1.65. Thus, "IQ ≤ 70" is plotted at height 1.65 in Figure 6.1 with the separate odds ratios around it. Each later chapter begins with a graph of similar information as a "profile" across all the risk or protective factors as they pertain to that outcome, one at a time.

The entire set of odds ratios for these 21 Risk and Protective Factors is presented in Figure 6.1. The horizontal scale in this figure is a log scale, so that reciprocals (e.g., 4 and 1/4) are at equal distances from the centerline in opposite directions. These mirrored points represent equivalent odds ratios of either risk (left) or protection (right). The "Protective" Factors, which lie in the top half of the page, are the converse of the "Risk" Factors, which lie in the bottom half of the page. Each row on the figure represents a single Risk/Protective Factor. The one at the top of the page, "percent of life in a stable and nurturant household," is the strongest Protective Factor, on average, against the first six Secondary Disabilities described in Chapter 7. The median impact of this one Protective Factor on the six secondary Disabilities is represented by a black diamond. Risk/Protective Factors that have the least impact (odds ratios closest to 1.0, whether risky or protective) on these six Secondary Disabilities appear at the midpoint of the page, at the end of the list of 21. Arrows indicate scores that could not be calculated for one of the diamonds because there was a zero in either the numerator or the denominator of the odds ratio. The vertical column of decimal numbers to the left of the Risk/Protective Factor names on Figure 6.1 is the median of the six odds ratios observed for that Factor.

The white diamonds on each row represent the relationships of that Risk/Protective Factor to each of the six Secondary Disabilities studied in Chapters 8 through 13. Each of these chapters has a graph with one set of diamonds, reflecting how the 21 Risk/Protective Factors are related to the Secondary Disability discussed in that chapter. For simplification, these graphs only depict the Protective side; one can imagine the Risk side to be the reflection. These separate graphs appear in each chapter as its second figure. Each white diamond found on a graph can be found at exactly the same spot on Figure 6.1. The ordering of Risk/Protective Factors have been retained across chapters. The Risk and Protective Factors are ordered by median odds ratio seen in Figure 6.1, from most protective at the top through most risky at the bottom.

In Figure 6.1, two types of Risk and Protective Factors can be detected. Recall that the vertical line at the center differentiates the Risk side of the distribution (at the left) from the Protective side (right). Any Factor for which all the open diamonds are to the same side of center line is a "*Universal*" Factor. The Universal Protective Factors are those that are consistently protective for each of the six Secondary Disabilities. Except as noted in Table 6.1, the sample for each Risk and Protective Factor was divided at the median, which is the number appearing below. These Universal Protective Factors include: living in a nurturant and stable home at least 72% of life; being diagnosed before the age of 6 years; never having experienced violence; getting to stay longer than an average of 2.8 years in each household; experiencing a good quality of home (10 of 12 "good" qualities); being FAS (rather than FAE); and having basic needs met at least 13% of life. Of course, many of these items overlap substantially among themselves; we are making no claim that any of these Risk or Protective Factors are independent of others. Other Risk/Protective Factors are called "Specific" because they are Protective Factors for some Secondary Disabilities yet may be Risk Factors for others.

6.1 Risk/Protective Factors across 6 Secondary Disabilities among clients 12 years and older, max n = 253

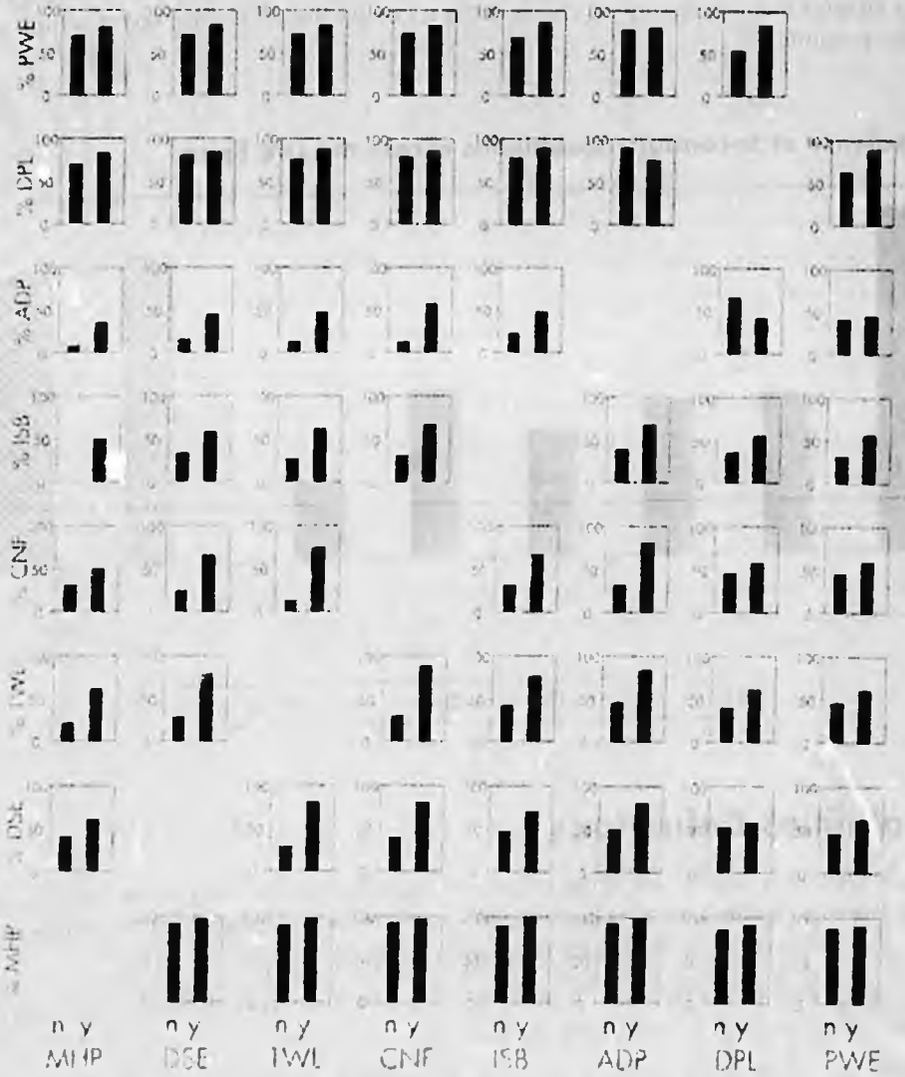


Odds ratios larger than 2 (or less than 0.5) indicate interesting protective effects (or risks). An odds ratio of about 2, such as seen for DDD eligibility, indicates that the chance of avoiding a Secondary Disability is about twice as high for a child who receives DDD services as for one who does not.

Two Secondary Disabilities pertaining only to adults are not included in Figure 6.1 due to the necessarily smaller sample size: Dependent Living and Problems with Employment. These could be assessed realistically only for clients who were 21 years of age and older. However, they were examined according to the same Risk and Protective Factors described in Table 6.1. These latter two Secondary Disabilities are described in Chapter 14 (Dependent Living) and Chapter 15 (Problems with Employment). The odds ratio graphs for these latter two Secondary Disabilities appear as the second graph in their respective chapter.

We also consider each of the eight Secondary Disabilities to be Risk and Protective Factors for any of the others. Figure 6.2 shows an 8 x 8 matrix of these binary 2 x 2 comparisons in graphical form. The only pair of Secondary Disabilities that are negatively associated—for which the prevalence of either is lower for the group coded "yes" for the other—is Alcohol and Drug Problems with Dependent Living.

6.2 Prevalences of each secondary disability controlling for the others one by one

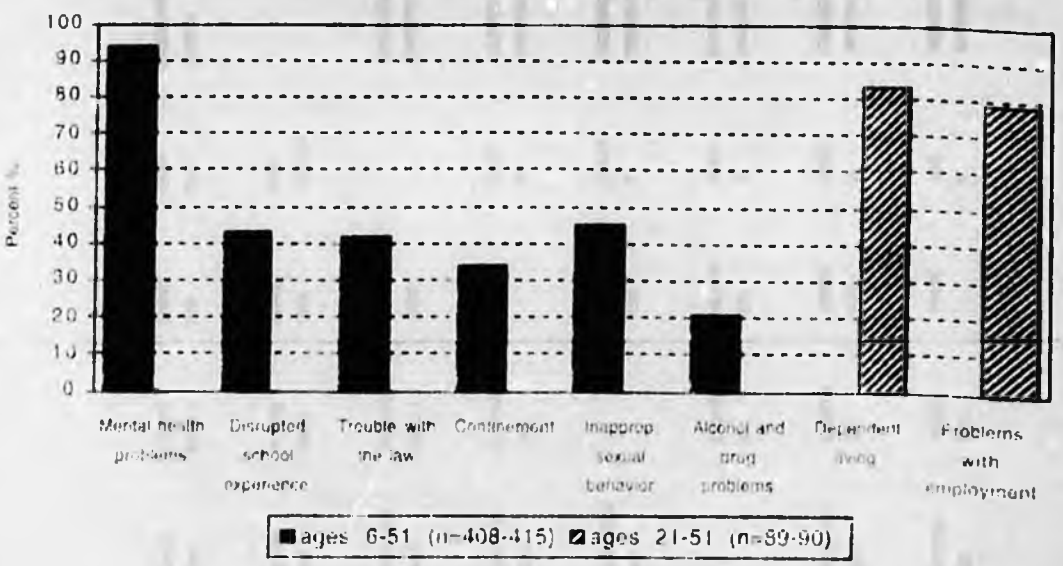


7 Secondary Disabilities: Definitions & Overview

Secondary disabilities are those that a client is not born with, and that could presumably be ameliorated (either fully or partially) through better understanding and appropriate interventions. The project examined altogether eight Secondary Disabilities. The first six pertain to clients of all ages and are easily quantifiable. The latter two, Dependent Living (DPL) and Problems with Employment (PWE), pertain only to adult clients (21 and over), restricting the sample size to 90 compared to 415 for the other Secondary Disabilities. DPL and PWE are by nature more subjective and required more complex and qualitative definitions. In the graphs that follow in this chapter, the two latter Secondary Disabilities are set apart from the others to draw attention to this difference. All data on Secondary Disabilities derive from the Life History interview (LHI). This means that the accuracy of the information is dependent on the knowledge of the informant, which varied depending on the age and living circumstances of the client.

Figure 7.1 shows the prevalence of all eight Secondary Disabilities across the entire sample of 408-415 clients. The remaining figures in this chapter focus primarily on clients 12 years of age and older, the age at which most of these Secondary Disabilities were manifest.

7.1 Prevalence of Secondary Disabilities across the Life Span



Secondary Disabilities Definitions

Mental Health Problems (MHP) was coded "yes" if the client was described as (a) ever having any of a list of mental health problems, or (b) gone to a psychiatrist, psychotherapist, or counselor for mental health problems, or (c) ever having been a client in a psychiatric or a mental health hospital. (Chapter 8)

Disrupted School Experience (DSE) was coded "yes" if the client was described as ever being suspended or expelled from school, or as having dropped out of school. (Chapter 9)

Trouble With the Law (TWL) was coded "yes" if the client was described as having been charged or convicted or in trouble with authorities for any one or more of these main categories of criminal behavior: crimes against persons (excluding sex-related), crimes against property, possession or selling of illegal substances, sex crimes, driving violations, parole violations, skipping bail, or escape, or other crimes (primarily victimless, such as running away from home). (Chapter 10)

Confinement (CNF) was coded "yes" if the client was described as ever having been incarcerated for a crime or having received inpatient treatment for mental health problems or for alcohol or drug abuse problems. (Chapter 11)

Inappropriate Sexual Behavior (ISB) was coded "yes" if the client had ever been sentenced to sexual offenders treatment or had ever been reported as "repeatedly" having one or more problems with sexuality. (Chapter 12)

Alcohol and/or Drug Problems (ADP) was coded "yes" if the client was reported to have had alcohol abuse problems, drug abuse problems, and/or alcohol/drug treatment, whether inpatient or outpatient. (Chapter 13)

Dependent Living (DPL) was coded "yes" for clients *21 years old and over* and *not* independent. Independence requires *either*:

(a) —that the client can handle 12 daily living activities without help
or
(b) —that the client does not have another person organizing his or her life,

—does not live with a caregiver,

—needs help with at most 3 of the 12 critical daily activities, and

—can pay at least some of his or her own expenses. (Chapter 14)

Problems With Employment (PWE) was coded "yes" if a client is *21 years old and over* and *not* effectively employed. Effectively employed is defined as meeting *any* one of the following three criteria:

1. Having no other cash support except his/her own wages
2. Weekly earnings of $280 or more
3. Being currently employed 20 hours or more per week, *and*

—Having none or only mild job problems (that is, no repeated problems and a maximum of two "minimal problems;" minimal problem is a score of "1" on LHI questions that follow: trouble getting hired, trouble holding a job, being fired from a job, and losing a job without understanding why),
and
—Having had three or fewer jobs in the past two years. (Chapter 15)

Secondary Disabilities Overview

Figure 7.2 shows prevalences of the six major Secondary Disabilities by three age groups. Prevalence in adults does not exceed prevalence in adolescents except for Confinement and Alcohol and Drug Abuse.

7.2 History of Secondary Disabilities by three age groups at interview

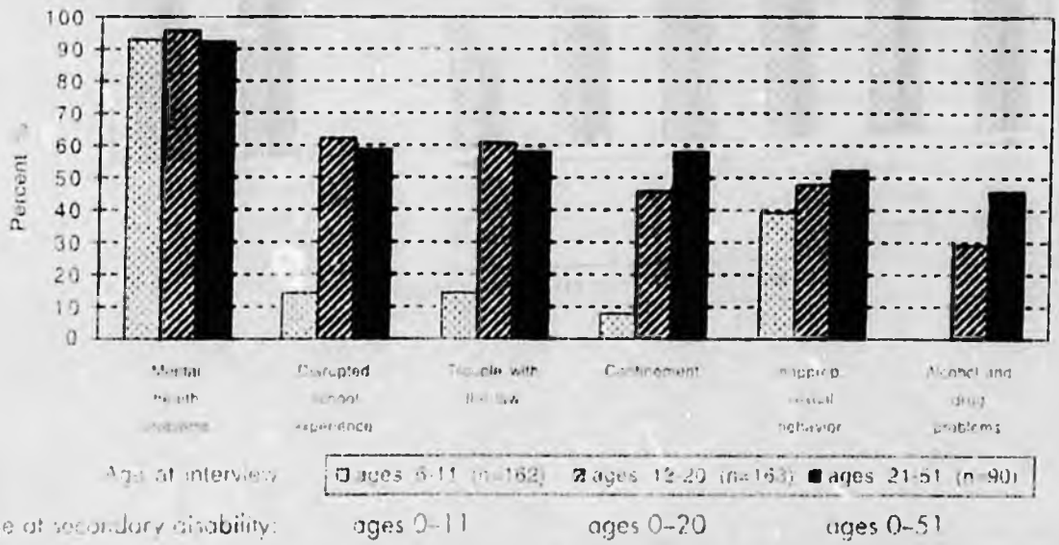
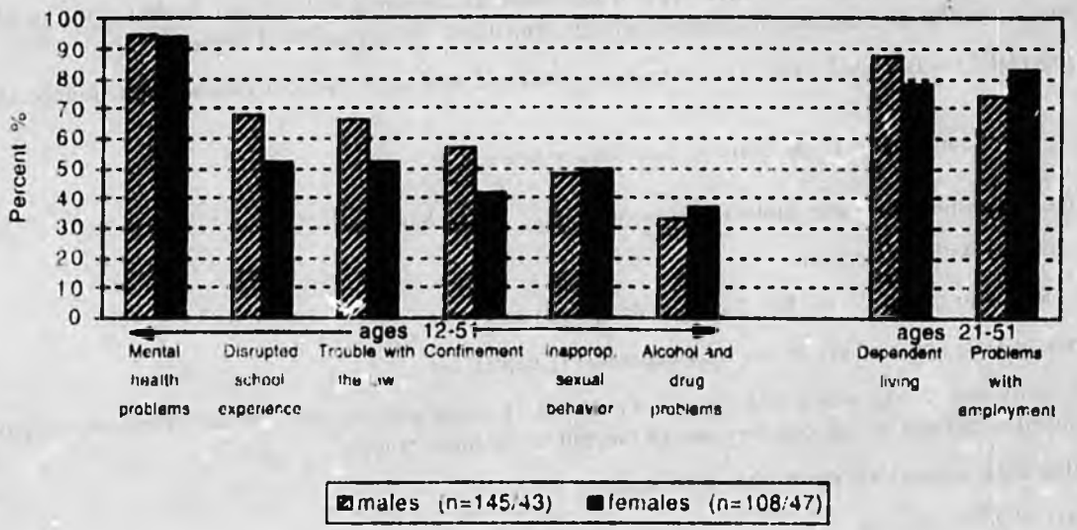


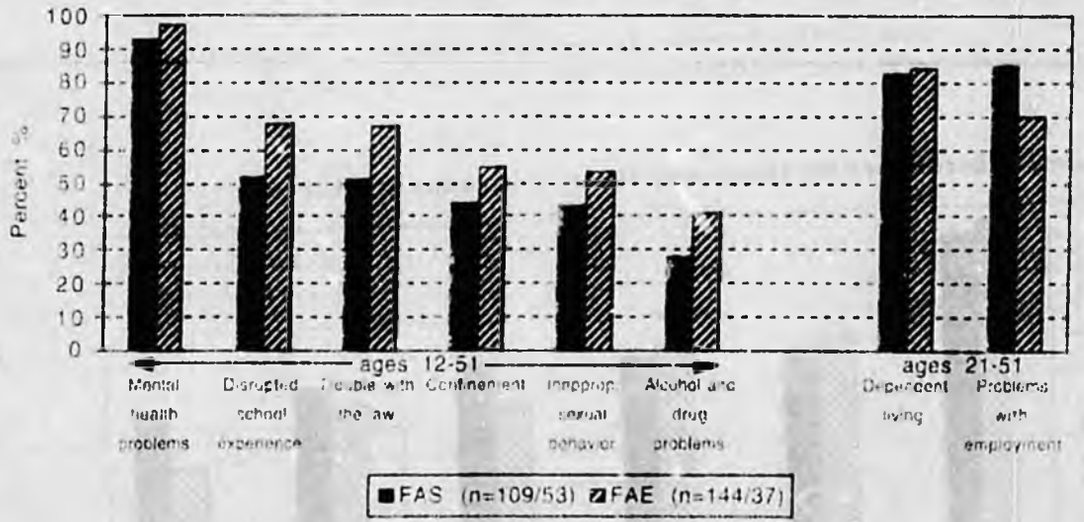
Figure 7.3 through 7.5 consider only those 253 clients 12 years and over. Figure 7.3 compares the prevalence of Secondary Disabilities for males and females. Males have higher rates of Disrupted School Experience, Trouble With the Law, and Confinement.

7.3 History of Secondary Disabilities among clients ≥ 12 years old by sex



There are mild but systematic differences between clients with FAS and those with FAE in terms of the prevalence of Secondary Disabilities (see Figure 7.4). In all matters except independence and employment, clients with FAE (although often thought to be more "mildly affected") have higher rates of the Secondary Disabilities.

7.4 History of Secondary Disabilities among clients ≥ 12 years old by diagnosis



Low IQ seems to have a similar pattern of "protective" effect as a diagnosis of FAS (with which it is formally tied through the CNS criterion of FAS). For the 38 clients technically classifiable as mentally retarded, there are lower rates of Alcohol and Drug Problems, Disrupted School Experience, Trouble With the Law, and Confinement. All of them are in dependent living situations, and 94% have employment problems (Figure 7.5). An IQ above 85 (average for this full sample) is clearly not "protective" and may actually be associated with additional legal troubles and additional confinements.

7.5 History of Secondary Disabilities among clients ≥ 12 years old by IQ level

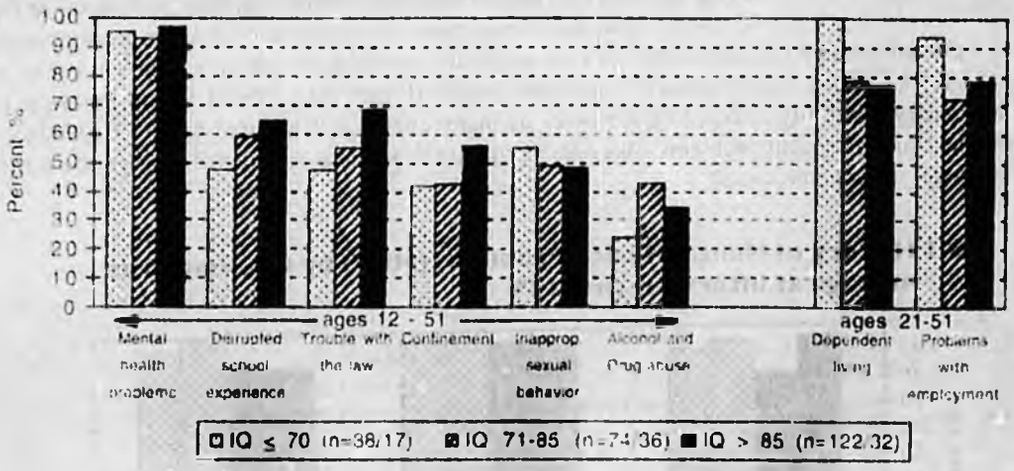
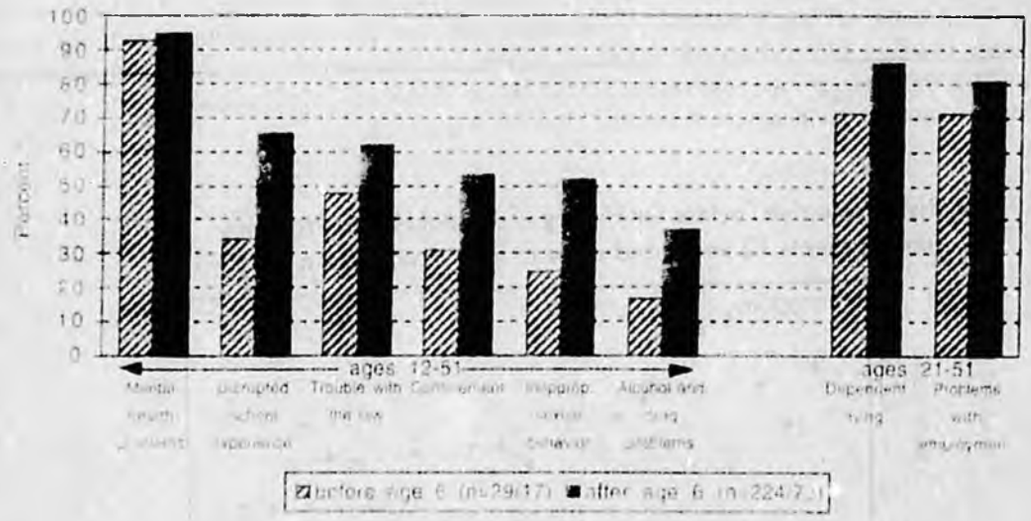


Figure 7.6 shows that a diagnosis before age 6 is related to lower prevalence of all secondary disabilities except perhaps Mental Health Problems.

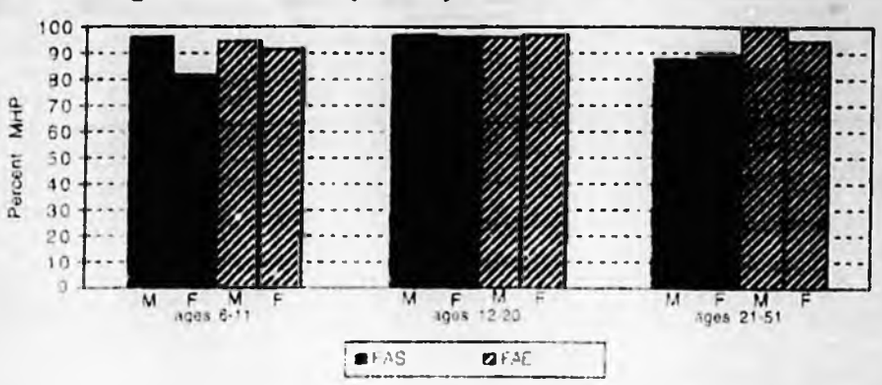
7.6 History of Secondary Disabilities among clients ≥ 12 years old by age at diagnosis



8 Mental Health Problems (MHP)

Mental Health Problems (MHP) is a binary summary of reported mental health concerns, problems, or treatment for clients of any age. It is coded 1 for those clients who had one or more of a long list of possible mental health problems, had ever gone to a psychotherapist or a counselor for a mental health problem, or had ever been a client in a psychiatric or mental hospital. At 94% of the full Secondary Disabilities sample (Figure 8.1), Mental Health Problems is by far the most prevalent Secondary Disability, accounting for twice as many clients as Disrupted School Experience or Trouble with the Law, the next most frequent problems. Because of the overwhelming prevalence of Mental Health Problems, hardly any clients were, in fact, "protected."

8.1 History of Mental Health Problems (MHP) by sex, diagnosis and age at interview (n=415)



For those who were protected, Figure 8.2 shows the strongest protective factors against MHP: (1) DDD services eligibility, (2) below median FABS score, (3) higher than the median number of years per living situation, (4) living in a home of above median quality (during childhood ages 8-12), and (5) living in a stable and nurturant household above median proportion of life (72-100%). Because the base rate of Mental Health Problems in this sample is so close to 100%, these odds ratios are more subject to sampling error than the others in Figure 6.1.

8.2 Risk/Protective Factors for History of Mental Health Problems among clients 12 years and older at interview, max n = 253

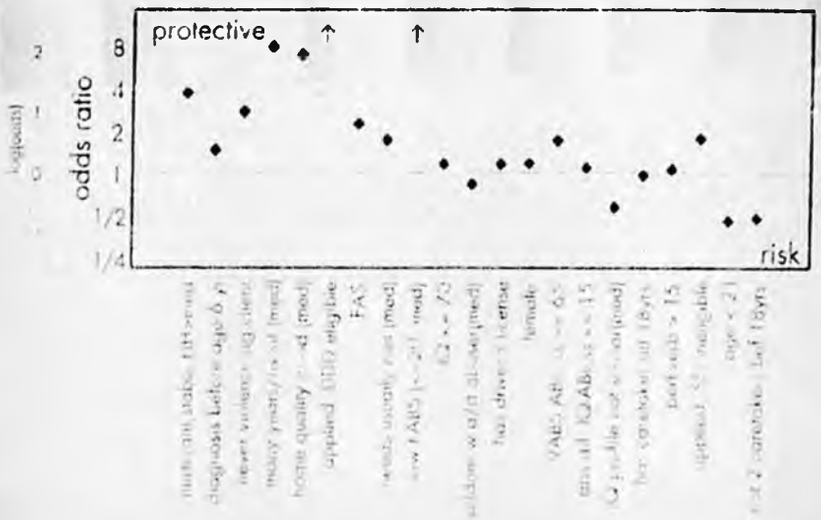


Figure 8.3 shows that most clients of any age with Mental Health Problems receive treatment for these problems.

8.3 History of Mental Health Problems: Components of the Secondary Disability by age at interview (n=415)

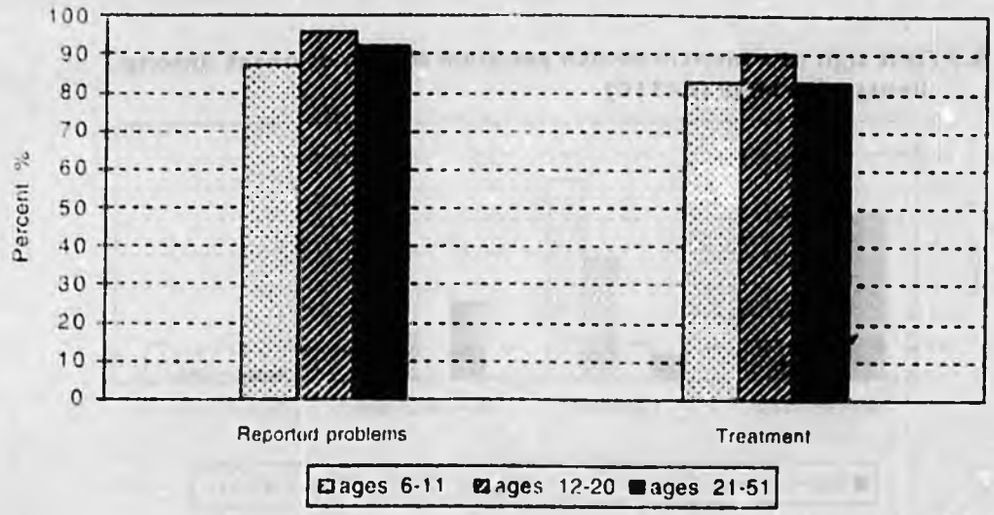


Figure 8.4 shows the rate of Mental Health Problems by age. The most frequent mental health problems for children and adolescents are attention deficit problems (61%), followed by depression and suicide threats. Over half the adults were reported to have depression problems, 43% have made suicide threats, and 23% have made suicide attempts; 20% of adults have psychotic symptoms.

8.4 History of mental health problems by age at interview (n=415)

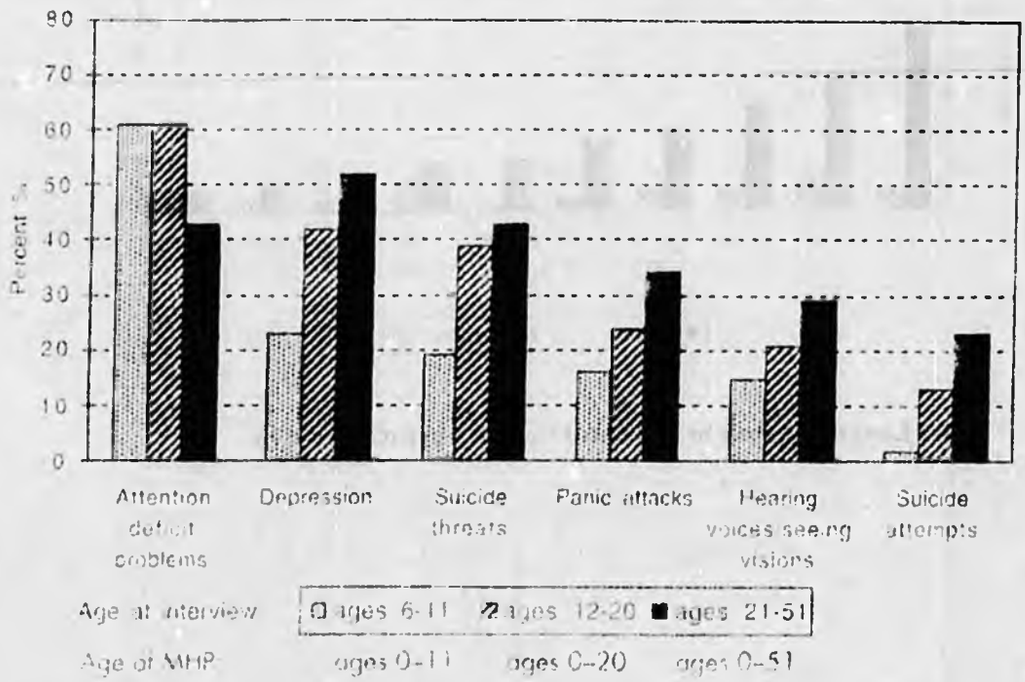
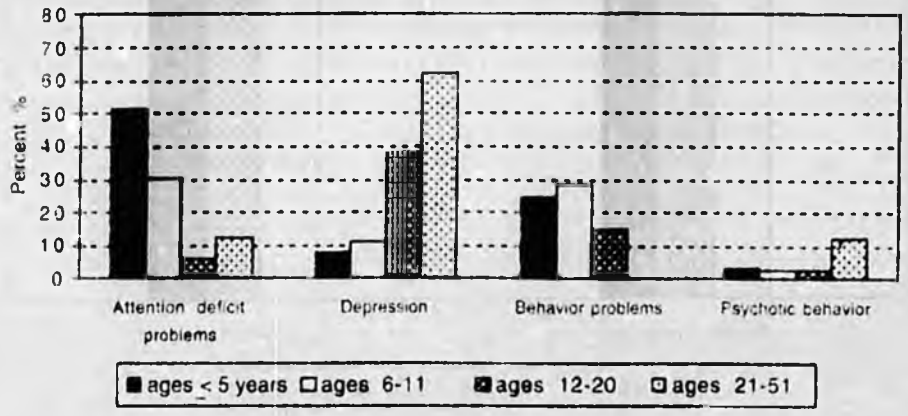


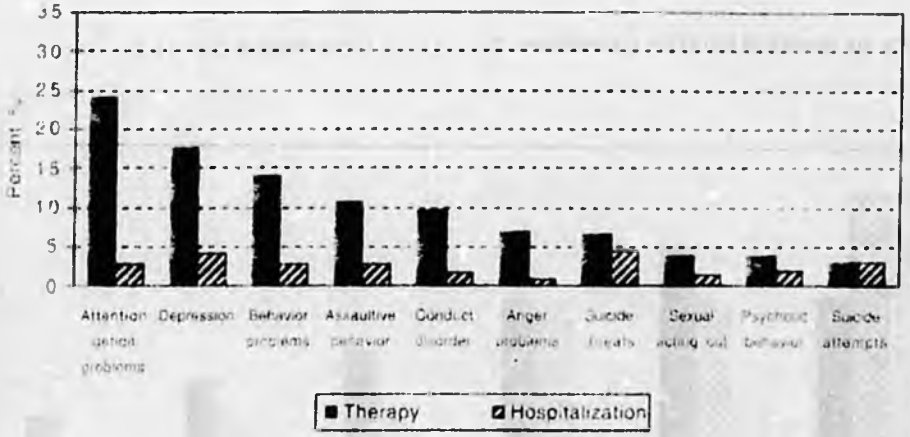
Figure 8.5 shows that among clients who were reported to have a mental health problem, the first sign of mental health problems with onset at age five or under, was attention deficit problems (51%), followed by behavior problems (25%) including conduct problems (6%) and assaultive behaviors (7%). By contrast, if the onset of mental health problems was after age 21, the most commonly reported Mental Health Problem was depression (62%), or psychotic behavior (12%).

8.5 First sign of a mental health problem by age of onset among clients with MHP (n=310)

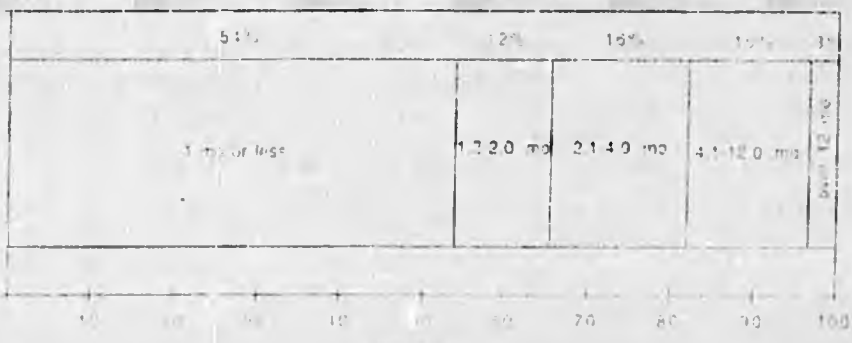


The most frequent reason reported for obtaining outpatient mental health treatment is attention problems, followed by depression. For inpatient treatment, the primary reasons are suicide threats and depression (Figure 8.6). One in three of all hospitalized clients have been hospitalized for over two months, including 3% for over one year (Figure 8.7).

8.6 Mental Health Problems: Prevalence of therapy and hospitalization by reason for treatment



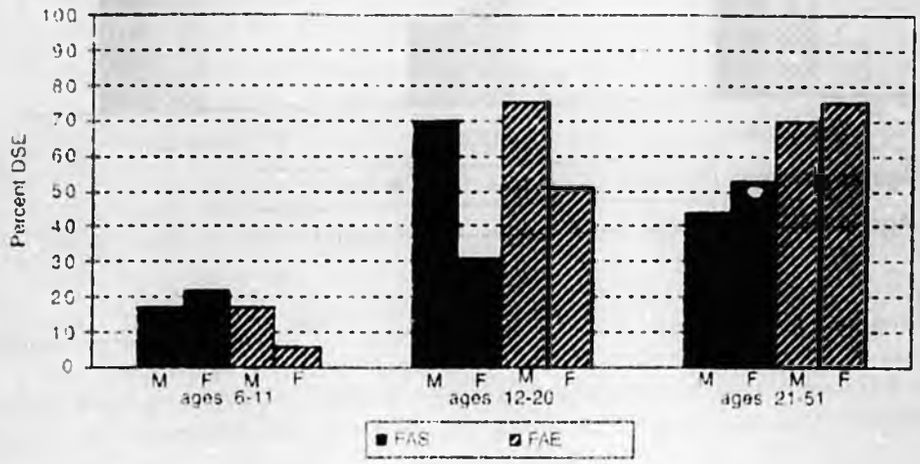
8.7 Length of stay in a mental health hospital (n=67)



9 Disrupted School Experience (DSE)

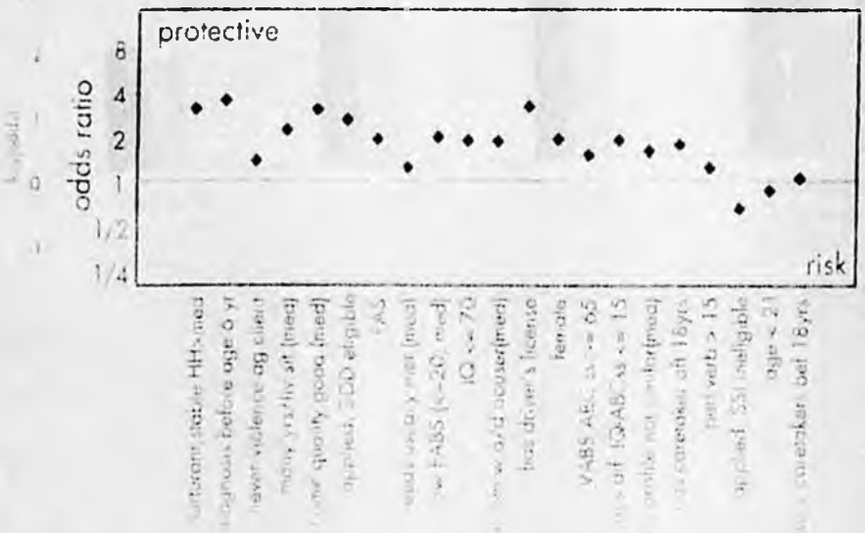
Disrupted School Experience (DSE) is a binary summary of reported disruptions of schooling for clients of any age. It is set to 1 for those clients who ever were suspended from school, expelled from school, or dropped out of school. Figure 9.1 shows that 60% of clients 12 years and older have had Disrupted School Experience.

9.1 History of Disrupted School Experience (DSE) by sex, diagnosis and age at interview (n=411)



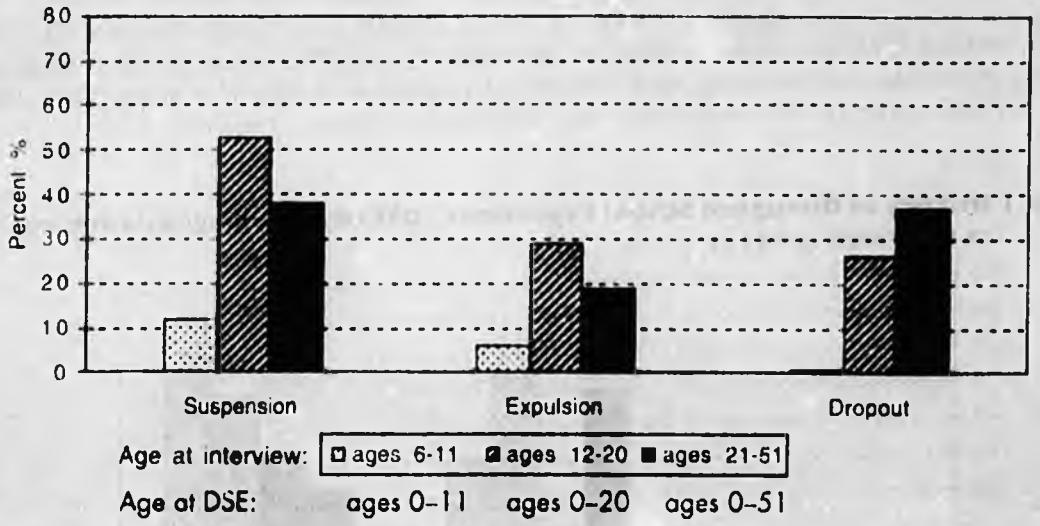
The important protective factors against DSE (items in Figure 9.2 that lower the odds of DSE) include: an early diagnosis, longer duration of living situations, longer duration in a stable and nurturant home, living in a good quality home, and having a driver's license. In addition, having applied for DDD (Division of Developmental Disabilities) services and found to be eligible was a specific protective factor against DSE.

9.2 Risk/Protective Factors for History of Disrupted School Experience among clients 12 years and older at interview, max n = 250



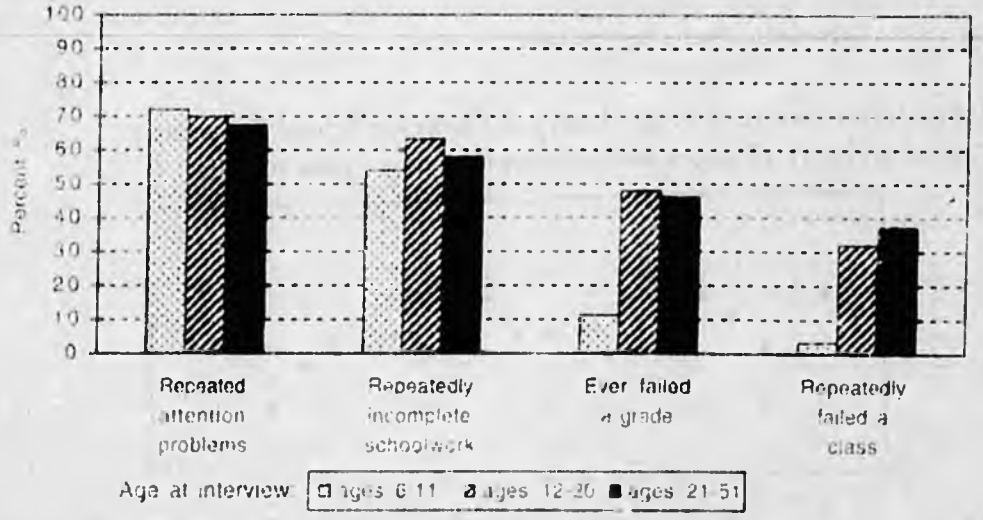
The rate of DSE is higher after childhood when one in two adolescents have been suspended, one in four expelled, and more than one in four have dropped out of school (Figure 9.3).

9.3 Disrupted School Experience: Components of the Secondary Disability by age at interview (n=411)

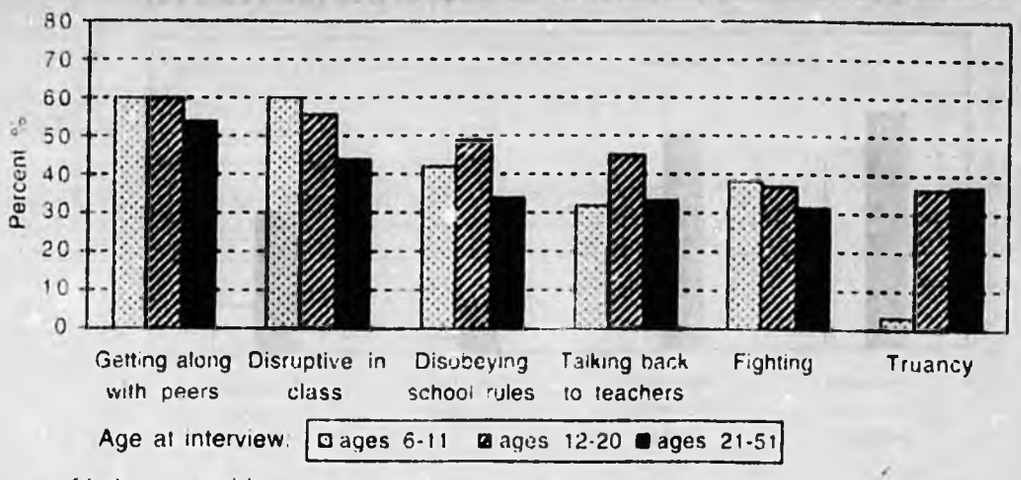


The most frequent learning problems (Figure 9.4) are attention problems (70%) and repeatedly incomplete school work (55-60%). Nearly half the adolescents and adults had failed a grade in school. The most frequent behavior problems ever experienced (Figure 9.5) were repeated problems in getting along with peers (~60%) and repeatedly being disruptive in class (55-60%). Clients with DSE had about twice as many of these problems as compared to clients without DSE (Figure 9.6).

9.4 Learning problems by age at interview (n=395-407)

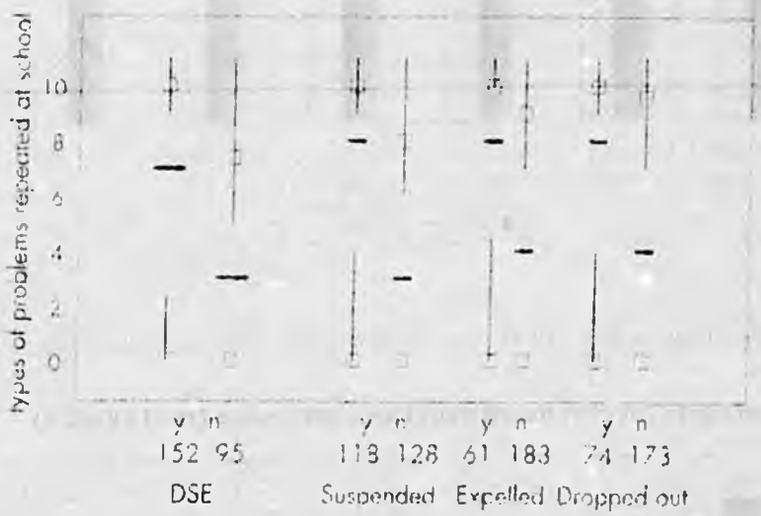


9.5 Repeated behavior problems by age at interview (n=403-408)



Figures 9.6 through 9.8 show that DSE is correlated with learning problems and behavior problems. Although rates of repeated poor attention are high whether or not students also experience DSE, rates of failing grades and repeatedly failing classes are much higher among those who also had DSE. Being suspended, expelled from school or dropping out is an unfortunate concomitant for students with problems doing the school work and/or have behaviors that are disruptive or aggressive. School truancy is a frequent behavior problem (48%). Clearly children who are not at school for any reason are unable to benefit from the structure and support that the school offers for the time they are away from school.

9.6 Distributions of number of problems observed repeatedly in school among patients 12 years and older



9.7 Learning problems by presence or absence of DSE (n= 235-244)

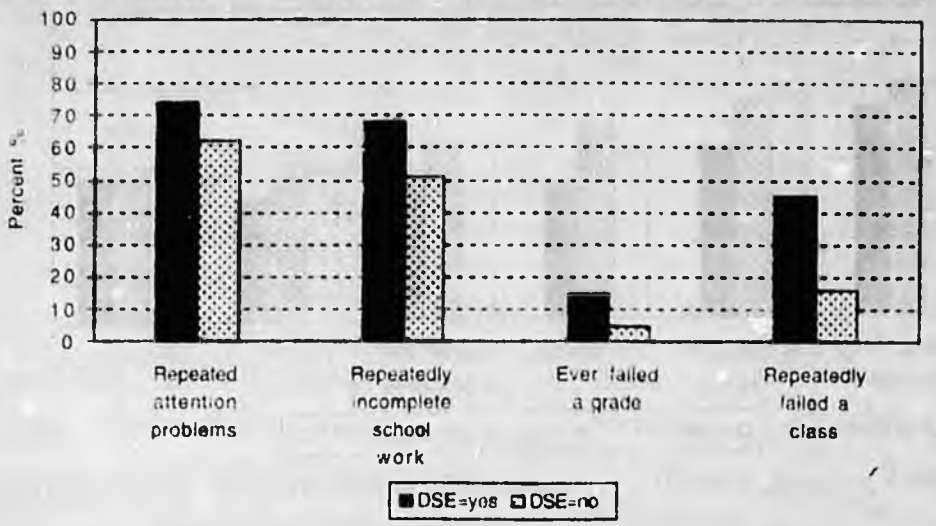


Figure 9.8 shows that all repeated behavior problems display higher rates among clients with DSE.

9.8 Repeated behavior problems by presence or absence of DSE (n= 240-245)

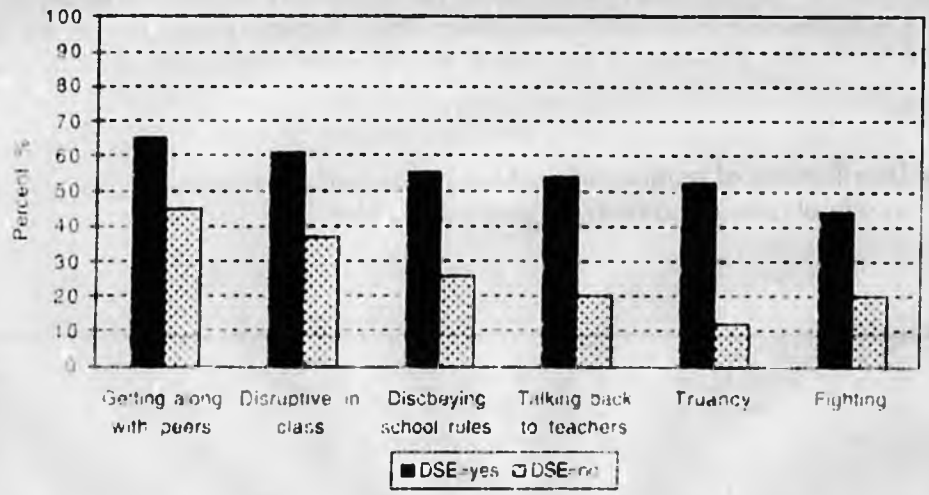
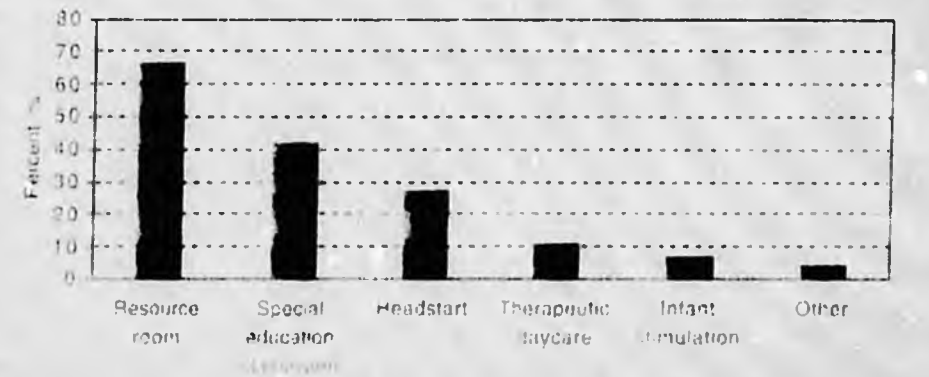


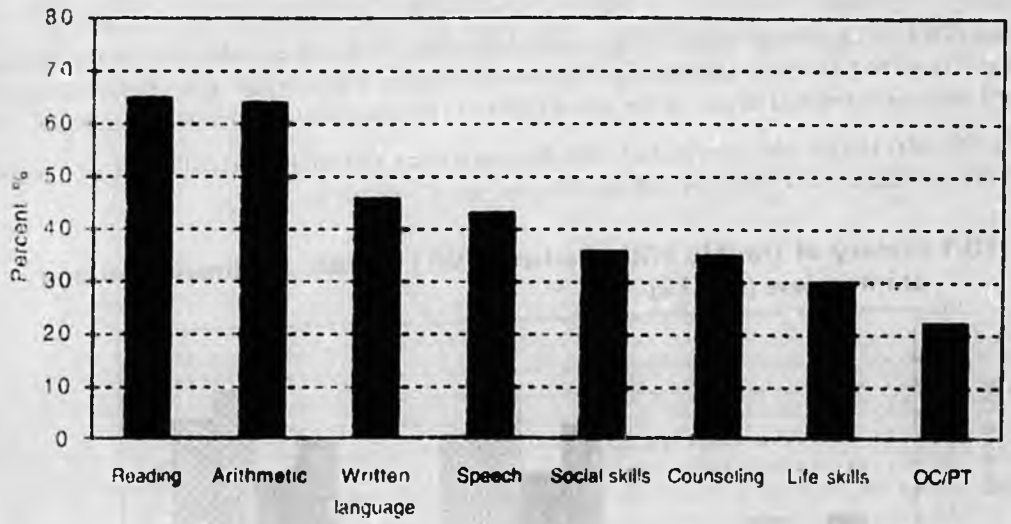
Figure 9.9 shows that 40% of the clients with FAS/FAE were known to have been in special education.

9.9 Types of early intervention programs attended (N=369-404)



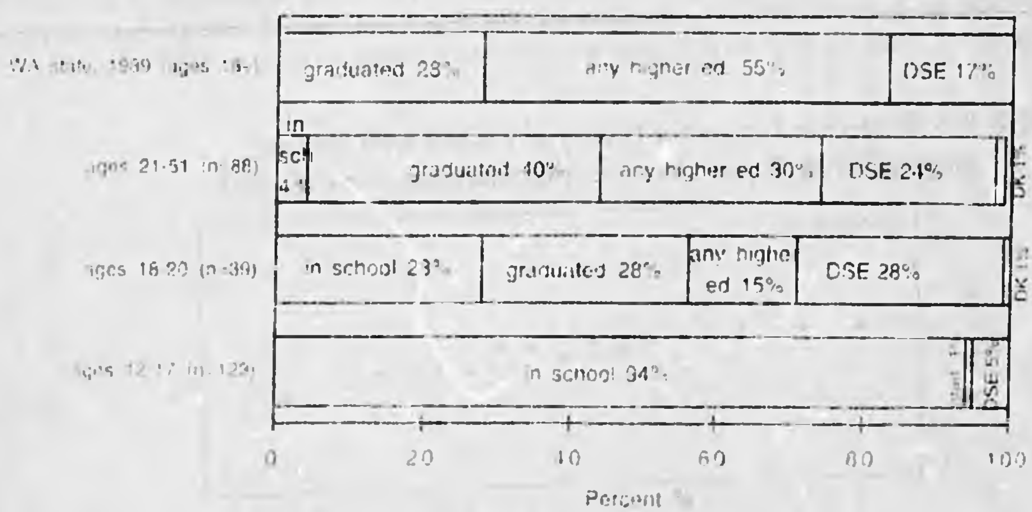
Where schools put emphasis on remediation is of interest, given that over 80% of clients over age 21 are in dependent living situations. It may be more effective for schools to focus more on practical daily living skills training. We found that 65% of the clients with FAS/FAE had received remedial help in Reading and Arithmetic, but fewer than one in three had received life skills training, and only one in five had received occupational or physical therapy (Figure 9.10).

9.10 Types of remedial interventions received at school (N=393-397)



Compared to Washington State statistics (Figure 9.11), clients with FAS/FAE graduate less frequently from high school than other students (counting all types of graduation including special education, GED, etc.). Even after age 21 years only 30% have gone to any type of post-secondary school education. The category membership of a person in the LHI sample is determined hierarchically from left to right for Figure 9.11. Thus a 16 year old who is both in school and has been suspended twice is coded as being among the 94% who are "in school." The 5% of 12-17 year olds graphed as DSE are those who are not still in school.

9.11 Educational status in full study sample and in WA state



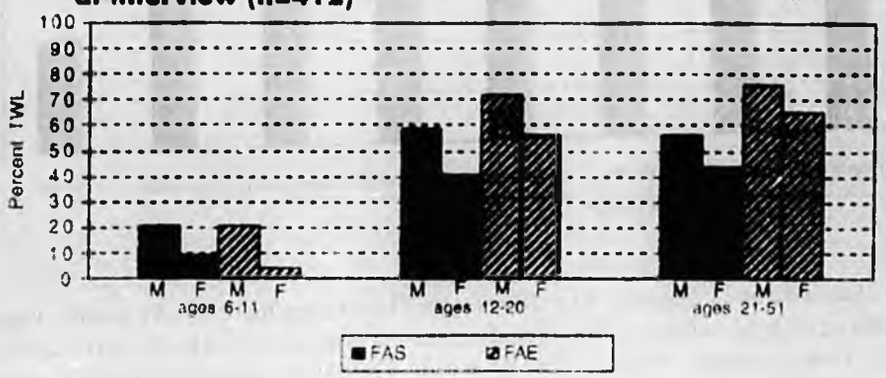
Notes:
"In school" means currently attending *and* does not yet have a high school diploma. This includes a few clients who may be attending community college GED programs.
"Graduated" means the client does have a high school diploma (any kind), but does not have any higher education experience.
"Higher education" means the client *does* have a high school diploma and has received (or is receiving) some higher education.
"DSE" refers to clients who are not in school and never graduated and are DSE positive.
[illegible] who have a high school diploma (any type) [illegible] "graduated" plus "higher education"

10 Trouble With the Law (TWL)

Trouble with the Law (TWL) is a binary summary of reported interactions with police, authorities, or the judicial system for clients of any age. It is set to 1 for those clients who ever were in trouble with the police or authorities, or were ever arrested for, charged with, or convicted of any of the seven types of criminal behavior delineated in Figure 10.3.

TWL is reported for 14% of 6-11 year olds, and higher rates in adolescence and adulthood (61% and 58%, respectively). Figure 10.1 shows the prevalence of TWL by sex, diagnosis, and age at interview.

10.1 History of Trouble With the Law (TWL) by sex, diagnosis and age at interview (n=412)



The most effective factor protecting against TWL is eligibility for DDD (Division of Developmental Disabilities) services (Figure 10.2). Of clients 12 years and over, 62 had applied for DDD (applying, by itself, is neither a risk nor a protective factor); 35 were found eligible and 27 were not. Of the 27 "not eligible," 21 (or 78%) were coded yes for TWL. Of the 35 found eligible for DDD services, 16 (46%) were coded yes for TWL. (No data on the relative timing of these events is available.) Whereas DDD provides services (case managers, job placement and coaching, and shelter), SSI provides only money; eligibility for SSI (Supplemental Security Income) was *not* a protective factor against TWL.

10.2 Risk/Protective Factors for History of Trouble with the Law among clients 12 years and older at interview, max n = 251

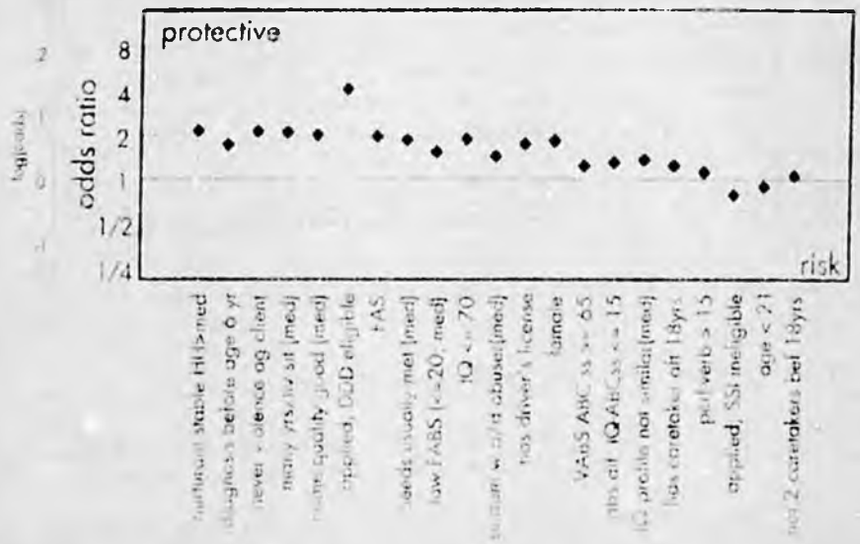


Figure 10.3 shows that crimes against persons are the most frequently reported in every age group. This category encompasses theft (including shoplifting), burglary, assault, and murder.

10.3 History of Trouble with the Law: Components of the Secondary Disability by age at interview (n=407-412)

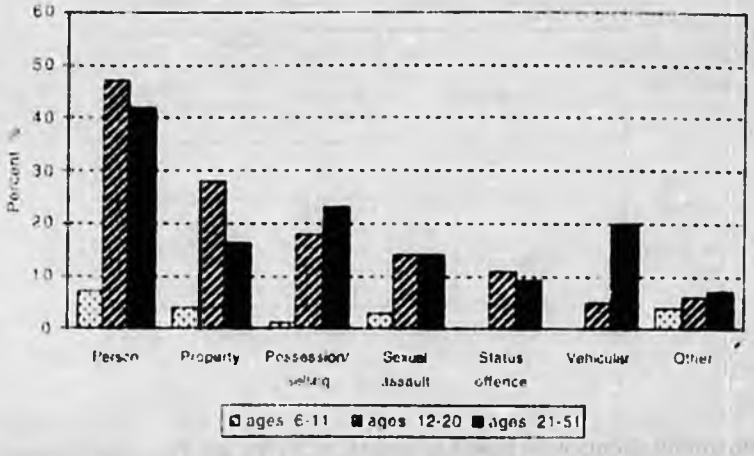
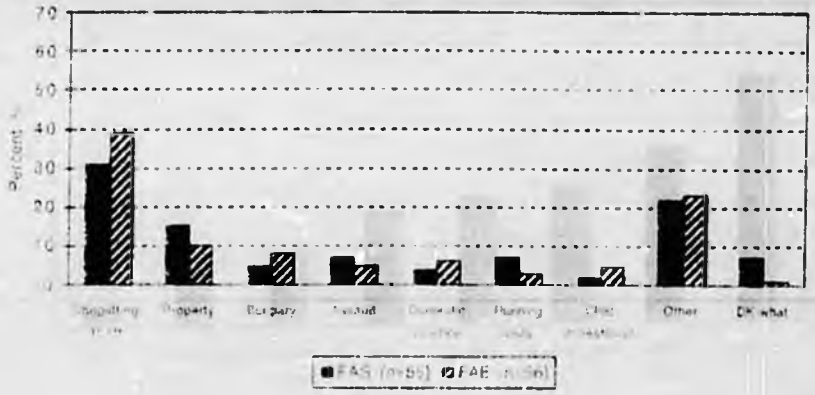


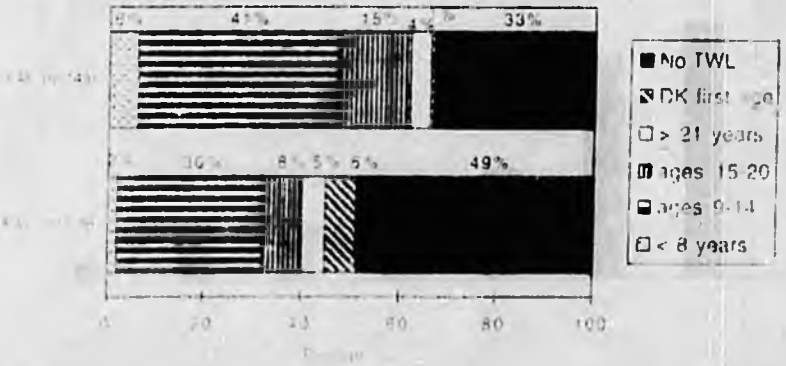
Figure 10.4 shows that shoplifting/theft is most often the first type of crime reported.

10.4 Nature of first trouble with the law among clients ≥ 12 years old with TWL by diagnosis (n=151)



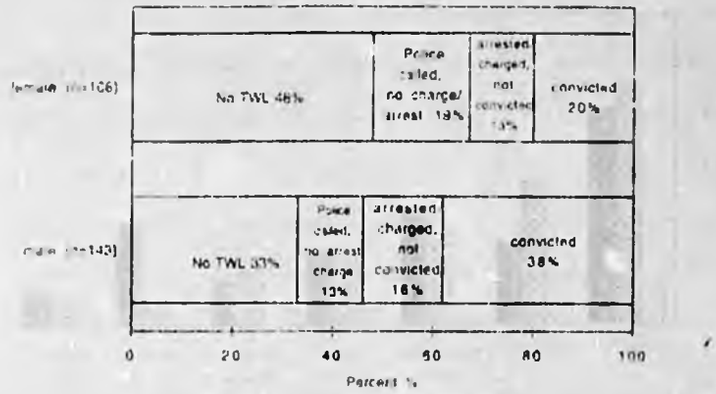
About one in three clients 12 years and older committed a first crime between 9 and 14 years of age. Very few clients had their first TWL after age 20 (Figure 10.5). The rate of TWL was mildly lower in the FAS subgroup, but distributions of first offenses for the two diagnoses were similar (Figure 10.4).

10.5 Age at first trouble with the law by diagnosis among clients ≥ 12 years old at interview



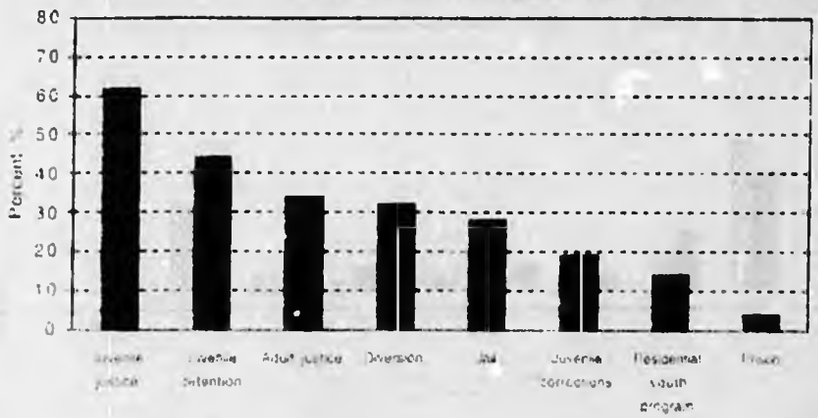
Females were less likely to be charged after the police were called, and less likely to be convicted than were males (Figure 10.6).

10.6 Trouble with the law: arrests, charges, convictions by sex among clients ≥ 12 years old at interview

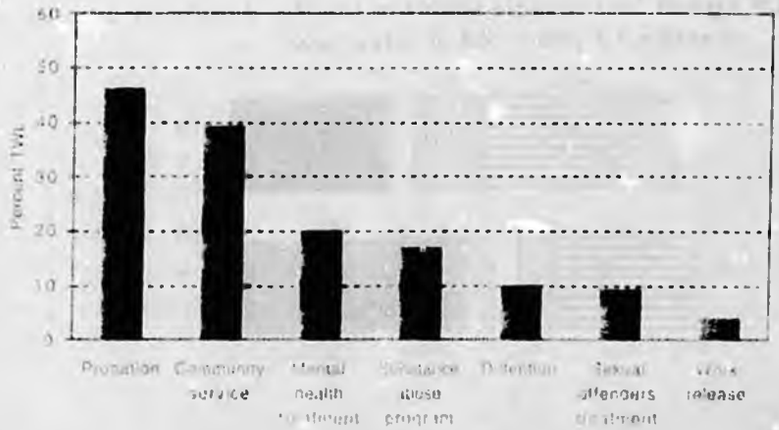


Figures 10.7 and 10.8 show that among clients who have had trouble with the law, the most prevalent types of sentencing are juvenile justice and juvenile detention, and the most prevalent sentencing alternatives are probation and community service.

10.7 Trouble with the law: type of sentence among clients ≥ 12 years old at interview with TWL (n=151)

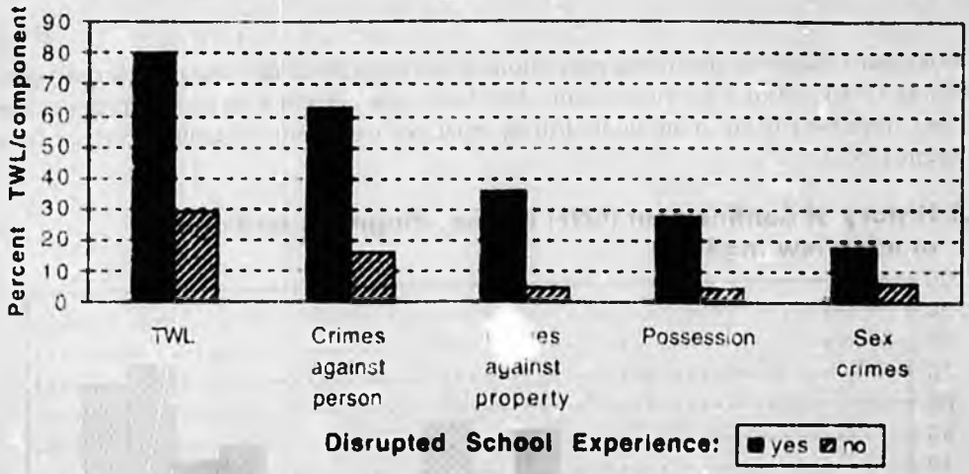


10.8 Trouble with the law: type of sentencing alternatives among clients ≥ 12 years old at interview with TWL (n=150)

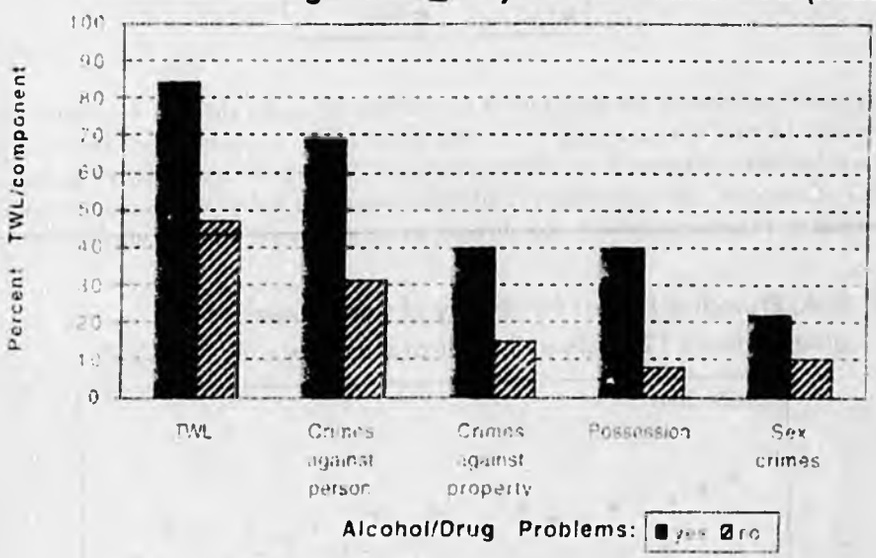


Figures 10.9 and 10.10 examine TWL in relation to two other Secondary Disabilities: Disrupted School Experience (DSE) and Alcohol and Drug Problems (ADP). Staying in school is related to a lower rate of TWL by a factor of 2.2. Absence of Alcohol and Drug Problems (ADP) is also a factor against TWL, decreasing the rate by almost half.

10.9 History of TWL and its components by Disrupted School Experiences among clients ≥ 12 years old at interview (n=248)



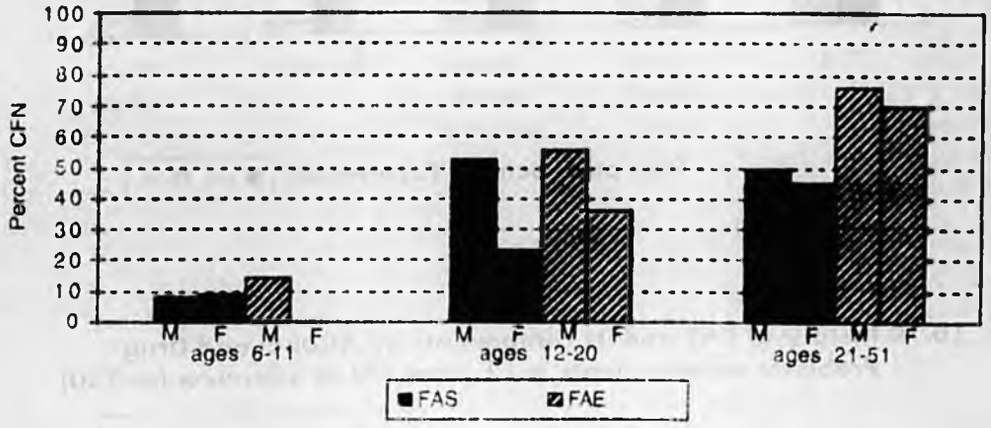
10.10 History of TWL and its components by Alcohol and Drug Problems among clients ≥ 12 years old at interview (n=250)



11 Confinement (CNF)

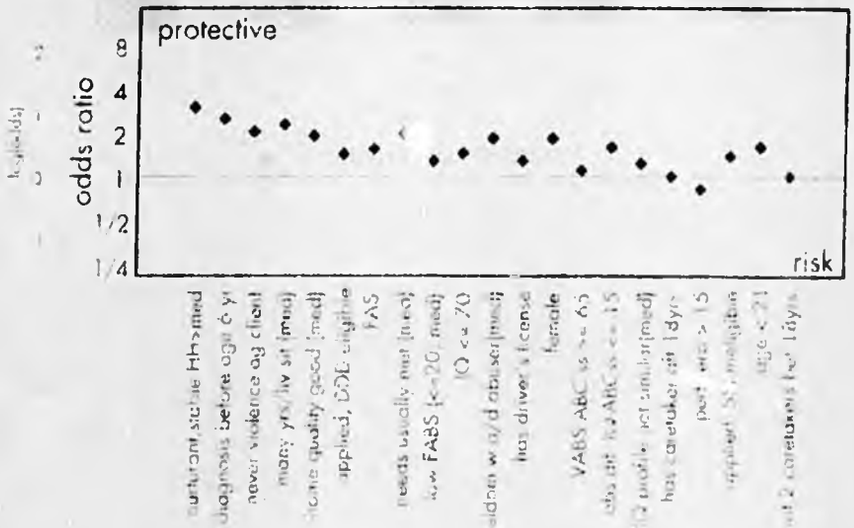
Confinement (CNF) is a binary score summarizing restrictions of personal freedom—the most serious consequence of any secondary disability. CNF is set to 1 for those clients who have ever been in a mental hospital (23% of the clients over 12 years of age), have ever been in an alcohol/drug inpatient treatment program (15%), or have ever been incarcerated for a crime (35%).

11.1 History of Confinement (CNF) by sex, diagnosis and age at interview (n=412)



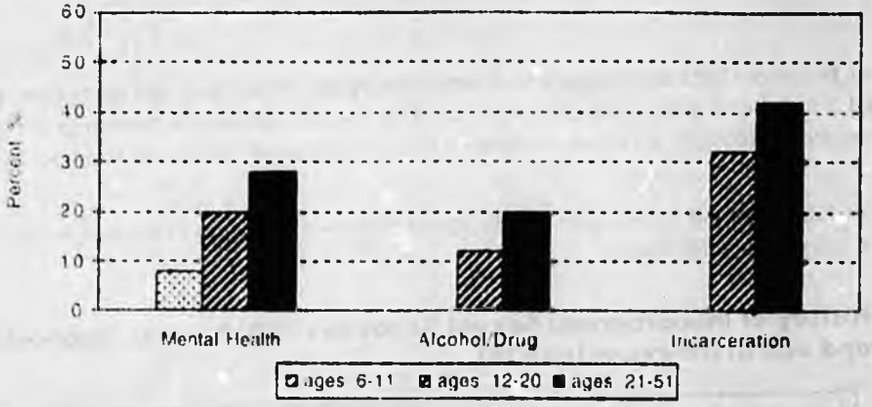
The protective factors against Confinement are the same as the "universal" set for the first six Secondary Disabilities as a group (notice how smooth the profile is in Figure 11.2). This score seems to extract the essence of the three most serious specific secondary disabilities that we have already examined. What protects the client against confinement is what protects him or her against the other secondary disabilities, namely a stable and nurturant household, an early diagnosis, not being a victim of violence, relatively few distinct living situations, and the like.

11.2 Risk/Protective Factors for History of Confinement among clients 12 years and older at interview, max n = 251



Confinement was reported by caregivers of clients under 12 years of age at the time of interview only for mental health problems (Figure 11.3), but Figure 11.4 shows that age at first confinement was often younger than 12 years.

11.3 History of Confinement: Components of the Secondary Disability by age at interview (n=410–415)



11.4 Age of first confinement by type of confinement among clients ≥ 12 years old at the time of interview

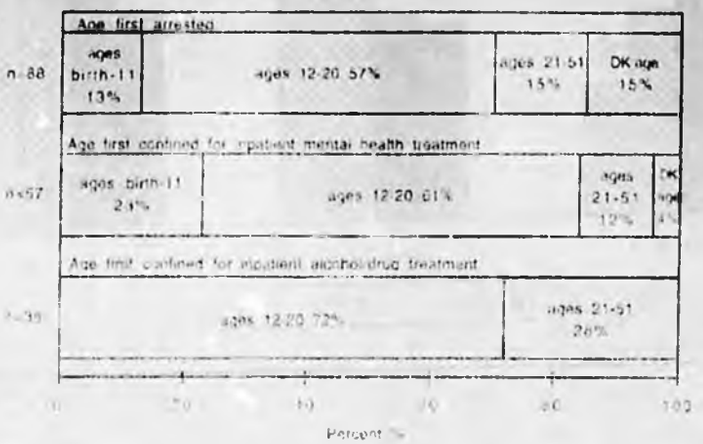
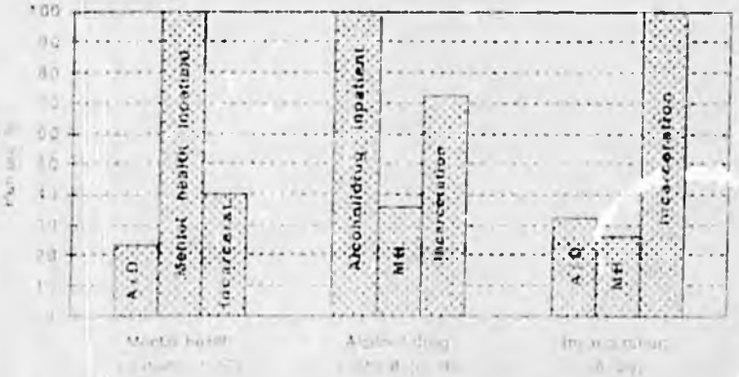


Figure 11.5 indicates that among the clients who were confined, many were confined for more than one reason. For example, clients who had been in mental health inpatient treatment, had also been in alcohol and drug inpatient treatment (22%) or had also been incarcerated (40%). Furthermore, 13 clients were reported to have experienced confinement of all three types.

11.5 Types of confinements in combination with each other among clients ≥ 12 years old at interview

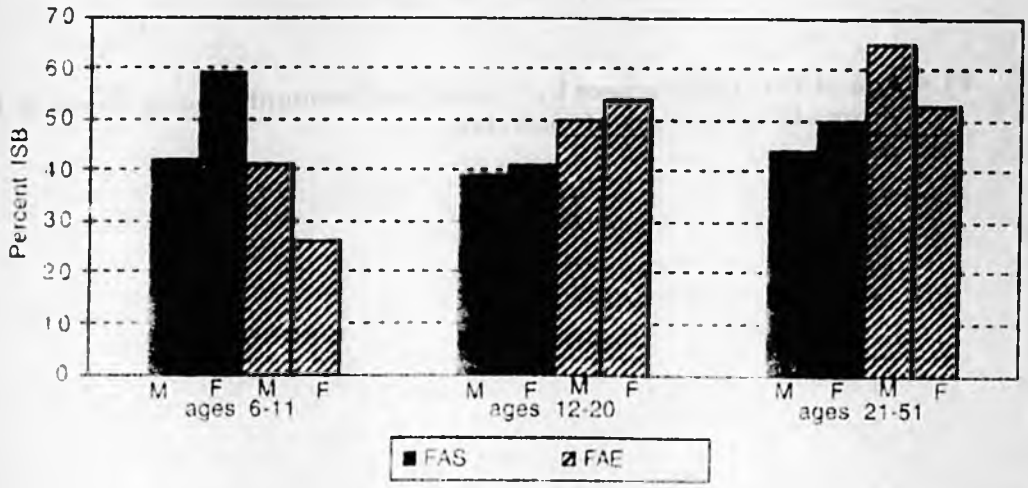


12 Inappropriate Sexual Behavior (ISB)

Inappropriate Sexual Behavior (ISB) is a binary score summarizing problems with sexual behavior among clients of any age. ISB is coded 1 for clients who were ever sentenced to a sexual offender's treatment program or who were reported to have "repeated" problems with one or more of the 10 inappropriate sexual behaviors identified in Figure 12.3.

Figure 12.1 shows prevalence of ISB by sex, age, and diagnosis. There do not seem to be important differences in rates of ISB by these three client characteristics.

12.1 History of Inappropriate Sexual Behaviors (ISB) by sex, diagnosis and age at interview (n=408)



The strongest risk factor against ISB is violence against client (Figure 12.2). Being a victim of violence increases the odds of sexually inappropriate behavior by fourfold. Inappropriate Sexual Behavior is the only one of the six main Secondary Disabilities (Figure 6.1) for which low IQ is not a protective factor. (As we will see in Chapters 14 and 15, IQ≤70 is also not protective for the two adult problems.) The reason that low IQ does not protect against ISB is that low IQ is a *risk* factor for three components of ISB, namely masturbating in public (odds ratio 6.5), inappropriate advances (odds ratio 2.8), and inappropriate touching (odds ratio 2.6).

12.2 Risk/Protective Factors for History of Inappropriate Sexual Behavior among clients 12 years and older at interview, max n = 247

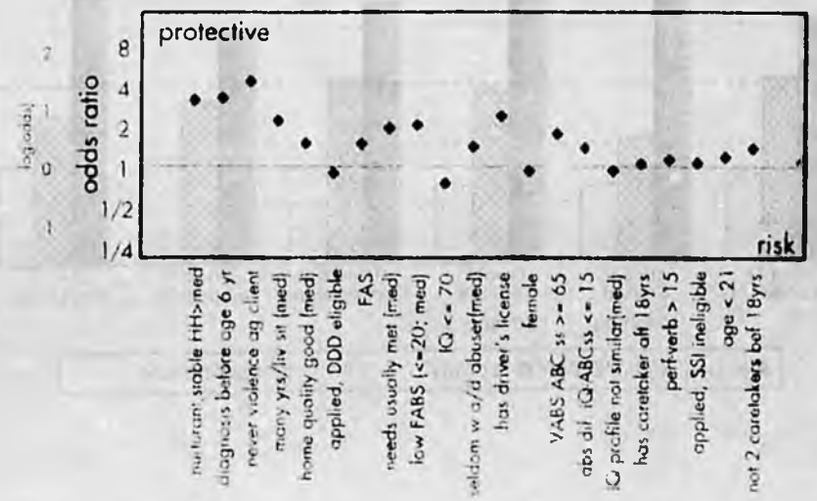
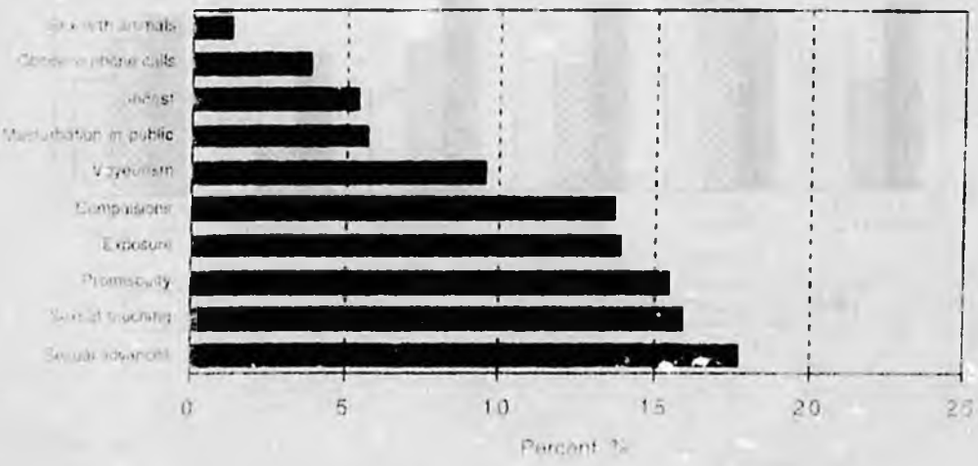


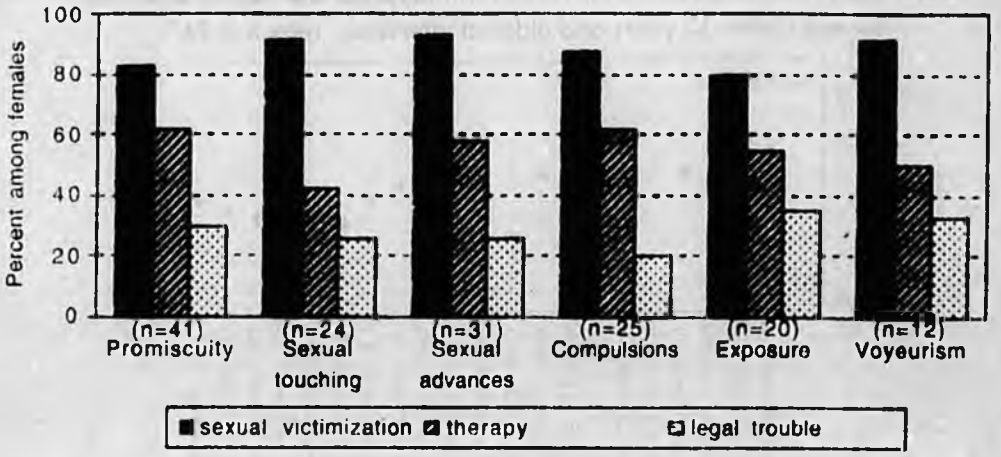
Figure 12.3 itemizes 10 inappropriate sexual behaviors and their prevalence in this sample. Repeated sexual advances toward others are the most prevalent, at 18% of the sample overall.

12.3 History of Inappropriate Sexual Behaviors reported as repeated behaviors (n=388-408)

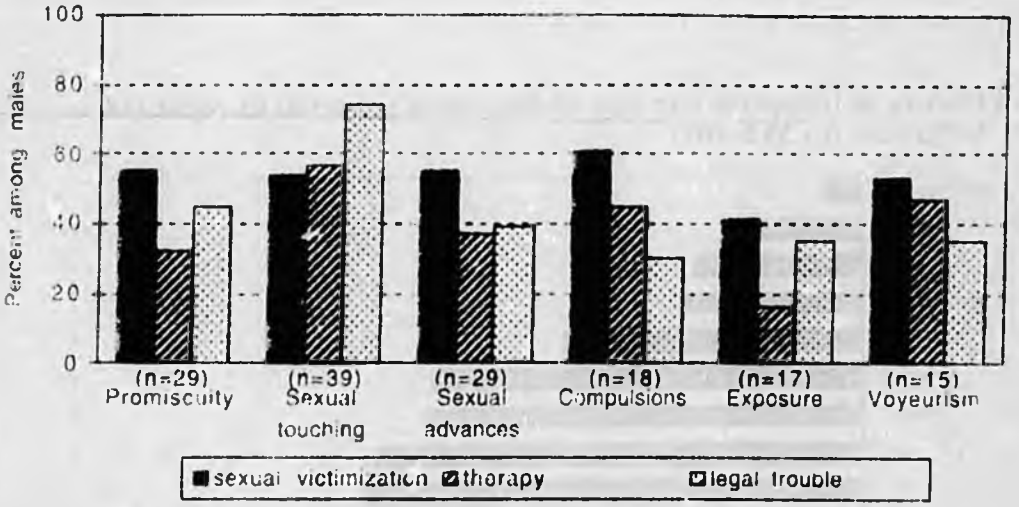


Figures 12.4 and 12.5 show that female clients who exhibited inappropriate sexual behaviors, were more likely to have experienced sexual victimization, and to receive therapy to treat their ISB. Whereas male clients who exhibited inappropriate sexual behaviors were more likely to get involved in legal trouble.

12.4 Prevalence of sexual victimization, therapy for ISB, and trouble with the law for sexual behavior by six common inappropriate sexual behaviors: Among females



12.5 Prevalence of sexual victimization, therapy for ISB, and trouble with the law for sexual behavior by six common inappropriate sexual behaviors: Among males

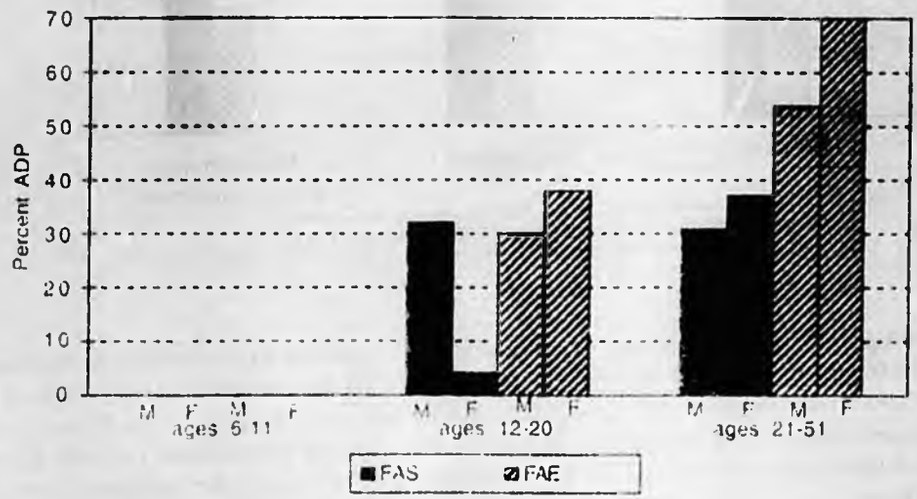


13 Alcohol and Drug Problems (ADP)

Alcohol and Drug Problems (ADP) is a binary score summarizing problems with alcohol or drug habits among clients of any age. ADP is coded 1 for clients who have ever had alcohol abuse problems, drug abuse problems, or have ever been in alcohol or drug abuse treatment (either outpatient or inpatient).

Figure 13.1 shows that report of ADP is not different for male versus female clients, but is related to age at interview and to diagnosis.

13.1 History of Alcohol/Drug Problems (ADP) by sex, diagnosis and age at interview

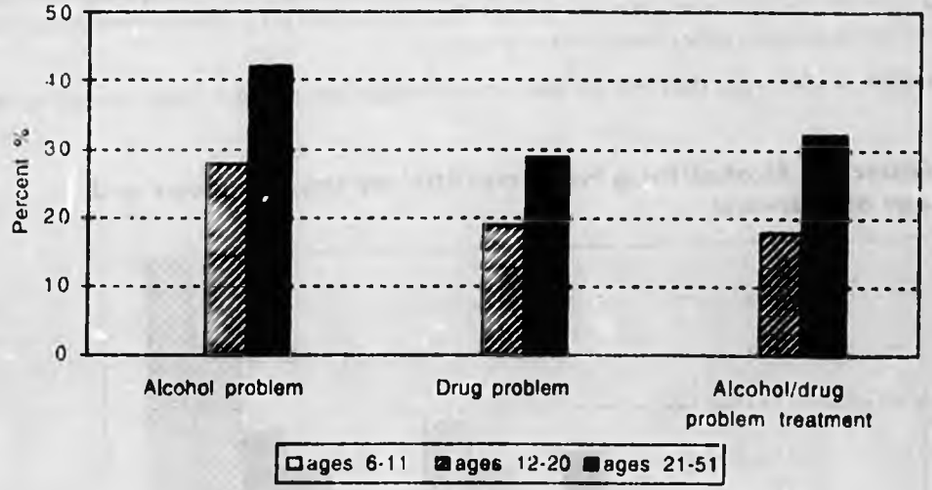


The obvious specific risk factor for ADP is living with alcohol abusers and drug users. Other important risk factors are from the "general" RPF set: late diagnosis of FAS/FAE, and violent behavior against clients (Figure 13.2).

13.2 Risk/Protective Factors for History of Alcohol/Drug Problems among clients 12 years and older at interview, max n = 252

Figure 13.3 shows that among clients who were still younger than 12 years at interview, there was no Alcohol and Drug Problems reported. However, as will be seen in subsequent figures, problems often began at ages younger than 12 years among clients 12 years and older at the time of the interview (Figure 13.4). Overall ADP-related rates among adolescents and adults were 33% for alcohol problems, 23% for street drug problems, and 23% for treatment. Overall ADP was noted for 35% of the clients 12 years and older.

13.3 Alcohol/Drug Problems: Components of the Secondary Disability by age at interview



The 57 clients with street drug abuse problems are almost entirely "nested" within the 81 clients with alcohol problems. The same is true for use of treatment programs. Among clients with both alcohol and street drug problems, alcohol abuse began on average about 2 years before the abuse of street drugs. Sixty-five percent of clients 12 years and older who had abused alcohol later abused street drugs. Also, among clients engaging in treatment for both alcohol and street drug abuse, the age at first treatment was the same for alcohol as for drug use, as if the multiple addictions were often needed to ensure action.

Possibly quicker treatment for alcohol abuse could lower the rate of later street drug abuse.

13.4 Age of onset of alcohol problems, by sex and diagnosis among clients with alcohol problems

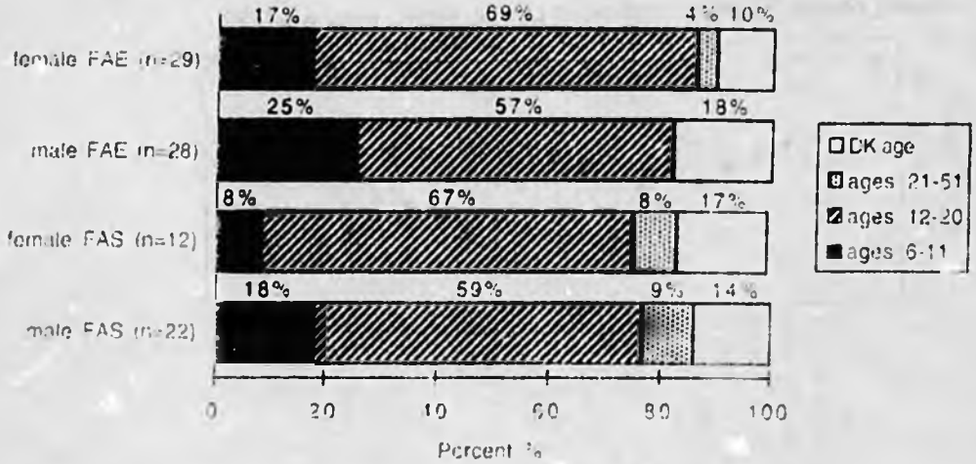
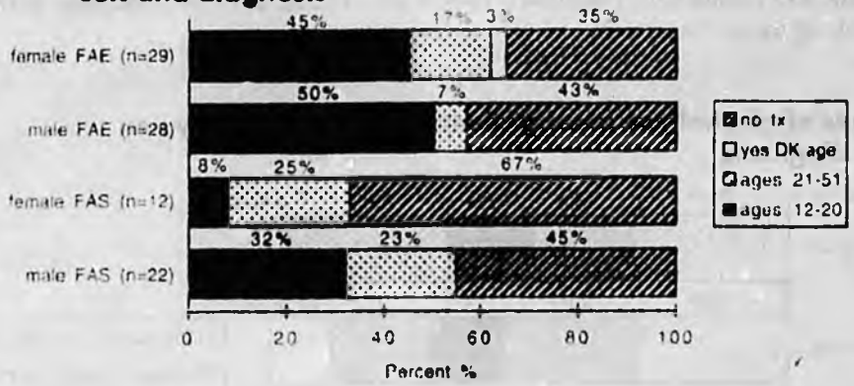


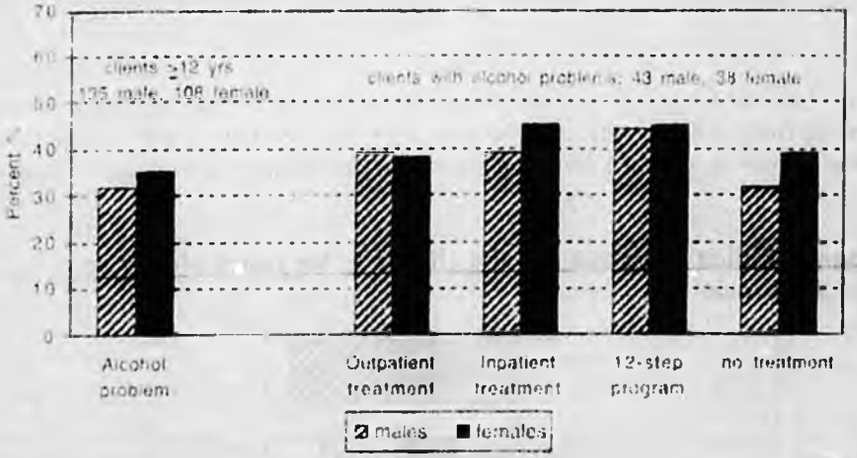
Figure 13.5 shows that 70% of clients who have been in treatment had their first alcohol treatment before age 21

13.5 Age of first alcohol treatment among alcohol abusers, by sex and diagnosis



Figures 13.6 and 13.7 show the choices of treatment used by clients with alcohol abuse problems and drug abuse problems by sex of client. There is not much difference in use of the different treatment types by sex. There also does not seem to be an overall difference in rate of utilization of different treatment types. Inpatient treatment is as highly utilized as other types of treatment.

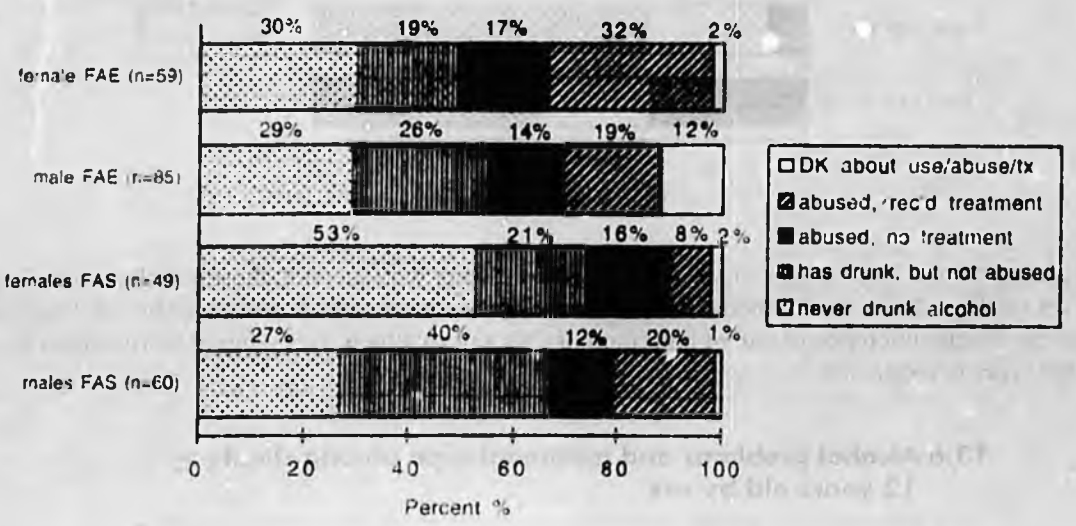
13.6 Alcohol problems and treatment type among clients ≥ 12 years old by sex



13.7 Illicit drug problems and treatment type among clients ≥ 12 years old by sex

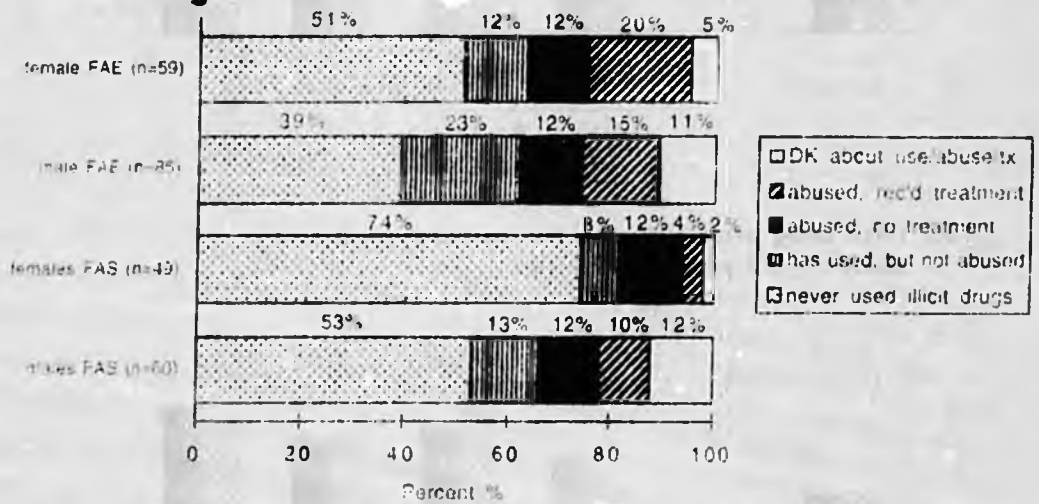
Figures 13.8 and 13.9 depict the four stages of alcohol and drug use respectively: "no use"/"using, but not abusing / "abusing, but no treatment yet"/"abusing and treatment received." Female FAS clients have the highest rate of abstinence. Among those who become alcohol abusers, they have the lowest rate of treatment (40% compared to 65% for alcohol abusers as a group). Male FAS clients have the highest rate of use. Among those who become alcohol abusers, they also have the highest rate of treatment.

13.8 Stages of alcohol use among clients ≥ 12 years old by sex and diagnosis



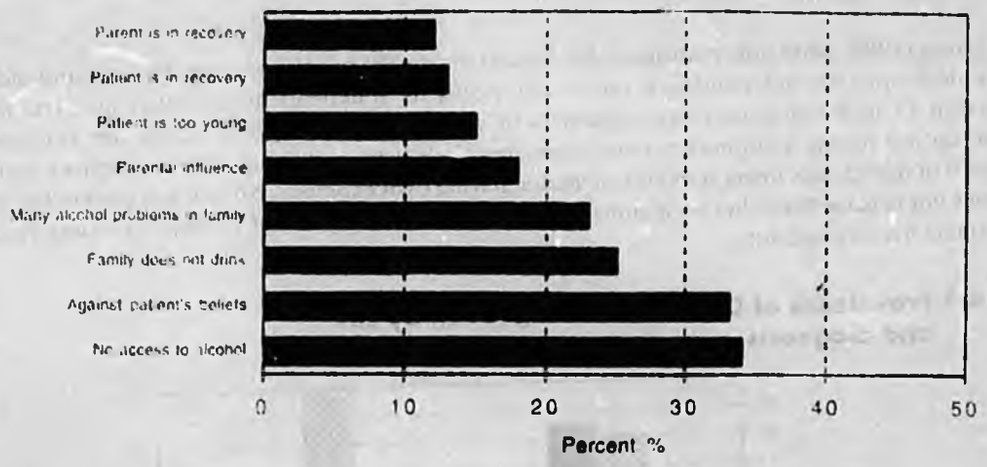
A very similar pattern is observed for street drug use (Figure 13.9). Female FAS clients have the highest rate of street drug avoidance, but among those who become drug abusers, they have the lowest rate of treatment (33% compared to 58% for all street drug abusers as a group). Male FAS clients have the highest rate of street drug use.

13.9 Stages of illicit drug use among clients ≥ 12 years old by sex and diagnosis



Many clients have avoided alcohol use completely. The reasons caretakers report for the clients abstaining from alcohol are as presented in Figure 13.10.

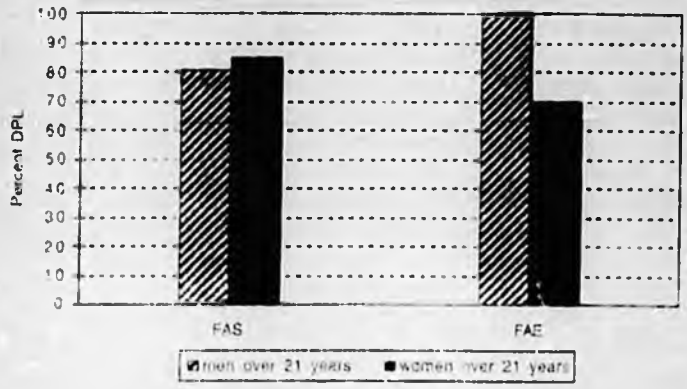
13.10 Reasons for abstinence among clients ≥ 12 years old reported not to consume alcohol at present (n=163)



14 Dependent Living (DPL) Over 21 Years

Dependent Living (DPL) could only reasonably be defined for the 90 people who are 21 years and older. Two sets of criteria were developed for independence; one could qualify as "independent" by either one. The first focuses on independence in 12 daily living activities (regardless of whether or not support people are available); the second focuses more on *not* having a support person organizing their lives, *not* living with a caregiver, and being able to handle at least 9 of the 12 daily living activities, including paying own expenses. No one was counted as an independent adult who does not manage his or her own money (See Figure 14.3 for this list of 12 daily activities). Figure 14.1 shows that 83% of adults live dependently.

14.1 Prevalence of Dependent Living (DPL), by sex and diagnosis



Only one of our "universal" RPF's is protective against DPL diagnosis before age six. Several RPF's specific to DPL are apparent in Figure 14.2, including a VABS ABC score of 65 or above, IQ above 70, a VABS ABC being within 15 points of IQ, a low FABS score (below the median), and being female. The environmental RPF's include having a driver's license and not having (presumably, not needing) two caretakers.

Dependent living and problems with employment each characterized approximately 80% of the adults with FAS/FAE: 70% had both. Only 8% (7 clients) had neither.

14.2 Risk/Protective Factors for Dependent Living among clients 21 years and older at interview, max n = 89

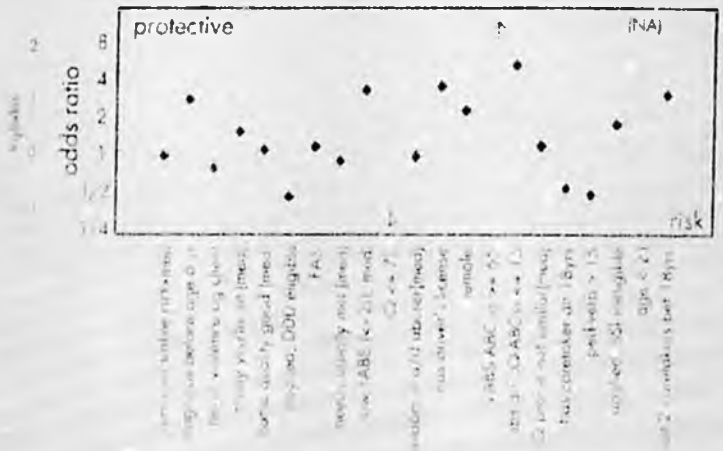


Figure 14.3 lists 12 daily activities that people sometimes or frequently need help with. The daily tasks requiring help by the largest numbers of clients 21 years and older include managing money and making decisions.

14.3 Daily life activities among clients ≥ 21 years old (n=90)

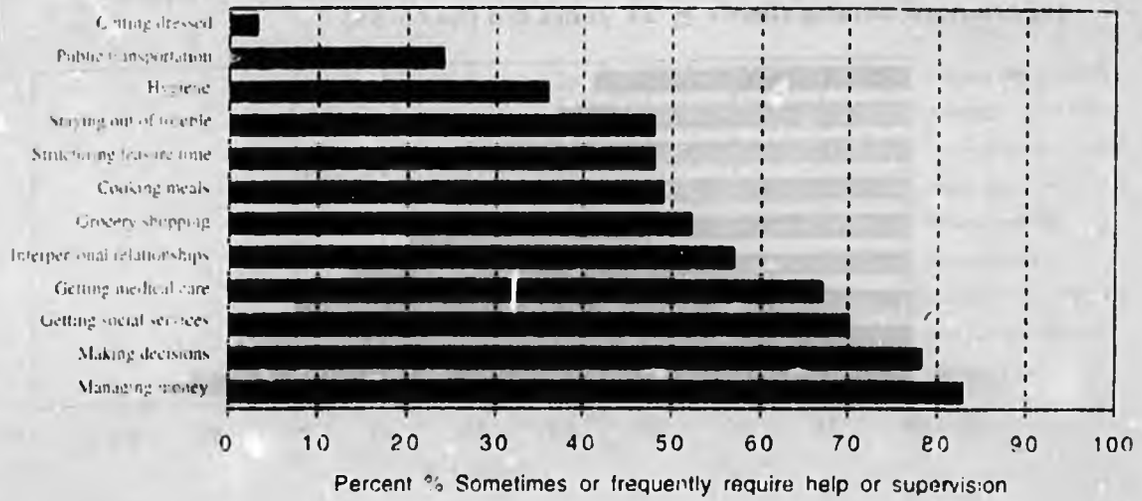


Figure 14.4 shows that female FAE clients are most likely to be able to do all 12 daily activities without help, but all 20 are over 21 years old, and only 5 (25%) of them are reported to be capable of doing these tasks.

14.4 Number of daily activities among clients ≥ 21 years old, by sex and diagnosis

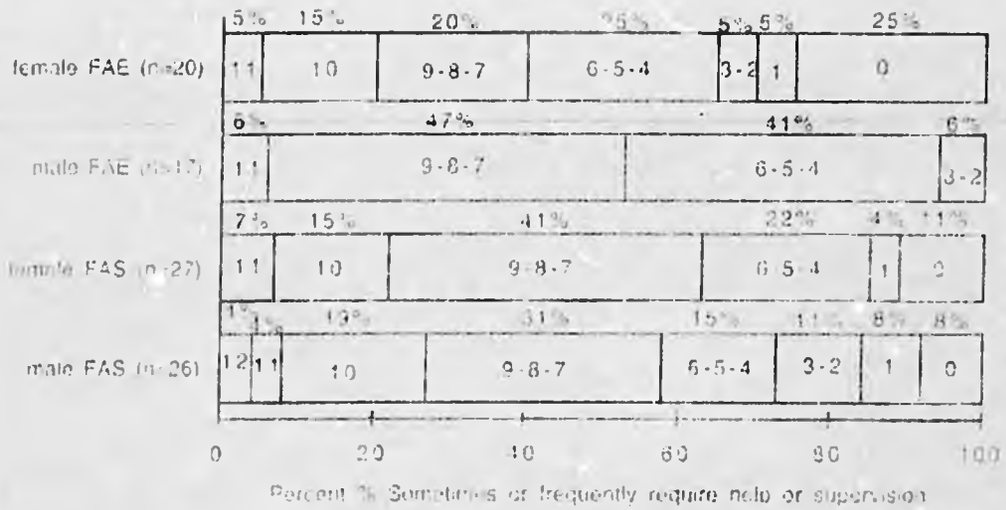
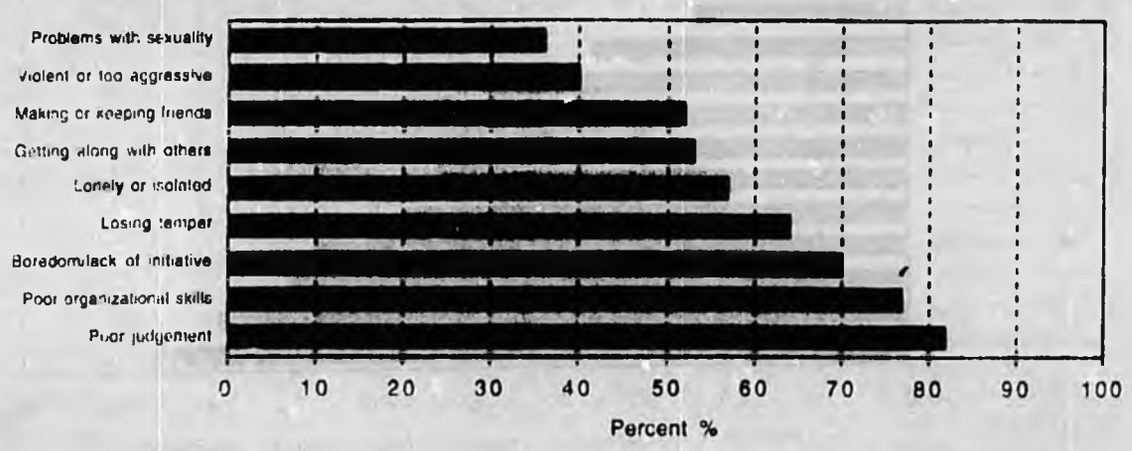


Figure 14.5 shows that even as adults, people with FAS and FAE experience social problems which significantly compromise their daily functioning. Hence, it is not surprising that over 80% of these adults have difficulty living independently and need intensive help and supervision with managing their daily activities.

14.5 Current caregiver reports of social problems "sometimes" or "frequently" experienced among clients ≥ 21 years old (n=76-88)



15 Problems With Employment (PWE)

Problems With Employment (PWE) were endemic and variable in this group of clients. We ended up defining a group who were *relatively* problem-free. The clients in this group have little in common except that they are all employed. Beyond that, we have combined three more specific groups, overlapping, but not nested, defined as follows:

Group 1. No financial support except own earnings.

Group 2. Earns $280 a week or more.

Group 3. This category was added based on the characteristics of several specific individuals who seemed to be effectively employed but didn't meet any of the preceding criteria. These were people who were not in a sheltered workshop, were working at least half time, and had no more than 3 jobs in the past 2 years. In addition, from the list of problems under Group 1, they had no repeated problems and only 1 or 2 problems of any kind.

PWE is defined by all clients 21 years and older who are *not* relatively problem-free. Figure 15.1 shows that 79% of clients 21 years and older have PWE.

15.1 History of Problems With Employment (PWE) among clients ≥ 21 years old, by sex and diagnosis (n=90)

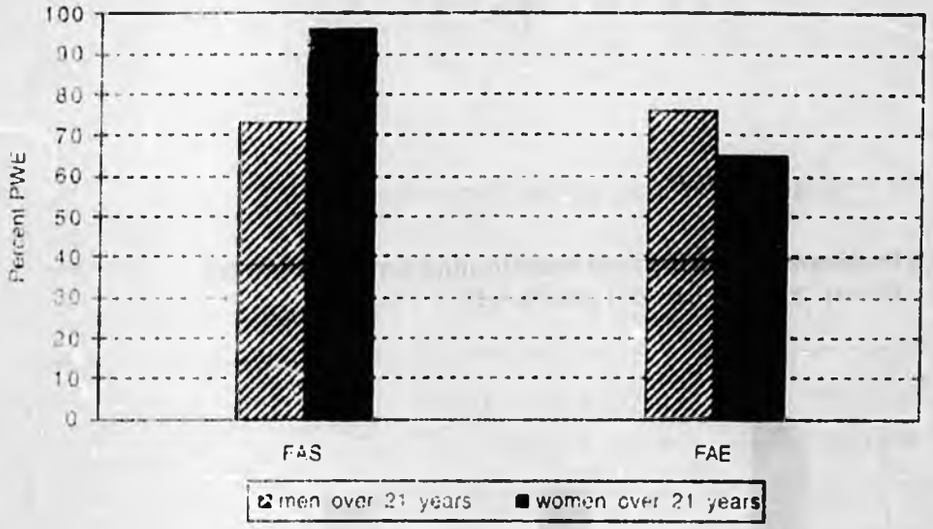


Figure 15.2 shows that a VABS Adaptive Behavior Composite higher than the median is a protective factor for successful employment. There are also two clear intrinsic risk factors against successful employment: being FAS (as opposed to FAE) and having a low IQ. No person with FAS or FAE who had an IQ 70 or below met our criteria for successful employment, even though low IQ was not explicit in the definition. In addition, one specific protective factor emerged (having a driver's license), and some of the "universal" set of protective factors emerged: more than the median number of years per living situation followed closely by never experiencing violence, an early diagnosis, and living in a nurturant and stable home for over 72% of life.

15.2 Risk/Protective Factors for Problems With Employment among clients 21 years and older at interview, max n = 90

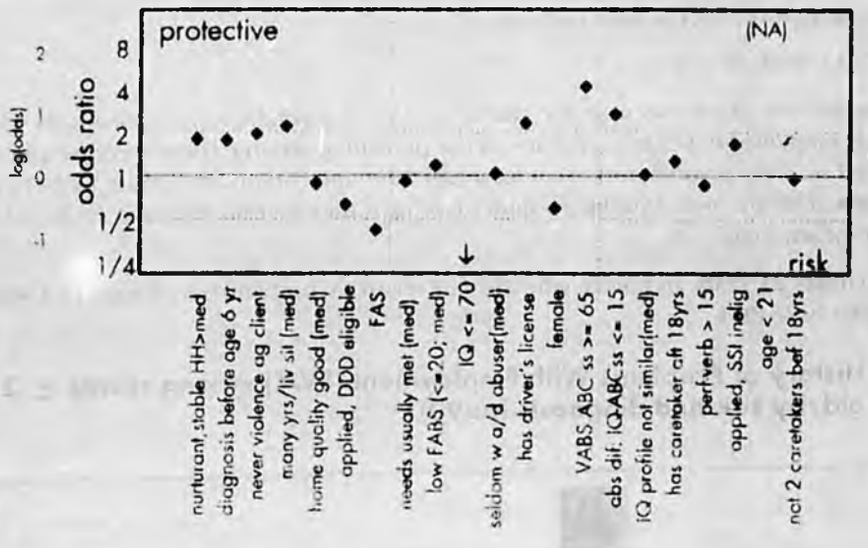


Figure 15.3 shows that holding a job is a bigger problem than getting a job.

15.3 Problems acquiring and maintaining employment by clients ≥ 21 years old (n=78-83)

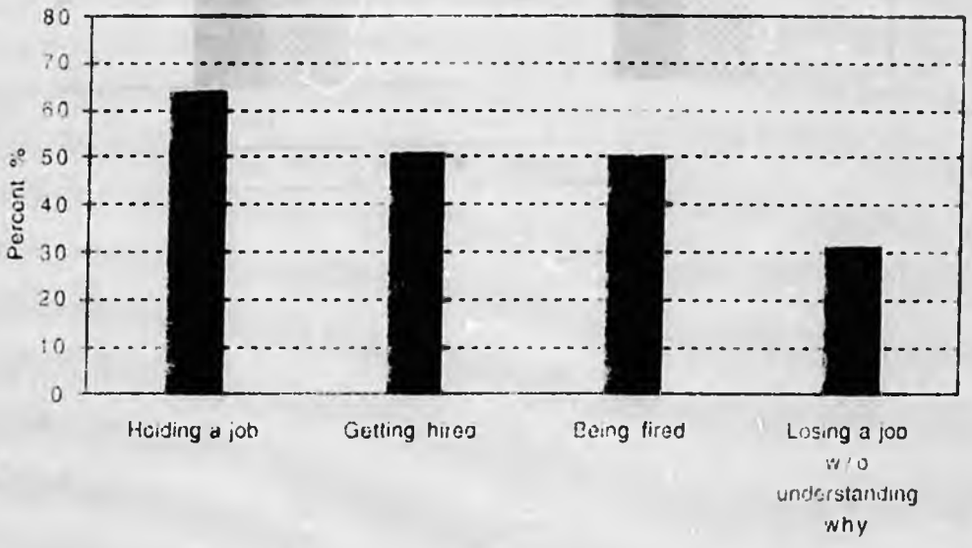
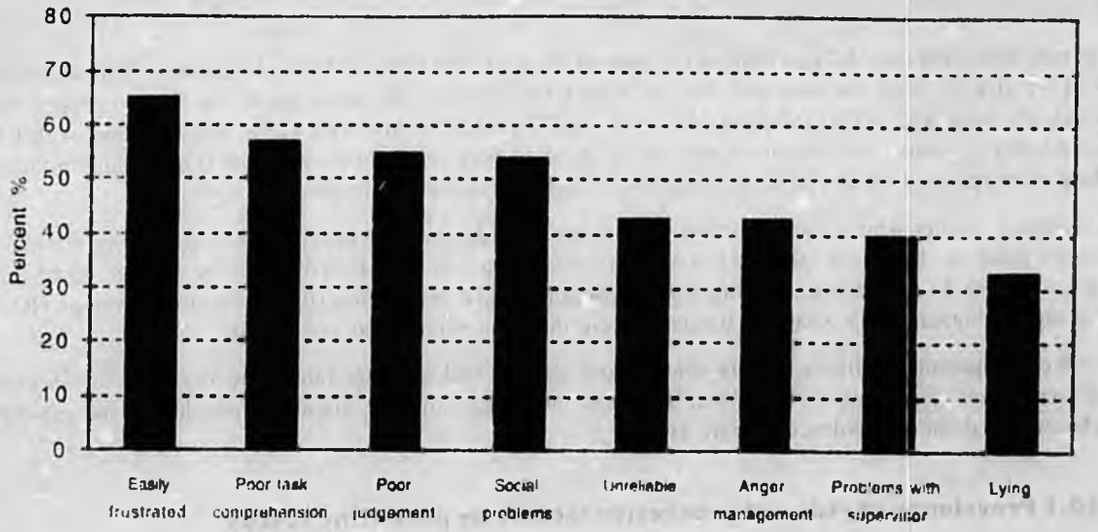


Figure 15.4 itemizes many problems that clients have on the job. At least one, "poor task comprehension" (57%), may reflect poor job placement. Educating personnel directors and job placement services staff to special characteristics of clients with FAS or FAE may be mutually beneficial both to the clients and employers.

15.4 Type of employment problems experienced while on a job (n=80-83)



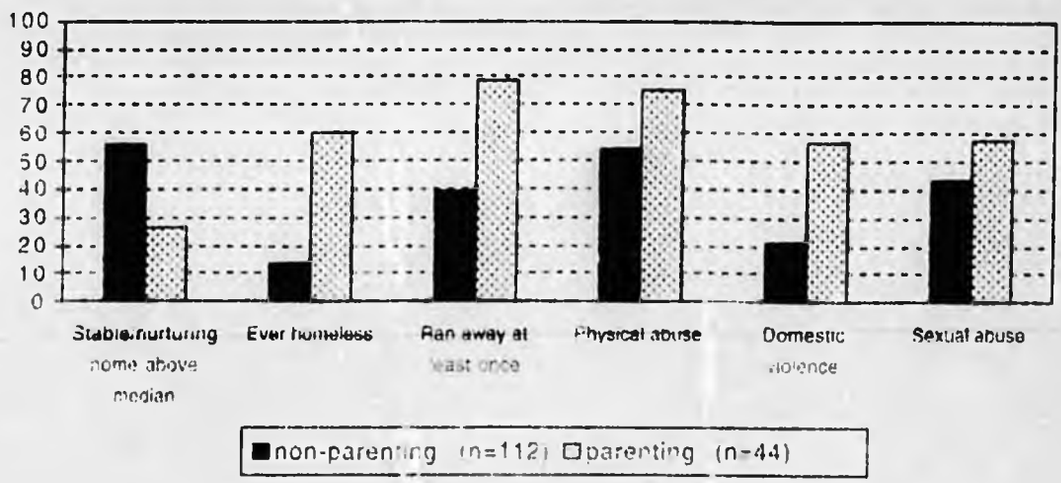
16 Problems with Parenting (PWP)

Of the 253 clients who were over 12 years old at the time of the LHI, 44 (17%) had become parents; 30 females and 14 males (28% of females 12 years and over and 10% of males). For females, the mean age of the first pregnancy was 18 years, for males, the mean age of first fathering of a child was 20 years. The youngest age at which a client with FAS or FAE had a child was 13 years. The maximum number of children born to a mother was four (Only children known to the respondent were reported on the LHI, as clients were not interviewed themselves).

In order to compare clients who became parents with those who did not, a subset of "non-parenting clients" was selected from the database, based on age of client at interview. There was little difference in the average IQ of the two groups. Average IQ was 84 for parents, ranging from borderline mental retardation (IQ 70) to above average (IQ 117). Parents had a slightly higher VABS Adaptive Behavior score than non-parents (66 versus 60).

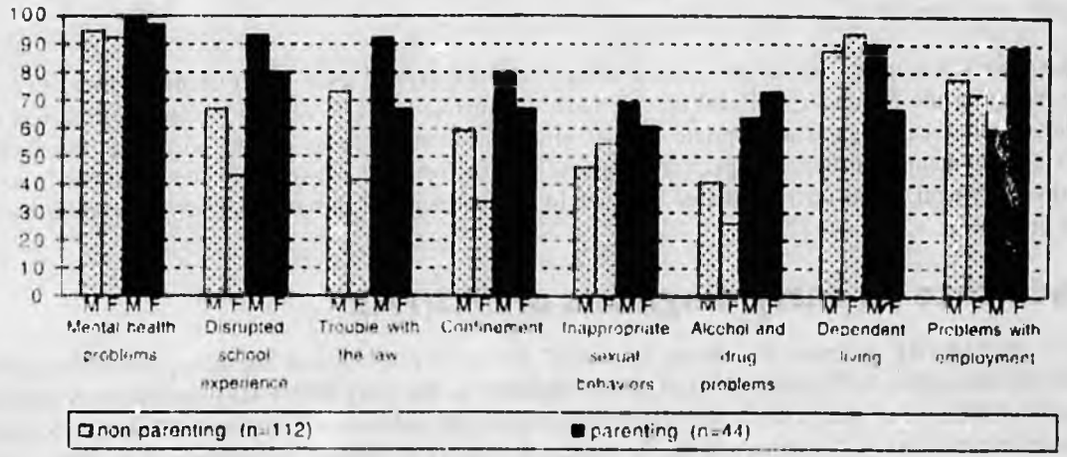
Compared to the non-parenting clients, clients who became parents had a higher rate of history of living in unstable homes. They were much more likely to have been homeless, more likely to have run away from home, and experienced over twice the rate of domestic violence (Figure 16.1).

16.1 Prevalence of risk and protective factors by parenting status



Parenting clients had more Disrupted School Experience, more Trouble with the Law, more Confinement, and more Alcohol and Drug Problems, compared to non-parenting clients (Figure 16.2). They were over two times more likely to have dropped out of school (66% versus 26%).

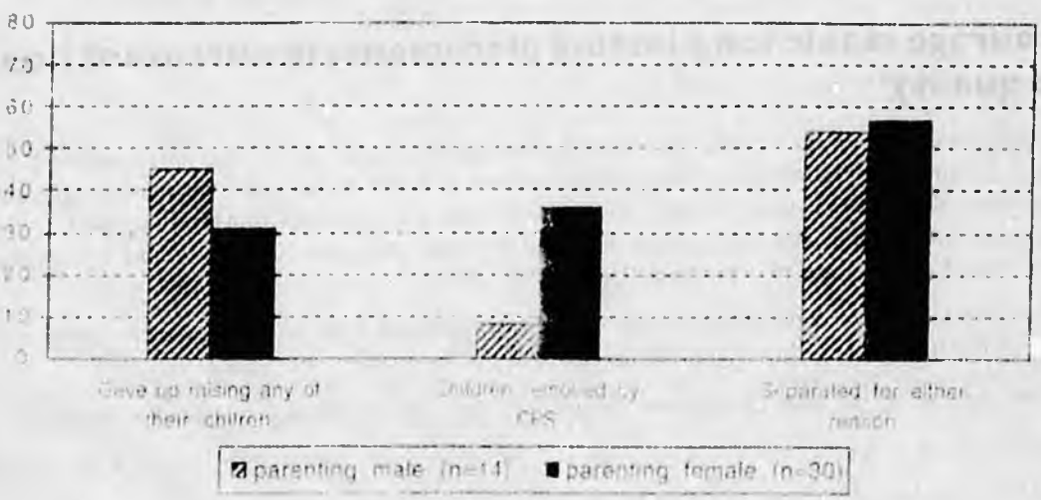
16.2 History of Secondary Disabilities: Comparing non-parenting and parenting clients



Fifty-nine percent of the parents were diagnosed FAS or FAE after they had become parents; 30% before they became parents and for the rest, the two ages were too close to evaluate in this regard. The 44 parents had produced 76 children, at least half of whom were no longer being cared for by the client (Figure 16.3). Thirty six percent of female clients had their children removed from their care by CPS, whereas 45% of male clients had given up raising their children.

Parenting clients were more likely to be married (23% versus 4%). They were more likely to have ever been on welfare (81% versus 48%), but somewhat less likely to have ever received SSI than non-parents (44% versus 50%). 10% of the parents had applied for and received eligibility for DDD versus 20% of the non-parents.

16.3 Separation of parent from child among parenting clients: Comparing male and female clients



As shown in 10% of the female parents were drinking during pregnancy, 17% had a child who had been diagnosed FAS or FAE, and another 17% had children that the respondents suspected of being fetal alcohol affected.

17 Recap and Recommendations

In this chapter, we summarize some of the main findings from this report, draw conclusions, and make recommendations for overcoming the Secondary Disabilities we have documented. While causation can't be inferred from these data, they nevertheless can suggest appropriate courses of action. First we focus on the "extrinsic" risk factors—those that suggest environmental influences, specific programs and so forth. Then we go to the "intrinsic" risk factors—those that reveal typical client characteristics that would demand special protection or consideration by caretakers and service providers.

17.1 Facilitate an early diagnosis of FAS/FAE

Although an early FAS/FAE diagnosis is a strong "universal" protective factor for all Secondary Disabilities (Figures 6.1), only 11% of the clients had a diagnosis prior to age 6 (Table 6.1). An early FAS/FAE diagnosis may help the family better understand the root of their child's developmental delays and behavioral problems and empower the family to advocate for appropriate services particularly in the crucial first years at school. A diagnosis is an effective communication tool that enables caregivers to educate others about the special needs of alcohol-affected individuals.

Many actions could be taken to foster an early diagnosis. These include:

- A statewide network of FAS Diagnostic Clinics such as is already underway in Washington State through the University of Washington Medical School (Clarren & Astley, 1997).
- A referral network system whereby children at risk of having FAS/FAE are screened during infancy and the preschool period for possible FAS/FAE. Those children identified at risk (i.e., from those being adopted from alcohol-abusing mothers, those who are under the supervision of Children's Protective Services for neglect or abuse, and those entering the foster care system) are referred to their local FAS Diagnostic Clinics. A foster care screening program is presently underway in King County, Washington.
- Routinely obtaining prenatal exposure information at each point at which the child and family are evaluated by the system (prenatal care, delivery, and pediatric care school entry, criminal justice, mental health, and so forth).
- Training school nurses to screen for FAS/FAE as part of the school entrance examination. The effectiveness of this program in two counties of Washington State has already been demonstrated.

17.2 Encourage stable long-lasting placements in nurturant homes of "good quality"

Desirable characteristics of the client's home life (stability, nurturance, "good quality") are universal protective factors for all Secondary Disabilities (Figures 6.1). This common sense protective factor is a fundamental right for the well being of all children. The fact that many alcohol-affected individuals have come from dysfunctional, transient, and abusive living situations demands that we reiterate the need for more effective community and family support services, perhaps modeled on the Birth to 3 program (Grant et al., 1996).

Environmental risk factors for secondary disabilities that must be modified if we are to prevent or decrease secondary disabilities are exemplified by the following problems revealed by this study:

- Half of our clients over 12 years of age have *not* lived at least 72% of life in a stable and nurturant environment.
- Half have *not* lived in a home with at least 10 of 12 positive qualities between the ages of 8 and 12 years.
- Half had *not* stayed in each living situation for an average of more than 2 years, and
- Half of our clients 12 years and older had *not* had their basic (food and shelter) needs met for more than 72% of life.

By identifying environmental risk factors, service providers can work together with the family to prevent secondary disabilities in alcohol affected individuals.

- Early identification of children born to "high risk" women with alcohol and drug problems should draw community resources to these children and their families, ideally during the prenatal period, the postpartum period, and onward into infancy and childhood.
- Advocates/case managers in close personal contact with high risk families can work to improve the quality of the home. When the child's safety in the home cannot be safeguarded, the child should be moved to an alternative long-term home or placed for permanent adoption as early as possible.
- An early diagnosis can identify children with FAS/FAE living in high risk homes, so that biological families can obtain the same state resources that should be available for foster and adoptive families (family support services, medical coverage, home visits, respite care, and case management opportunities and so forth).
- On a policy level, requiring state personnel to disclose the full medical/mental health background history before placing a child in foster care or adoptive placement should insure that the parents will know about the special needs of their children with FAS/FAE from the onset of parenting.
- A better system for educating and training parents about children with FAS/FAE is needed, so that parents and all caregivers can use their energies most efficaciously on behalf of their children.
- Group homes providing stable, long-term residences with personal and job supervision appropriate to the special needs of youth and adults with FAS/FAE are urgently needed. As a start, a model program should be funded, implemented, and evaluated.

17.3 Improve the circumstances of children in alcoholic/drug abusing homes

Living with people who have alcohol/drug problems was a risk factor for five of the eight Secondary Disabilities studied: Alcohol and Drug Problems, Confinement, Disrupted School Experience, Trouble with the Law, and Inappropriate Sexual Behavior.

Half of the clients who were 12 years old and older, had spent at least 30% of their lives living with a person who had an alcohol/drug problem.

Based on our findings, we recommend that efforts be focused on:

- Detecting high risk alcohol and drug abusing mothers and providing appropriate services (during prenatal care, at delivery, at FAS Diagnostic Clinics, and at community treatment centers).
- Expanding alcohol and drug treatment services for women so that they can keep their children with them and their families intact during inpatient treatment.
- Developing advocacy services for alcohol/drug abusing mothers and using advocates as a liaison with CPS for monitoring the safety of children in alcohol/drug-abusing homes (as has been successfully accomplished in the Seattle Birth to 3 Program: Grant et al, 1996).

17.4 Intervene to prevent violence against people with FAS/FAE

Violence against the client is almost a universal risk factor for all Secondary Disabilities, impacting six of the eight studied (Figure 6.1). It is alarming to find that 72% of the clients with FAS/FAE who were 12 years and older have experienced violence (either physical or sexual abuse, and/or domestic violence), and that many have experienced several types of violence in their lifetimes.

(Being) experienced violence is by far the strongest risk factor for Inappropriate Sexual Behavior. At 45%, Inappropriate Sexual Behavior is the second most prevalent Secondary Disability in people with FAS/FAE across the lifespan (Figure 7.1). Regardless of age, between 46% and 52% of clients in the three main age groups studied had engaged in Inappropriate Sexual Behavior. In turn, Inappropriate Sexual Behavior has the strongest relationship to two other Secondary Disabilities, namely, Trouble with the Law and Confinement. These latter are the most costly, serious, and disruptive societal responses to unacceptable, misunderstood, or problem behaviors (Figure 7.2). Clearly, there are strong economic and humanistic reasons for reducing all of these Secondary Disabilities and the risk factors related to them.

Both children and adults with FAS/FAE are vulnerable to being victims of violent physical and sexual behavior, perhaps as a result of both their prenatal brain damage and the high risk environments in which they often live.

Based on our findings, we recommend the following efforts be made to prevent violence against these vulnerable clients:

- Advocates, such as those described in the Birth to 3 program, can serve as an effective liaison with Children's Protective Services (CPS) for monitoring the safety of children and adults with FAS/FAE in high risk homes.
- Several groups of professionals must be informed about the presence of people with FAS/FAE among their client populations, so that the most efficacious treatment models can be developed and implemented. These groups include: sexual deviancy counselors, the sexual abuse treatment field, and those dealing with domestic violence.
- The possibility of prenatal alcohol exposure should be explored (along with a history of physical and sexual abuse) among all patients coming into trouble with the law, mental health, or judicial confinement settings.
- Further research on the most effective response of the criminal justice system to the expression of Inappropriate Sexual Behavior by people of all ages with FAS/FAE is urgently needed. Sentencing alternatives, methods of enhancing familial supervision, and programs to enhance social skills and job skills are needed.

17.5 Develop, evaluate, and implement methods to detect subgroups of people with FAS/FAE who are in special need of interventions

The recommendations in 17.1–17.4 pertain to environmental influences resulting from the discoveries in this study about the "extrinsic" risk factors for secondary disabilities. This study has also addressed the relationship of "intrinsic" characteristics of certain subgroups of people with FAS/FAE that might put them at special risk of developing secondary disabilities. These include:

- people with FAE, who do not have the full facial stigmata of FAS and thus may not readily qualify for services,
- people with FAS or FAE whose IQ level is above 70 and who consequently often fail to qualify for special services,
- people with FAS/FAE who have a marked discrepancy between their IQ levels and their level of Adaptive Behavior, and
- people with FAS/FAE who have a particular cluster of characteristic behaviors as identified by a high FABS score on the Fetal Alcohol Behavior Scale.

Recommendations follow:

- Further research is urgently needed to quantify the prenatal brain damage from alcohol in people who do not have the physical signs of FAS and/or who do not have an IQ score permitting classification as mentally retarded (i.e., IQ below 70).
- The identification and evaluation of new quantification methods should facilitate diagnosis as well as permitting the development of more appropriate guidelines for providing needed services.
- One promising new scale developed for this study that needs further evaluation is the Fetal Alcohol Behavior Scale (FABS). As a high FABS score is a risk factor for numerous secondary disabilities, providing specialized services for this subset of clients might be particularly cost effective.
- Another promising marker derives from the "IQ/Adaptive Behavior Discrepancy" score which is also associated with secondary disabilities. Further study of this and the use of other techniques for evaluating specific cognitive, linguistic, and neuropsychological problems in people with both FAS and FAE, particularly those with IQ scores too high to readily qualify for services, should be a high priority for future research.
- Finally, of course, effective strategies for remedial interventions appropriate to the needs of people with FAS/FAE need to be developed, evaluated, and implemented.

17.6 Promote communities, families, and clients with FAS/FAE working together

Just as all children need immunizations against diseases, people with FAS/FAE appear to need special "immunization" against many inadequacies and dangers in our society. Their functioning is often far below their apparent intelligence. Many people with FAS/FAE appear to learn only inadequately through normal channels about their environment and how to interact with it. Working around the disabilities that these clients are born with is not the family's responsibility alone, but neither is it solely the government's or community's responsibility. Communities, families, and clients working together toward this mutual goal of reduction of Secondary Disabilities may foster better optimization of quality of life for both people with FAS/FAE and their communities.

The Secondary Disabilities data indicate that clients with FAS/FAE come in contact with many different community professionals and agencies. For example: over 90% deal with Mental Health professionals, 60% with the criminal justice system, 23% with alcohol and drug treatment personnel (Figures 8.1, 10.1, 13.3), and 100% with school personnel. The finding that an early diagnosis is a universal protective factor against *all* Secondary Disabilities suggests that information about the diagnosis is useful to have in responding appropriately to a child's problems. People with FAS/FAE and their families could facilitate more beneficial and humane services by sharing the diagnostic information with professionals they work with.

Half of the clients 12 years and older display Inappropriate Sexual Behavior (Figure 12.1). Although the rates of these behaviors are about the same for females and males, the outcome is very different. Thirty nine percent of the males 12 years and older with Inappropriate Sexual Behaviors are "in Trouble with the Law" over these behaviors, while about 10% of the females go to treatment. The inappropriate sexual behavior that gets males into trouble with the law is "inappropriate touching". Females most frequently go to treatment for promiscuity, compulsions, and sexual advances. People with FAS/FAE and their families should know that Inappropriate Sexual Behavior does not just begin in adolescence. Among 6-11 year olds, approximately 37% of girls and 41% of boys are already exhibiting these behaviors. Families, criminal justice, and mental health professionals need to work together to develop new intervention strategies that will truly reduce rather than increase the level of Secondary Disabilities.

Alcohol problems occur in 33% of clients with FAS/FAE over the age 12 (Figure 13.1)--of these, 65% have gone on to abuse street drugs, at an average of two years after the onset of alcohol abuse. Early parental recognition and intervention of alcohol problems among youth with FAS/FAE could result in the prevention of other drug abuse problems. Families should also be apprised that female clients have as high a rate of alcohol problems as male clients, and that females are much less likely to receive treatment for their alcohol problems. Clients with FAS/FAE and their families should be aware of the special vulnerability to alcohol problems that is carried by all children of alcoholics, and develop appropriate early family practices to guard against the onset of alcohol problems among alcohol-affected individuals.

Approximately 80% of the adults with FAS/FAE in this study do not appear to be achieving either an independent living status or problem-free employment (Figures 14.1, 15.1). People with FAS/FAE, their families, school personnel, and mental health professionals need to start planning long before adulthood for a lifetime involving some degree of support. Training of appropriate living and working skills needs to start long before adulthood.

Many recommendations have been made regarding what the government agencies can do to help lower the rates of secondary Disabilities observed in this client sample. Families can do a lot too. Certainly, communities also need better education about people with FAS/FAE. But it is the cooperation among families, communities, government agencies, and clients that permits a focusing of combined energies toward solutions that are beneficial to all.

18 References

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19 Glossary of Terms and Abbreviations

- **ABC score** — Adaptive Behavior Composite—the summary score from the VABS, derived from combining the four domains of adaptivity measured: Communication Skills, Daily Living Skills, and Socialization. The ABC is a standard score, like IQ, which is set to the same parameters as the Wechsler IQ tests: 100=normal and 15=one standard deviation
- **ADP** — Alcohol and Drug Problems
- **Arith** — Arithmetic—subtest of Wechsler IQ tests
- **ARND** — Alcohol Related Neurodevelopmental Disorder
- **Birth to 3** — The Seattle Advocacy Model Program for high risk mothers abusing alcohol and drugs. (See Grant et al., 1996)
- **BlkDes** — Block Designs—subtest of Wechsler IQ tests
- **CDC** — Centers for Disease Control and Prevention
- **CFN** — Confinement
- **CNS** — Central Nervous System
- **Coding** — Coding—subtest of Wechsler IQ tests
- **Comp** — Comprehension—subtest of Wechsler IQ tests
- **CPS** — Children's Protective Services
- **DDD** — Division of Developmental Disabilities
- **DigSp** — Digit Span—subtest of Wechsler IQ tests
- **DK** — Don't Know
- **DPL** — Dependent Living
- **DSE** — Disrupted School Experience
- **DSM-IV** — Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
- **DVR** — Department of Vocational Rehabilitation
- **Dx** — Diagnosis
- **Extrinsic RPF** — A Risk and Protective Factor that describes something in the client's environment or something that has happened to the client
- **FABS** — Fetal Alcohol Behavior Scale—The FABS is a list of 36 behaviors (selected out of 72 items on a Personal Behaviors Checklist) that parents and caretakers have frequently used to describe people with FAS. The 36 items are characteristic of people with FAS irrespective of age (except infants and the elderly) and IQ (except the profoundly retarded). (See Streissguth, Barr and Press, 1996)
- **FADU** — Fetal Alcohol and Drug Unit
- **FAE** — Fetal Alcohol Effects
- **FAS** — Fetal Alcohol Syndrome
- **Info** — Information—subtests of Wechsler IQ tests

- **Intrinsic RPF** A Risk and Protective Factor that involves some characteristic of the clients themselves (like IQ)
- **IOM** Institute of Medicine
- **IQ** Intelligence Quotient. This is a standard score, with the population mean=100, and 15=one standard deviation.
- **ISB** Inappropriate Sexual Behaviors
- **LHI** Life History Interview
- **Max** Maximum
- **Med** Median
- **MHP** Mental Health Problems
- **NPCP** National Perinatal Collaborative Project
- **ObjA** Object Assembly—subtest of Wechsler IQ tests
- **Odds Ratio** The ratio of two ratios describing the relation of a two-valued outcome (say, A and B) to a two-valued predictor (say, y and n). It is the ratio (yB/yA)/(nB/nA), or (yB*nA)/(yA*nB). (See Chapter 6 for examples)
- **PFAE** Possible or Probable Fetal Alcohol Effects
- **PFAS** Possible or Probable Fetal Alcohol Syndrome
- **PicA** Picture Arrangement—subtest of Wechsler IQ tests
- **PicC** Picture Completion—subtest of Wechsler IQ tests
- **PIQ** Performance Scale IQ—from the Wechsler IQ tests
- **PWE** Problems With Employment
- **RPF** Risk and Protective Factors
- **SD** Secondary Disabilities
- **Sim** Similarities—subtest of Wechsler IQ tests
- **Specific RPF** A Risk and Protective Factor that only applies to some of the eight Secondary Disabilities studied, or may be Risky for some and Protective for others
- **SS** Standard Score: the rescaling of any numerical variable so it has an easily remembered standard deviation (in the case of Wechsler IQ tests, the WRAT-R and the VABS, the average=100 and the standard deviation around the average is 15 points).
- **SSI** Supplemental Security Income
- **TWL** Trouble With the Law
- **Tx** Treatment
- **Universal RPF** A Risk and Protective Factor which is uniformly protective or risky for all six of the main Secondary Disabilities described in Figure 6.1 and Table 6.1
- **VABS** Vineland Adaptive Behavior Scale
- **VIQ** Verbal Scale IQ—from the Wechsler IQ tests
- **Vocab** Vocabulary—subtest of Wechsler IQ tests
- **WISC-R** Wechsler Intelligence Scale for Children-Revised
- **WPPSI-R** Wechsler Preschool and Primary Scale of Intelligence Revised
- **WRAT-R** Wide Range Achievement Test Revised

Secondary Disabilities

Information | Age Comparison Table | Developing Baby | Secondary Disabilities | FAQ's

Other problems, or secondary disabilities, arise when needs go unmet for children with alcohol-related birth defects.

In a 1996 study of 415 FAS/FAE patients ranging in age from 6 to 51 years, Dr. Ann Streissguth of the University of Washington identified a number of secondary disabilities that a person is not necessarily born with. These include:

- 90% had mental health problems
- 80% of those over 21 were dependent on others for daily needs
- 80% (21 and older) had employment problems
- 60% (12 and older) were expelled or dropped out of school
- 60% (12 and older) had trouble with the law
- 50% (12 and older) inappropriate sexual behavior
- 50% (12 and older) were incarcerated or confined for mental health reasons
- 30% (12 and older) had alcohol or drug problems

This study also identified several universal "protective factors" that - if addressed early on and consistently - helped minimize the secondary disabilities.

- Living in a stable nurturing home for over 72% of life
- Being diagnosed before the age of six years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years
- Experiencing a good quality home from age six to twelve years
- Having applied for and been found eligible for Developmental Disability Services
- Having a diagnosis of FAS rather than FAE
- Having basic needs met for at least 13% of life

Fetal Alcohol Spectrum Disorders

Fetal Alcohol Spectrum Disorders

Protective Factors for Children with FAS

Several positive factors have been identified that might help reduce secondary conditions that result from fetal alcohol syndrome (FAS). Some of these protective factors are:

Early Diagnosis - Children with FAS who are identified early have an improved prognosis. A child who is identified early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. In addition, early diagnosis helps families and school personnel understand why the child might act or react differently from other children in some situations.

Involvement in Special Education and Social Services - Children who receive special education geared towards their specific needs and learning style are more likely to achieve their developmental and educational potential. Children with FAS show a wide range of behaviors and severity of symptoms. Special education allows for individualized educational programs. In addition, families of children with FAS who receive social services, such as respite care or stress and behavioral management training, have more positive outcomes than families who do not receive such services.

Loving, Nurturing, and Stable Caretaking Environment - While all children benefit from a loving and stable home life, children with FAS can be particularly sensitive to disruptions, transient lifestyles, or harmful relationships compared to children who do not have FAS. Community and family support are needed to prevent secondary conditions in individuals with FAS.

Absence of Violence - Individuals with FAS who live in stable or non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives. Children with FAS need to learn and be taught other ways of showing their anger or frustration.

Source:
Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

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Date: May 2, 2006
Content source: National Center on Birth Defects and Developmental Disabilities

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Surgeon General's Advisory on Alcohol Use in Pregnancy [PDF document]

MMWR Recommendations and Reports - Guidelines for Identifying and Referring Persons with Fetal Alcohol Syndrome

Report on alcohol consumption among women who are pregnant or who might become pregnant

Curricula Available

Contact Info

Fetal Alcohol Syndrome
NCBDDD, CDC
Mail-Stop E-86
1600 Clifton Road
Atlanta, GA 30333
1-800-CDC-INFO (232-4636)

404-498-3040 FAX
Email: cdcinfo@cdc.gov

Thank you for visiting the CDC-NCBDDD Web site. Click here to contact the National Center on Birth Defects and Developmental Disabilities

We are not able to answer personal medical questions. Please see your health care provider concerning appropriate care, treatment, or other medical advice.

Programs & Campaigns

Science Ambassador

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National Center on Birth Defects & Developmental Disabilities

Attachment B

Fetal Alcohol Spectrum Disorders, The Basics
U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration

CS

2/27

Tim Kelley

AK Medical Association

- concerned w/ line 9810 of SB 267
- gave number for Jim Jordan 562 0304 AK State Med Assoc.
- claims doctors are already doing it 244-4487

- ~~[redacted]~~ age of majority + 2 (20yrs)

586-4273 = fax #

SB 25

Call Cissna

Jim Jordan

- shorting
- med. record is property of med. professional
- ~~[illegible]~~ "that's the best practice"
- can't write a letter

- allerted to hearing on Mon

fax: 561-2963

Alaska State
Legislature
State Capitol
[redacted]
907 465-3756 fax
From the Office of Senator Bettye Davis

To: Legal Services **Fax:** 465-2029; phone: 465-2450

From: Thomas S. Obermeyer **Date:** 3/3/2008

Re: Request for CS for SB 267, 25-LS1471\A **Pages:** __3_ pages including cover

CC:

Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

RUSH PLEASE – HEARING AT 1:30 TODAY

Notes: To Whom It May Concern:

Please prepare a CS for Senate Bill 267 per attached amendment prepared by Jan Ruthdale, Dept. Law, and approved by Senator Davis.

Copies of original and changes in "Amendment" are attached.

Please call if you have any questions.

Thomas S. Obermeyer
907-465-3762

DRAFT

25G-2
2/27/2008
2:04 pm)

AMENDMENT

OFFERED IN THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

BY _____

TO: SB 267

Page 1, lines 5 - 14:

Delete all material and insert:

"**Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol.** (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file. Information described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024. The documentation must be in the form or format required by the board.

(b) Except as provided in AS 47.17.024, information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care of the child.

(c) In this section, "infant" means a child who is less than 12 months of age."

Thomas Obermeyer

From: Rutherdale, Jan A (LAW) [jan.rutherdale@alaska.gov]
Sent: Sunday, February 24, 2008 4:01 PM
To: Thomas Obermeyer
Cc: Laughlin, Wilda J (HSS); Sen. Bettye Davis
Subject: DOL comments to SB 267

Tom,
As noted in my earlier email to you, I understand from Mike Ford that you would like an outline of what concerns the Department of Law has with SB 267. Below is a recap of what the bill is trying to accomplish and our position that it does not accomplish that result; in practice, it may accomplish the opposite. In addition, since this issue has already been addressed in a 2006 addition to the reporting statutes, we don't believe that there is a need for this bill.

1. Problem sought to be addressed:

SB 267 requires that a health care professional record an infant's pre-natal exposure to alcohol, if the mother so consents, in the infant's medical file. According to the sponsor statement, "This information is desired to assist with early FASD diagnosis's when applicable . . . A documentation of pre-natal alcohol exposure in the child's medical file will assist medical professionals in making more accurate diagnoses. . . . This legislation comports with the FAS Surveillance Project recommendations found in Fetal Alcohol Syndrome Prevalence in Alaska: "Health care providers should be encouraged to document the details of maternal alcohol use during pregnancy in the child's medical chart."

There is no question that documentation is important in diagnosing FASD. In my experience, the FASD evaluators will not even begin an assessment of a child or adult suspected to have FASD unless there is some sort of documentation that the mother of the person to be evaluated drank during pregnancy. For example, if someone saw the mother drinking during pregnancy or if the mother admits to drinking during pregnancy, the evaluators would want this fact documented, such as in a letter or records of some kind, including medical, police or OCS records.

Usually, FASD symptoms don't appear until the child is in school or older. The biggest problems of documentation arise when the child is an adult and 20-30 years have passed since the pregnancy. This bill tries to ensure that a health professional documents drinking behavior when the child is still an infant.

2. This bill does not solve the need for increased documentation because it allows the mother to prevent such documentation:

Instead of providing more documentation, this bill may have the unintended effect of making it more likely that the documentation of pre-natal exposure to alcohol exposure will not be made. If, as the sponsor statement states, it is important that the documentation is made in the first place, asking the mother and giving her veto power over this documentation creates a possibility that the documentation will not be made. The file is the infant's and this would prevent the doctor to do what is best for the infant. In other words, if making the documentation is good medical practice, the documentation should be made regardless of the mother's wishes.

3. AS 47.17.024 already addresses this issue:

AS 47.17.024, enacted in 2006, requires a "practitioner of the healing arts" (which includes a doctor) involved in the delivery or care of an infant to make a report to OCS if the practitioner determines that the infant has been exposed to alcohol. If the doctor makes a report of harm the doctor

will undoubtedly note this fact in the infant's file. Therefore, there is no need for this bill, since the documentation is already being made. In addition, given the reporting statute, OCS is going to have this prenatal exposure documented in their files, which will be helpful in later making an FASD diagnosis (at least when OCS is involved, which is often the case).

4. This bill may create confusion for doctors who are trying to follow AS 47.17.024.

If the mother objects to any documentation about prenatal exposure in the infant's file, the doctor is still obligated to make a report of harm under AS 47.17.024. but if the mother refuses to allow documentation, the doctor may be under the false impression that he/she does not have to comply with AS 47.17.024. Alternatively, the lack of documentation due to mother's refusal may make it more likely that the doctor will forget to make a report to OCS, or it will require the doctor to create a filing system apart from the infant's file so that the doctor can honor the mother's request but still keep a record that he made the report of harm pursuant to AS 47.17.024.

5. This bill is a departure from normal licensing requirements.

Normally, the state does not legislate best practices for a doctor. If it is good practice for doctors to document exposure to alcohol, the doctors will probably already be doing this. If more education is needed for doctors, there are better ways to satisfy this need than by legislation.

Thank you for providing this opportunity to share my concerns about this bill. Please feel free to call or email me if you have any questions are wish to discuss this matter further.

Jan Rutherdale
Deputy Section Chief
Child Protection Section
Attorney General's Office
(907)465-3608
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25-LS1471\A
Bullard
2/11/08

SENATE BILL NO.

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY SENATOR DAVIS

Introduced:
Referred:

A BILL

FOR AN ACT ENTITLED

"An Act requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the infant's prenatal exposure to alcohol in the infant's medical file, if the mother provides her consent to the inclusion of the information in the infant's medical file. The documentation must be in the form required by the department.

(b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care.

(c) In this section, "infant" means a child who is less than 12 months of age.

LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES
LEGISLATIVE AFFAIRS AGENCY
STATE OF ALASKA

(907) 465-3867 or 465-2450
FAX (907) 465-2029
Mail Stop 3101

State Capitol
Juneau, Alaska 99801-1182
Deliveries to: 129 6th St., Rm. 329

MEMORANDUM March 3, 2008

SUBJECT: Legal and practical issues relating to the requested CSSB 267(HES) (Work Order No. 25-LS1471\C)

TO: Senator Bettye Davis
Chair of the HESS Committee
Attn: Thomas Obermeyer

FROM: Alpheus Bullard
Legislative Counsel

You requested a committee substitute for SB 267 based on an amendment prepared by Jan Ruthdale of the Department of Law. I have several comments.

1. The requested committee substitute directed a person making a postnatal examination of a mother and infant to document "*observations, medical history, and other available information of the infant's prenatal exposure to alcohol in the infant's medical file.*" This is unclear. Whose "observations," whose "medical history," and what is "available information"? I redrafted this to read, "the person's observations," the mother's pertinent medical history" and other "information relevant" to the infant's prenatal exposure to alcohol.

2. The language you requested provides that *"[i]nformation described in this section that was obtained from statements of the mother made during the mother's examination that is confidential medical information of the mother may not be released without the consent of the mother, except upon court order, or as required by AS 47.17.024."* The committee substitute you requested makes changes to a provision that directs that certain information be recorded in an infant's medical file. This means that the mother's information is released to the infant's medical record. Any future provider of medical services to the infant will encounter the information provided by the mother in the infant's file. If the information obtained from the mother by a medical provider is not confidential, this is something of which she should be made aware. I'm not sure what the sense of "release" is supposed to be, but it does not seem to make sense in the context of what the bill requires.

Note too, that the concept of doctor-patient confidentiality would not apply just to "*confidential medical information of the mother*" but all noncriminal information shared by the mother in seeking the advice, care, and/or treatment of a physician for herself or her child. It is a generally accepted principle that individuals seeking medical help or

advice should not be inhibited by any fear that their medical concerns or conditions will be disclosed to others. Patients entrust personal knowledge of themselves to their physicians, which creates an uneven relationship in that the vulnerability is one-sided. There is usually an expectation that physicians will hold that special knowledge in confidence and use it exclusively for the benefit of the patient. See Alaska Rule of Evidence 504(b) which provides:

> **General Rule of Privilege.** A patient has a privilege to refuse to disclose and to prevent any other person from disclosing confidential communications made for the purpose of diagnosis or treatment of the patient's physical, mental or emotional conditions, including alcohol or drug addiction, between or among the patient, the patient's physician or psychotherapist, or persons who are participating in the diagnosis or treatment under the direction of the physician or psychotherapist, including members of the patient's family.

The committee substitute would have such information recorded in the infant's medical file, but not *"released without the consent of the mother, except for court order, or as required by AS 47.17.024."* I don't know how a court would interpret this language, but I believe that it is certainly possible that the changes affected by the committee substitute could be interpreted as an unconstitutional violation of a mother's right to privacy.

3. Senate Bill 267 requires a person licensed under AS 08.64 to document "*an infant's prenatal exposure to alcohol*" in the infant's medical file, and that the information "*may not be used except for the purposes of providing medical diagnosis, treatment, or care.*" AS 47.17.024 imposes a duty on practitioners of the healing arts to notify the Department of Health, Education and Social Services of an infant's condition that the practitioner has determined has been adversely affected by, or is withdrawing from exposure to, a controlled substance or alcohol. The duty imposed by AS 47.17.024 is a different duty than that created under the bill. SB 267 deals only with the documentation of information in an infant's medical file relating to a mother's consumption of alcohol, not a practitioner's determination that an infant has been adversely affected by alcohol. These are legally and practically distinct actions and responsibilities.

If you have any questions, please do not hesitate to contact me.

ALB:lmb
08-051.lmb

Enclosure

Don Burnell

From: Marilyn Dodd [akafp@gci.net]
Sent: Friday, February 29, 2008 2:44 PM
To: Sen. Bettye Davis
Subject: sb267

Attachments: ATT00001.htm; sb267.doc

RECEIVED
MAR 0 3 2008

ATT00001.htm (4 KB) sb267.doc (31 KB)

Maryann Roland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

We believe this bill is unnecessary and has unintended legal consequences. Practitioners already have a statutory and ethical duty to report suspected alcohol or drug abuse affecting a child. The Medical Practice Act requires all pertinent information to be entered into a medical record. Furthermore, to restrict use of any information only for the purpose of providing medical diagnosis or treatment limits its use in any potential legal case. Since this would affect how evidence may be used, it may require a more wide-reaching change in court rules.

The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Roland, M.D.
President Elect, AKAFP

Alaska Academy of Family Physicians

35565 Spur Highway #266, Soldotna, AK 99669 akafp@gci.net www.alaskaafp.org 907 258-2255 office 530 326-5612 fax

Maryann Foland, MD
President Elect, Alaska Academy of Family Physicians

Dear Senator Davis:

The Board of Directors of the Alaska Academy of Family Physicians represents over 365 primary care physicians who practice throughout Alaska. We oppose Senate Bill No. 267. This bill requires documentation in an infant's medical record any prenatal exposure to alcohol, but only with the mothers consent.

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The benefits of early diagnosis and treatment for Fetal Alcohol Syndrome Disorder are undeniable. However, we do not believe this bill adds any encouragement to better document a medical history. It would not help with either early diagnosis or treatment. Therefore, we strongly urge that SB267 be defeated.

Sincerely,

Maryann Foland, M.D.
President Elect, AKAFP

25-LS1471\C
Bullard
3/3/08

CS FOR SENATE BILL NO. 267(HES)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR DAVIS

A BILL

FOR AN ACT ENTITLED

"An Act relating to requiring certain persons licensed by the State Medical Board to document an infant's prenatal exposure to alcohol in the infant's medical file."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 08.64 is amended by adding a new section to article 3 to read:

Sec. 08.64.364. Health care professionals to document an infant's prenatal exposure to alcohol. (a) For the purpose of screening for fetal alcohol spectrum disorder, a person licensed under this chapter attending or making a postnatal examination of a mother and infant shall document the person's observations, the mother's pertinent medical history, and other information relevant to the infant's prenatal exposure to alcohol in the infant's medical file. Information described in this section that was obtained from statements of the mother made during the postnatal examination that is confidential medical information of the mother may not be released without the consent of the mother, except by court order, or as required by AS 47.17.024. The documentation must be in the form or format required by the

L

New Text Underlined [DELETED TEXT BRACKETED]

department.

(b) Except as provided in AS 47.17.024, information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care of the infant.

(c) In this section, "infant" means a child who is less than 12 months of age.

permission for release

Jan - child in need of aid - exception of confidentiality

Michael Baldwin - Family clinician - Anchorage

Tim Kelley - concerns w/ original
forwarded copy to attorney

* Diane Casto
FAS administration
465-3033
Testify for SB 267
No parental consent

Rick Ionnoino 463-7373
Juneau

Don Burrell

From: Susan Hargis
Sent: Friday, February 01, 2008 2:02 PM
To: Sen. Bettye Davis
Cc: Thomas Obermeyer; Rep. Andrea Doll
Subject: FASD Bill
Attachments: HB0300A.pdf; HB300 FASD Sponsor Stmt.doc

Senator Davis,

Here's the bill and sponsor statement for the FASD bill. Rep Doll asked me to send it to you and your staff per your discussion.

Thanks for your support on it!

Regards,
Sudie Hargis
Office of Representative Andrea Doll
susan.hargis@legis.state.ak.us
(907) 465-3744

Leg liaison office SB 267
4021
Wilda

Alaska State Legislature
Representative Andrea Doll
House District 4

Sponsor Statement
HB 300 Documentation of Prenatal Alcohol Exposure

HB 300 requires certain health care practitioners making a post-natal examination to document information in an infant's medical record about the mother's alcohol consumption, if the mother provides consent. This information is vital for use in later diagnosis when children begin to show symptoms of abnormal development, and can help doctors determine whether or not the child may have Fetal Alcohol Spectrum Disorder (FASD).

The scope of the bill is purposely limited to alcohol and does not include drug use. The bill specifies that information related to a mother's use of alcohol can only be used for diagnostic and medical purposes, not as evidence against the woman's fitness or in an attempt to remove her custodial rights.

State Capitol, Juneau, AK 99801-1182 Phone: 907-465-3744 Fax: 907-465-2273
Rep_Andrea_Doll@legis.state.ak.us www.akdemocrats.org/doll

HOUSE BILL NO. 300

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY REPRESENTATIVE DOLL

Introduced: 1/15/08
Referred: Labor and Commerce, Health, Education and Social Services

A BILL

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SENATE BILL NO. 267

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-FIFTH LEGISLATURE - SECOND SESSION

BY SENATOR DAVIS

Introduced: 2/13/08
Referred: Health, Education and Social Services, Finance

AMA Alaska Medical Board

emph is on educ. of med. professionals

A BILL

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title 18 -

(b) Information received under this section may not be used except for the purposes of providing medical diagnosis, treatment, or care. of the child

(c) In this section, "infant" means a child who is less than 12 months of age.

reports can be made up to the age of 6
- birth defects registry

pre-existing condition? for insurance

Thomas Obermeyer

From: Rutherdale, Jan A (LAW) [jan.rutherdale@alaska.gov]
Sent: Friday, February 29, 2008 9:59 AM
To: Thomas Obermeyer
Cc: Sen. Bettye Davis; Laughlin, Wilda J (HSS)
Subject: SB 267 proposed amendment
Attachments: SB 267 amendment 022708

Hello Tom,
As we spoke on the phone, attached is a proposed amendment to the bill. The changes from the first version are in lines 6-12 and line 15. I'm hoping this amendment is self explanatory. It keeps the original bill's limitation to postnatal examinations, but, in our opinion, it cures the problem in the original bill – giving the mother veto power over information that the doctor gleans outside of the mother's statements (such as the doctor's observations or information from others) or the mother's statements made when the infant, not the mother, is the patient.

If you have any questions about this amendment or wish to discuss further, please let me know.
Jan

Jan Rutherdale
Deputy Section Chief
Child Protection Section
Attorney General's Office
(907)465-3608
Fax: (907)465-3019

Jana – Let's discuss.
Tom

MEMORANDUM
(Confidential)

DATE: February 25, 2008
TO: Senator Bettye Davis
FROM: Thomas S. Obermeyer
RE: SB 267 – Concerns by Department of law per attached notes by Asst. A.G., Jan Rutherdale, 2/24/08

Summary of Attorney Rutherdale's Comments

1. The bill may have the unintended result of requiring the physician or health practitioner, to act contrary to the best interests of the infant.
2. This bill, contrary to normal licensing practices, legislates "best practices" for a physician, with a new licensing section, AS 8.64.364, "Health care professionals to document an infant's prenatal exposure to alcohol."
3. AS 47.17.024, "Child Protection," already requires a "practitioner of the healing arts" to report to the department (OCS) if he/she determines the infant has been exposed to fetal alcohol. It follows that if the health practitioner reports harm, this information routinely is placed in the infant's file.
4. If OCS investigates and makes a finding of FAS, the mother's prenatal alcohol use may still wind up in the infant's file, regardless of this bill which addresses licensing and documentation of health care professionals.
5. This bill allows the mother to refuse documentation of her prenatal alcohol consumption in the infant's file, which is the only file that is permanent and will be forwarded with the child's history to other providers or institutions, or routinely called into question in evidentiary matters or discovery in legal proceedings for child custody, etc. concerning mother's prenatal alcohol use.
6. The file is the INFANT'S, not the mother's, not the doctor's. It is made for the benefit of the infant, not the mother, or doctor.
7. The doctor still must report to OCS under this bill, and if he/she cannot make a report to the infant file, he/she may wish to keep his/her own private separate file for protection from liability for malpractice. This auxiliary file serves no purpose but to protect the doctor, not the infant.