FETAL ALCOHOL SYNDROME HANDBOOK



the university of south dakota. SCHOOL OF MEDICINE & HEALTH SCIENCES CENTER FOR DISABILITIES

A University Center for Excellence in Developmental Disabilities Education, Research and Service

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To request permission contact:

Director of Information and Resources
Center for Disabilities
Department of Pediatrics
The University of South Dakota
School of Medicine
1400 West 22nd Street
Sioux Falls, South Dakota 57105

(605) 357-1439 1-800-658-3080 (Voice/TTY)

On the web - http://www.usd.edu/cd

To receive this product in an alternative format, please contact the above.

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Notes



Welcome to the updated *Fetal Alcohol Syndrome Handbook!*

The staff of the Center for Disabilities is pleased to provide you with this overview of Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects (ARE). This handbook uses the Institute of Medicine terminology. That terminology divides the spectrum of Fetal Alcohol Syndrome into two broad categories Fetal Alcohol Syndrome (with or without confirmed maternal alcohol exposure) and Alcohol Related Effects which encompasses Partial Fetal Alcohol Syndrome, Alcohol-Related Birth Defects, and Alcohol-Related Neurodevelopmental Disorder - see the Current Diagnostic Criteria for Fetal Alcohol Syndrome article on page 11 for more information. These terms do not include Fetal Alcohol Effect which is still frequently used in literature regarding Fetal Alcohol Syndrome. The term Fetal Alcohol Effect (FAE) was often used as a diagnosis when full Fetal Alcohol Syndrome wasn't present. The Institute of Medicine terminology helps to better identify the different categories on the Fetal Alcohol Syndrome spectrum. While the term Fetal Alcohol Syndrome is often used to refer to the entire spectrum of physical, developmental and behavioral disabilities, it is important to remember that Fetal Alcohol Syndrome is only one part of an entire spectrum.

This handbook is meant to provide a brief overview of some of the issues associated with Fetal Alcohol Syndrome and to direct readers to other resources. It is not meant to act as a diagnostic tool or as a comprehensive study of Fetal Alcohol Syndrome. In an effort to provide the reader with the most upto-date information on Fetal Alcohol Syndrome, the articles in this handbook refer to some of the latest books and journal articles on the subject. If you would like more detailed information, please consult the resources listed in the bibliographies on pages 22 and 23 or the resources listed beginning on page 42 of this handbook.

This handbook focuses on seven specific issues related to Fetal Alcohol Syndrome. Those issues are the history of Fetal Alcohol Syndrome, the incidence and prevalence of Fetal Alcohol Syndrome, the characteristics associated with Fetal Alcohol Syndrome, the current diagnostic criteria for Fetal Alcohol Syndrome, the effects of prenatal exposure to alcohol on brain development, the secondary disabilities often associated with Fetal Alcohol Syndrome, and the prevention of Fetal Alcohol Syndrome.

A section of frequently asked questions regarding Fetal Alcohol Syndrome begins this handbook to give the reader a quick overview of some of the most often discussed issues surrounding Fetal Alcohol Syndrome. This handbook also includes educational techniques for students with developmental disabilities which may be applicable to students with Fetal Alcohol Syndrome. A listing of resources is included to give the reader places to go for more information. These resources include websites, organizations, books, videos, and journal articles. A glossary of terms is included to provide further explanation of some of the terms used in this handbook.

As you read and use this *Fetal Alcohol Syndrome Handbook*, please keep in mind that the term Fetal Alcohol Syndrome is often used to describe a wide range of physical characteristics, developmental difficulties, and behaviors. Not every individual diagnosed with Fetal Alcohol Syndrome or a related disorder exhibits every characteristic, developmental difficulty, or behavior in listed in the diagnostic criteria. There can also be a great deal of variation in the severity of the characteristic, developmental difficulty, or behavior. It is also important to remember that while there is no cure for Fetal Alcohol Syndrome - Fetal Alcohol Syndrome is **100% Preventable**.



FAS FAOs

When was Fetal Alcohol Syndrome first described?

The effects of drinking alcohol during pregnancy have long been noted. It wasn't until 1973, however, when the term "Fetal Alcohol Syndrome" was first coined. For more on the history of Fetal Alcohol Syndrome, see the "Historical Overview of Fetal Alcohol Syndrome" on page 4 of this handbook.

What is the difference between Fetal Alcohol Syndrome and Alcohol Related Effects?

The basic difference between Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects (ARE) is the extent of the physical damage and the resulting behavioral problems caused by prenatal exposure to alcohol. For the current diagnostic criteria for the entire spectrum of Fetal Alcohol Syndrome and Alcohol Related Effects, see page 11 of this handbook.

How many people have Fetal Alcohol Syndrome/Alcohol Related Effects?

For a detailed look at the incidence and prevalence of Fetal Alcohol Syndrome/Alcohol Related Effects, see page 6 of this handbook.

What is the cost of Fetal Alcohol Syndrome?

When discussing the costs associated with Fetal Alcohol Syndrome, it is important to remember that no dollar amount can begin to express the costs to the individuals with Fetal Alcohol Syndrome. The costs of a disability on the life of a person and their family is immeasurable.

Several studies have reported on the monetary cost of Fetal Alcohol Syndrome. The National Organization on Fetal Alcohol Syndrome estimates "the institutional and medical costs for one child with FAS are \$1.4 million over a lifetime." While "cost estimates for the United States range from \$75 million to \$9.7 billion" (Institute of Medicine, page 19).

Recent cost analysis studies conducted by the North Dakota Fetal Alcohol Syndrome Center place the annual cost of Fetal Alcohol Syndrome in the United States at \$7,378,000,000 (approximately \$7.4 billion) and the five year cost at \$36,890,000,000 (approximately \$36.9 billion). The same study estimates the daily cost of Fetal Alcohol Syndrome in the United States at \$16,347,397 (approximately \$16.3 million).

Do all people with Fetal Alcohol Syndrome have mental retardation?

No. While Fetal Alcohol Syndrome is the leading cause of mental retardation and the only preventable cause of mental retardation, not all people with Fetal Alcohol Syndrome have mental retardation. In fact the range of IQ for individuals with Fetal Alcohol Syndrome can stretch from very low to normal.

Isn't Fetal Alcohol Syndrome only a problem for some racial or economic groups?

No. Fetal Alcohol Syndrome is caused by maternal alcohol consumption during pregnancy. Fetal Alcohol Syndrome affects every segment of the population. All racial groups and economic classes are affected by Fetal Alcohol Syndrome. While studies indicate there are

higher rates of Fetal Alcohol Syndrome in certain groups, it is not solely the race or economics of the group that accounts for this difference. Social, economic and environmental factors all contribute to the higher rates of Fetal Alcohol Syndrome in some populations.

Is there a cure for Fetal Alcohol Syndrome?

No. The effects of prenatal alcohol exposure are **irreversible.** Individuals with Fetal Alcohol Syndrome and their families deal with the effects of the syndrome by managing the behaviors it causes and addressing the medical implications of the syndrome. But an individual with Fetal Alcohol Syndrome will always have the syndrome, there is no cure.

Is it ever safe to drink alcohol during pregnancy?

No. There is no time during pregnancy when drinking alcohol is safe. In fact, it is recommended that women stop drinking when planning to become pregnant. The effects of prenatal exposure to alcohol can occur even in the earliest weeks of pregnancy, before some women know they are pregnant. Studies indicate that alcohol consumed at anytime during pregnancy can cause damage to the developing fetus. This applies both to sustained and habitual consumption of alcohol as well as occasional events of binge drinking.

Can a father's drinking cause Fetal Alcohol Syndrome?

To date, there is no physical link between a father's drinking and Fetal Alcohol Syndrome. However, a mother's drinking can be influenced by the drinking behaviors of those around her, including her partner. A partner can have a positive or negative effect on a mother's drinking behaviors during pregnancy. A supportive non-drinking environment can be a great help to the pregnant woman.

If a person with Fetal Alcohol Syndrome has children, will their children have Fetal Alcohol Syndrome?

No. Unlike some disabilities which are passed genetically from one generation to another, Fetal Alcohol Syndrome is not genetic. Fetal Alcohol Syndrome only occurs when alcohol is consumed during pregnancy. Women with Fetal Alcohol Syndrome can have children without Fetal Alcohol Syndrome if they refrain from drinking while pregnant.

What are the most important pieces of information to remember about Fetal Alcohol Syndrome?

Fetal Alcohol Syndrome is only one part of the spectrum of disabilities caused by prenatal exposure to alcohol.

Fetal Alcohol Syndrome is the leading cause of mental retardation.

Fetal Alcohol Syndrome is the only entirely **preventable** cause of mental retardation.

Bibliography - See page 22.



Historical Overview of FAS

The connection between prenatal maternal alcohol consumption and the subsequent difficulties encountered by children has seemingly been known throughout history. Perhaps the most frequently quoted ancient reference is the book of Judges in the Old Testament of the Bible. One verse says, in part, "Behold, thou shalt conceive, and bear a son: and now drink no wine or strong drink" (Judges 13:7). Another of the most commonly quoted ancient sources is the Greek philosopher Aristotle who wrote, "Foolish, drunken, and harebrained women, most often bring forth children like unto

themselves, morose and languid" (Streissguth, page 35). And then there is the Carthaginian ritual that "forbade the drinking of wine by the bridal couple so that a defective child would not be conceived" (Streissguth, page 35). While these ancient references cannot indicate that history has always been sure of the connection between prenatal alcohol consumption and the subsequent developmental difficulties encountered by children, it seems likely that even in ancient times the connection was noticed.

It wasn't until relatively modern times that the medical profession took notice of the connection between prenatal maternal alcohol consumption and developmental difficulties in children. Among one of the first well known historical references to the connection between prenatal maternal alcohol consumption and the development of children was during the so-called "gin epidemic" in England during the 1700's. During this time period the price of gin dropped dramatically and in "1714 the annual consumption was about two million gallons of gin; by 1750 consumption was up to 11 million gallons" (Abel, page 4). In 1725, the College of Physicians drafted a letter to Parliament which read in part,

"Behold, thou shalt conceive, and bear a son, and now drink no wine or strong drink." Judges 13:7

"the fatal effects of the frequent use of several sorts of distilled spirituous liquors upon great numbers of both sexes rendering them diseased, not fit for business, poor, a burthen to themselves and neighbors and *too often the cause of weak, feeble, and distempered children* [italics Abel's]" (Abel, page 4)

One of the first scientific studies on the effect of prenatal maternal alcohol consumption and its effect on children was published in 1899. In the study, Dr. William Sullivan, a Liverpool, England prison physician, compared the

"pregnancy outcomes in 120 female prisoners who were alcoholics.... Sullivan compared these alcoholics with 28 of their blood relatives who were married to sober husbands and had also given birth to children.... Compared to the 44 % mortality rate among the alcoholic population, the mortality rate among children born to these nonalcoholic blood relatives was 24%.... [H]e also found that women who entered prison early in their pregnancies gave birth to children who were healthier than women who entered prison late in their pregnancies. Presumably this was because those who entered prison late in pregnancy had been drinking for a longer time during pregnancy." (Abel, page 6-7)

Despite historical evidence for Fetal Alcohol Syndrome, it wasn't until modern times that the connection between maternal drinking and child development began to be studied in depth by the

medical profession. In 1973, Dr. David Smith and Dr. Ken Jones, pediatric dysmorphologists at Harborview Hospital in Seattle, Washington, began to study the effects of prenatal alcohol exposure. Another physician at the hospital brought to their attention

"six infants with failure to thrive [who] all had alcoholic mothers. . . . [Drs. Smith and Jones] perceived an unusual pattern of physical anomalies in these children that were unlike any they were aware of. A child psychologist, Dr. Ann Streissguth, was subsequently asked to examine these children, and she diagnosed varying degrees of mental deficiency in them." (Abel, page 10)

Drs. Smith and Jones published their initial findings in *Lancet*. A second *Lancet* article that same year finally provided the characteristic pattern of physical and mental characteristics with a name - Fetal Alcohol Syndrome (often known by it's acronym FAS). In the following years, Fetal Alcohol Syndrome was recognized as only one part of the spectrum of disabilities resulting from prenatal alcohol exposure. This spectrum included Fetal Alcohol Effect (FAE) and Alcohol Related Birth Defects (ARBD). In recent years many professionals working in the field of Fetal Alcohol Syndrome have replaced the terms Fetal Alcohol Effect (FAE) and Alcohol Related Birth Defects (ARBD) with the terminology created by the Institute of Medicine. This terminology created five categories on the Fetal Alcohol Syndrome without confirmed maternal alcohol exposure, Fetal Alcohol Syndrome without confirmed maternal alcohol exposure, Alcohol Related Effects (ARE) which included the three categories - Partial Fetal Alcohol Syndrome (PFAS), Alcohol-Related Birth Defects (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND).

Ancient references, the "Gin Epidemic" and Sullivan's Liverpool prison study show that the link between prenatal alcohol exposure and developmental delays or disabilities have long been the subject of speculation. But it is only in recent history that the syndrome was given a name much less was studied with rigorous scientific methods. Each year scientists continue to devote their time and energy to understanding the biological and psychological effects of prenatal alcohol exposure. Through their efforts the effects of alcohol on the developing fetus are being better understood. In addition, there is a better understanding of individuals affected by Fetal Alcohol Syndrome and the difficulties they face.

Bibliography - See page 22.



Incidence and Prevalence

Finding statistics for Fetal Alcohol Syndrome in recent publications is relatively simple. Finding statistics that agree with each other is another story all together. There are three things that affect the variations in statistics for Fetal Alcohol Syndrome - the type of study used to generate the statistics, the under diagnosis of Fetal Alcohol Syndrome and Alcohol Related Effects, and the difference between incidence and prevalence.

There are two main ways in which Fetal Alcohol Syndrome statistics are calculated - registry studies and clinical studies. Registry studies rely on the examination of existing medical records including birth certificates. The drawback with this type of study is that Fetal Alcohol Syndrome is rarely diagnosed at birth. There is no definitive test that can be done on a newborn to determine the presence of Fetal Alcohol Syndrome. Fetal Alcohol Syndrome is more often diagnosed later in an individual's life based on a wide range of criteria.

Clinical studies rely on the examination of individuals within a specific population. These studies apply the diagnostic criteria for Fetal Alcohol Syndrome to the individuals within the study. The drawback with this type of study is that the rates for Fetal Alcohol Syndrome can vary greatly based on the population in which the clinical study is conducted.

Any difficulty in finding statistics for Fetal Alcohol Syndrome is complicated by the fact that "Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) are widely under diagnosed. Some experts believe between one-third and two-thirds of all children in special education have been affected by alcohol in some way" (National Organization on Fetal Alcohol Syndrome). And most experts agree that the rates of Alcohol Related Effects may be up to three times the reported rate of Fetal Alcohol Syndrome.

Incidence quantifies the number of new events or cases of Fetal Alcohol Syndrome that develop in a population of individuals at risk during a specified time interval. Prevalence quantifies the proportion of individuals in a population who have the Fetal Alcohol Syndrome at a specific instant.

Therefore, when considering the following numbers it is important to keep the proceeding caveats in mind.

The Centers for Disease Control, National Center on Birth Defect and Developmental Disabilities places the Fetal Alcohol Syndrome prevalence rates for the United States in the "range from 3 to 22 cases per 10,000 live births. This means that each year in the united statues 1,300 to 8,000 children are more with FAS. Many more children are born with alcohol-related neurodevelopmental disorder (ARND)." While these statistics are based several national studies using varying methods and data sources.

For a comparison, the following incidence and prevalence rates for Fetal Alcohol Syndrome and Fetal Alcohol Effect are based on a recent study completed by the North Dakota Fetal Alcohol Syndrome Center, extrapolating the numbers for North Dakota to the entire United States.

The incidence rate for Fetal Alcohol Syndrome in the general population is generally estimated in the range of 0.5 to 3.0 cases per 1,000 live births.

- Incidence estimates for Fetal Alcohol Effect are generally put at 12 cases per 1,000 live births.
- Based on 3,959,417 live births in the United States in 1999,
 - the estimated number of Fetal Alcohol Syndrome cases would be 7,919,
 - the estimated number of Fetal Alcohol Effect cases would be 47,514, producing
- Assuming these incidence rates at any given period in time the prevalence rates of Fetal Alcohol Syndrome are:
 - ☆ Children, birth to 18 years old, in the United States
 - with Fetal Alcohol Syndrome 127,889,
 - with Fetal Alcohol Effect 767,353,
 - \$\top \text{ producing a combined FAS/FAE total of 895,242.}
 - Adults, aged 19-69 years of age, in the United States
 - with Fetal Alcohol Syndrome 343,281,
 - with Fetal Alcohol Effect 2,059,737,
 - producing a combined FAS/FAE total of 2,403,018.
 - individuals with Fetal Alcohol Syndrome (both children and adults) 471,170,
 - individuals with Fetal Alcohol Effect (both adults and children) 2,877,090,
 - producing a total number of individuals (children and adults aged birth to 69 years old)
 3,298,260.

These statistics are only from one study. There are numerous published studies of the incidence and prevalence of Fetal Alcohol Syndrome. While there isn't a definitive study to cite, the above study provides a reasonable estimate of the incidence and prevalence of Fetal Alcohol Syndrome.

Bibliography - See page 22.



Characteristics of Fetal Alcohol Syndrome

The characteristics of Fetal Alcohol Syndrome fall into three categories - Growth Deficiency, Facial Anomalies and Central Nervous System Dysfunction. It is important to remember that all the characteristics described below can be present in the individual with Fetal Alcohol Syndrome in varying degrees. Also it is not necessary for all the following characteristics to be present for a diagnosis of Fetal Alcohol Syndrome.

Growth Deficiency

In Height In Weight

In Both Height and Weight Prenatal or Postnatal

Facial Anomalies

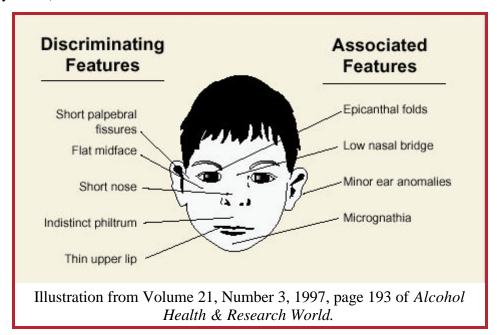
Smooth or Long Philtrum (Ridges between the nose and mouth.)

Short Palpebral Fissures (Eye Slits)

Flat Midface

Short Upturned Nose

Thin Upper Lip



Central Nervous System Dysfunction

Microcephaly (Small Brain Size) Attention Deficits

Tremors Learning Disabilities

Seizures Mental Retardation

Hyperactivity Developmental Delays

Fine Motor Difficulties Intellectual Disabilities

Gross Motor Difficulties

Fetal Alcohol Syndrome, especially without a confirmed history of prenatal alcohol exposure, is often diagnosed based on the complete set of characteristics present in the individual. As a person with Fetal Alcohol Syndrome ages, the effects of the syndrome can be seen in a variety of ways. The following lists characteristics seen in individuals with Fetal Alcohol Syndrome at various developmental stages. It is important to note that not every individual will exhibit all of the characteristics at a given age.

Characteristics often seen in Newborns or Infants

Difficulty Sleeping - Unpredictable Sleep/Wake Cycle

Electroencephalogram (EEG) Abnormalities

Failure to Thrive

Feeding Difficulties including Weak Sucking Reflex

Heart Defects, Kidney Problems, or Skeletal Anomalies

Increased Sensitivity to Light and Sound - Easily Overstimulated

Neurological Dysfunctions

Poor Fine Motor Control

Poor Gross Motor Control

Seizures, Tremors, or Jitteriness

Small Size

Susceptibility to Infections

Characteristics often seen in Preschool Aged Children

Emotional Over-Reaction and Tantrums

Hyperactivity

Lack of Impulse Control

Mental Retardation

Poor eye-hand and physical coordination.

Poor Judgment (Often seen as difficulty recognizing danger including not fearing strangers. Children of this age may seem overly friendly.)

Small Size

Speech Delays (May include poor articulation, slow vocabulary or grammar development, or perseverative speech.)

Characteristics often seen in Elementary School Aged Children

Attention Deficits

Hyperactivity

Language Difficulties (Delayed Development or Difficulties with Expressive or Receptive Language)

Learning Disabilities or Cognitive Disabilities

Memory Difficulties

Poor Impulse Control (Often seen as lying, stealing or defiant acts.)

Small Size

Social Difficulties (May include overly friendly, immaturity, easily influenced and difficulty with choices.)

Characteristics often seen in Adolescents and Young Adults

Difficulties with Abstract Reasoning
Difficulty Anticipating Consequences
Low Academic Achievement
Low Self-Esteem
Memory Impairments
More Pronounced Impulsiveness (Often seen as lying, stealing or defiant acts.)
Poor Judgment

Bibliography - See page 22.

Current Diagnostic Criteria for Fetal Alcohol Syndrome

There are currently two primary approaches to diagnosing Fetal Alcohol Syndrome. Both criteria seek to demonstrate the vast spectrum of disabilities contained inside the term Fetal Alcohol Syndrome.

The one of the most widely used diagnostic criteria was presented in <u>Fetal Alcohol Syndrome</u>: <u>Diagnosis, Epidemiology, Prevention and Treatment</u> which was published in 1996. In this landmark book, the Institute of Medicine proposed the following diagnostic criteria for Fetal Alcohol Syndrome and Alcohol-Related Effects. This criteria consists of five categories.

Fetal Alcohol Syndrome

[Category] 1. FAS with confirmed maternal alcohol exposure

- A. Confirmed maternal alcohol exposure
- B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone

(e.g., flat upper lip, flattened philtrum, and flat midface)

- C. Evidence of growth retardation, as in at least one of the following: low birth weight for gestational age decelerating weight over time not due to nutrition disproportional low weight to height
- D. Evidence of Central Nervous System (CNS) neurodevelopmental abnormalities, as in at least one of the following:

decreased cranial size at birth

structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-had coordination

[Category] 2. FAS without confirmed maternal alcohol exposure

- A. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)
- B. Evidence of growth retardation, as in at least one of the following:
 low birth weight for gestational age
 decelerating weight over time not due to nutrition
 disproportional low weight to height
- C. Evidence of [Central Nervous System] CNS neurodevelopmental abnormalities, as in at least one of the following:

decreased cranial size at birth

structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

[Category] 3. Partial FAS with confirmed maternal alcohol exposure

- A. Confirmed maternal alcohol exposure
- B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

- C. Evidence of growth retardation, as in at least one of the following: low birth weight for gestational age decelerating weight over time not due to nutrition disproportional low weight to height
- D. Evidence of [Central Nervous System] CNS neruodevelopmental abnormalities, as in:

decreased cranial size at birth

structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

E. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills or problems in memory, attention or judgment

Alcohol-Related Effects

Clinical conditions in which there is a history of maternal alcohol exposure, and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, which may co-occur. . . .

[Category] 4. Alcohol-related birth defects (ARBD) List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Tetralogy of Fallot
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Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidnesy Horseshoe kidneys	Ureteral duplications Hydronephrosis
Ocular	Strabismus	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to	

[Category] 5. Alcohol-related neruodevelopmental disorder (ARND)

A. Evidence of [Central Nervous System] CNS neurodevelopmental abnormalities, as in any one of the following:

decreased cranial size at birth

structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

and/or

B. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control' problems in social perception; deficits in higher level receptive and expressive language poor capacity for abstraction or metacognition; specific deficits in mathematical skills or problems in memory, attention or judgment" (Institutes of Medicine, pages 4-5)

The second widely used diagnostic criteria was developed by well-known researchers in the field of Fetal Alcohol Syndrome Sterling K. Clarren, M.D. and Susan J. Astley, Ph.D. "Diagnosing the Full Spectrum of Fetal Alcohol-Exposed Individuals: Introducing the 4-Digit Diagnostic Code" was published in the journal *Alcohol & Alcoholism* in 2000. This diagnostic criteria is based on providing a numerical reference to the absence or presence of certain Fetal Alcohol Syndrome characteristics.

"The four digits of the diagnostic code reflect the magnitude of expression of the four key diagnostic features of FAS in the following order: (1) growth deficiency; (2) the FAS facial phenotype; (3) brain damage/dysfunction; (4) gestational alcohol exposure." (Astley and Clarren, page 402).

Each of the four digits represent a different diagnostic feature, clinicians assign a number between 1 and 4 with "1 reflecting complete absence of the FAS feature and 4 reflecting a strong 'classic' presence of the FAS feature" (Astley and Clarren, page 402). The result is the "4-Digit Diagnostic Code." There are a total of 256 possible combinations of "4-Digit Diagnostic Codes." Each of the possible combinations of numbers are assigned to a diagnostic category. Unlike the Institutes of Medicines diagnostic criteria which only offer five categories, the "4-Digit Diagnostic Code" encompasses 22 diagnostic categories.

The diagnostic categories used with the "4-Digit Diagnostic Code" are

- A Fetal Alcohol Syndrome (alcohol exposed)
- B Fetal Alcohol Syndrome (alcohol exposure unknown)
- C Atypical Fetal Alcohol Syndrome (alcohol exposed)
- D Fetal Alcohol Syndrome Phenocopy (no alcohol exposure)
- E Sentinel Physical Findings/Static Encephalopathy (alcohol exposed)
- F Static Encephalopathy (alcohol exposed)
- G Sentinel Physical Findings/Neurobehavioral Disorder (alcohol exposed)
- H Neurobehavioral Disorder (alcohol exposed)
- I Sentinel Physical Findings (alcohol exposed)
- J No Cognitive/Behavioural or Sentinel Physical Findings Detected (alcohol exposed)
- K Sentinel Physical Findings/Static Encephalophy (alcohol exposure unknown)
- L Static Encephalopathy (alcohol exposure unknown)
- M -Sentinel Physical Findings/Neurobehavioural Disorder (alcohol exposure unk nown)
- N Neurobehavioural Disorder (alcohol exposure unknown)
- O Sentinel Physical Findings (alcohol exposure unknown)
- P. No Cognitive/Behavioural or Sentinel Physical Findings Detected (alcohol exposure unknown)
- Q Sentinel Physical Findings/Static Encephalopathy (no alcohol exposure)
- R Static Encephalopathy (no alcohol exposure)
- S Sentinel Physical Findings/Neurobehavioural Disorder (no alcohol exposure)
- T Neurobehavioural Disorder (no alcohol exposure)
- U Sentinel Physical Findings (no alcohol exposure)
- V No Cognitive/Behavioural or Sentinel Physical Findings Detected (no alcohol exposure)

(Astley and Clarren, page 404)

As these diagnostic categories show, Fetal Alcohol Syndrome encompass several categories with varying degrees of neurodevelopmental and behavioral implications. The "dose, timing, and conditions of [prenatal alcohol] exposure as well as . . . The individual characteristics of the mother and fetus" account for the wide range of the spectrum that is Fetal Alcohol Syndrome (Streissguth, page 4).

NOTE: For more complete definitions of some terms, please see the Glossary of Terms on page 66 of this handbook.

Bibliography - See page 22.



Prenatal Exposure to Alcohol and Brain Development

Most of the primary disabilities associated with Fetal Alcohol Syndrome can be related to damage to the brain during development of the fetus. Alcohol's effect on the developing brain is an area in which extensive research is being conducted. Alcohol is a teratogenic drug. According to the Oxford English Dictionary a teratogen is "an agent or factor which causes malformation of the developing embryo." Alcohol can affect the embryo as well as the fetus. It is important that women abstain from drinking not only when they know they are pregnant, but also when they are planning to become pregnant since alcohol can damage the embryo even before a woman knows she is pregnant.

How exactly does alcohol affect brain development? Ann Streissguth, Ph.D, a leader in the study of Fetal Alcohol Syndrome, points to two different ways. One affecting the structure of the brain and the other affecting the function of the brain.

"[E]xposure to prenatal alcohol can disrupt the normal proliferation and migration of brain cells, which produces structural deviations in brain development." and "Prenatal alcohol exposure can also disrupt the electrophysiology and neurochemcial balance of the brain, so that messages are not transmitted as efficiently or as accurately as they should be" (page 96).

Current research uses autopsies and Magnetic Resonance Imaging (MRI) to study the damage caused to the structure of the brain. To study the function of the brain researcher use electroencephalograms (EEGs) and Positron Emission Tomography (PET).

Given the spectrum of Fetal Alcohol Syndrome and Alcohol Related Effects, it stands to reason that the effect of prenatal alcohol exposure on brain development can be influenced by several different variables. Striessguth discusses these variables, as seen in animal research, in her book <u>Fetal Alcohol Syndrome</u>: A Guide for Families and Communities.

"Dose, timing and pattern of exposure modify the prenatal effects of alcohol.... Not only are children of mothers who are chronic alcoholics at risk.... Women who drink before they know they are pregnant or have an occasional heavy dose of alcohol (binge) may also cause damage to their children.

Individual differences in the mother and the child modify the effect of prenatal exposure in the individual . . . in terms of both the severity and the type of offspring effect. The fact that some offspring appear unaffected by prenatal alcohol at any point in time does *not* mean that alcohol is not tertogenic or that an individual who is free of alcohol-caused disabilities at one age will necessarily be free of them at another.

Brain damage from prenatal alcohol can occur without accompanying physical manifestations and from lower doses and frequency of exposure. . . . Those [individuals] with FAE and ARND can have brain damage just as surely caused by alcohol as those with FAS, and it can occur at lower exposure levels.

Brain-behavior relationships have been well established in animal studies. . . . Many of the puzzling and bizarre behaviors that people with FAS engage in may be

caused by their brain damage. This has major implications for their daily living and their social interactions.

The effects of prenatal exposure last into adulthood. Aberrant behaviors in children, adolescents, and adults can be caused by prenatal damage." (Pages 66-67)

The four regions of the brain most frequently referred to when discussing the effects of prenatal alcohol exposure are the basal ganglia, cerebellum, corpus callosum, and hippocampus. Neuroimaging studies show that all four of these brain regions are decreased in size in the brains of individuals who were exposed to alcohol prenatally. In the worst cases, the corpus callosum may be absent.

The impact of this damage to the brain is most readily seen by the various functions that each of these regions controls. It follows that damage to each of these

Hippocampus Corpus callosum

Basal ganglia

Cerebellum

Illustration from Volume 25, Number 3, 2001, page 187 of *Alcohol Health & Research World*.

regions would adversely affect the function for which each is responsible.

The basal ganglia "governs voluntary movement as well as some cognitive functions related to perception, thinking and memory" (Prenatal Exposure to Alcohol, page 33). The caudate nucleus, a portion of the basal ganglia, when affected by prenatal alcohol exposure can affect "skills such as the ability to shift from one task to another, inhibition of inappropriate behavior, and spatial memory" (Mattson, page 188).

The cerebellum is "thought to be involved primarily in movement but also in cognitive processes, such as attention" (Prenatal Exposure to Alcohol, page 33). Damage to the cerebellum has also "been implicated in learning deficits as well as in balance and coordination" (Mattson, page 189).

The corpus callosum connects the two halves of the brain and allows them to communicate. Damage to the corpus callosum has "been linked to deficits in attention, intellectual functioning, reading, learning, verbal memory, and executive and psychosocial functioning" (Mattson, page 188).

The hippocampus is involved in the function of memory. "Although the precise function of the hippocampus in specific aspects of memory is controversial, it probably plays a role in the consolidation of memory" (Mattson, page 189).

When any of these regions - the basal ganglia, cerebellum, corpus callosum or hippocampus - is damaged by prenatal exposure to alcohol it can have devastating effects. Each unique area of the brain, by itself and in connection with the rest of the brain, controls some function. The greater the damage to the brain, the greater the consequences. It is important to remember that brain damage caused by prenatal alcohol exposure can be present even in the absence of the classic facial features of Fetal Alcohol Syndrome.

Bibliography - See page 23.

4

Secondary Disabilities

Primary disabilities, when referring to Fetal Alcohol Syndrome, are those caused by brain damage both structural and functional (see Prenatal Alcohol Exposure and Brain Development on page 15 of this handbook). Secondary disabilities "are disabilities than an individual is not born with, but may be acquired as a result of the CNS [Central Nervous System] deficits associated with Fetal Alcohol Syndrome (FAS)" (National Center on Birth Defects and Developmental Disabilities). Not every individual with Fetal Alcohol Syndrome has or exhibits secondary disabilities. In fact "higher rates of secondary disabilities were observed for people who had FAE [Fetal Alcohol Effect] rather than FAS and an IQ score above rather than below 70 (Streissguth, page 111). It is important to note that not all individuals diagnosed with Fetal Alcohol Syndrome will be affected by all the secondary disabilities included in this article. The most commonly seen secondary disabilities are mental health problems, disrupted school experience, alcohol or drug use, legal problems, confinement, inappropriate sexual behavior, and dependent living.

Mental Health Problems

Anxiety Disorders
Attachment Disorder
Attention Deficit Disorder (ADD)
Attention Deficit Hyperactivity Disorder (ADHD)
Conduct Disorder
Depression
Eating Disorders
Hallucinations
Oppositional Defiance Disorder
Psychotic Episodes
Suicide Threats/Attempts

"More than 90% of the individuals in our [Streissguth, Barr, et. al., 1996] study had mental health problems, and more than 80% had had treatment for mental health problems. There was no difference in the prevalence of mental health problems for children versus adolescents and adults" (Streissguth, page 109).

Disrupted Schooling

Dropping Out Expulsions Suspensions

Behaviors which may lead to the above school disruptions.

Being Repeatedly Disruptive in Class Disobedience Disrespect Toward Teachers Learning Difficulties Not Getting Along with Peers Truancy "More than 60% of the adolescents and adults [in the Streissguth, Barr, et.al., 1996 study] had had a disrupted school experience and, surprisingly, so had 14% of the children. Suspensions were the most frequent disrupted school experience among individuals of all ages" (Streisguth, page 109).

Alcohol or Drug Use

"Problems with alcohol and other drugs were reported for 35% of adolescents and adults [in the Streissguth, Barr, et.al., 1996 study] but were not reported as a problem for children" (Streissguth, page 109).

Legal Problems

Assault
Child Molestations
Crimes Against Persons
Crimes Against Property
Domestic Violence
Running Away
Shoplifting
Theft

"Sixty percent of the adolescents and adults [in the Streissguth, Barr, et.al., 1996 study] and even 14% of the children had trouble with the law. . . . Individuals who didn't have disrupted school experiences were only 40% as likely to be in trouble with the law" (Streissguth, page 109). "Difficulty controlling anger and frustration, combined with problems understanding the motives of others, may result in many individuals with FAS being involved in violent or explosive situations. Individuals with FAS can be very susceptible to persuasion and manipulation, resulting in unwitting involvement in illegal activities" (National Center on Birth Defects and Developmental Disabilities).

Confinement

Incarceration (Jail)
In-Patient Alcohol Treatment
In-Patient Drug Treatment
In-Patient Mental Health Treatment

"Fifty percent of the adolescents and adults [in the Streissguth, Barr, et.al., 1996 study] but less than 10% of the children had been confined. Adolescents and adults were more likely to have been incarcerated (32% and 42%, respectively) than to have been in either inpatient mental health programs (20% -28%) or inpatient alcohol and other drug treatment programs (12%-20%)" (Streisguth, page 109).

Inappropriate Sexual Behavior

Compulsions Inappropriate Sexual Advances Inappropriate Sexual Touching Obscene Telephone Calls Promiscuity Voyeurism "Forty-nine percent of adolescents and adults [in the Streissguth, Barr, et.al., 1996 study] and 39% of children had displayed inappropriate sexual behavior" (Streissguth, page 110). Poor judgment, lack of impulse control and difficulty learning from experience can both contribute to inappropriate sexual behavior.

Dependent Living

"Adults with FAS generally have difficulty sustaining employment or living independently" (National Center on Birth Defects and Developmental Disabilities). "Group homes for FAS affected adults can be a nurturing and supporting environment, providing a degree of independence within a safe haven" (Alcohol Related Birth Injury (FAS/FAE) Resource Site).

None of these secondary disabilities exists in a vacuum. Legal problems can stem from alcohol and drug use. Disrupted school experiences can result from learning disabilities and impulse control. While it may seem that secondary disabilities would be difficult to prevent, there are several so-called "protective factors" which are associated with lower rates of secondary disabilities in individuals with Fetal Alcohol Syndrome. The protective factors are early diagnosis, receiving special education and/or social services, a stable, nurturing home environment, and an absence of violence.

Protective Factors

Early Diagnosis

"Early identification allows for enrollment of the child in appropriate educational classes and provides access to social services that may benefit the child and his or her family. In addition, early diagnosis provides families and school personnel with an explanation of why the child may act or react differently than other children in some situations" (National Center on Birth Defects and Developmental Disabilities).

Receiving Special Education and/or Social Services

"Children who receive special education geared towards their individual needs and learning style are more likely to achieve their developmental and educational potential. . . . 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" (National Center on Birth Defects and Developmental Disabilities).

Stable, Nurturing Home Environment

"Children with FAS may be particularly sensitive to disruptions, transient lifestyles, or dysfunctional relationships" (National Center on Birth Defects and Developmental Disabilities).

Absence of Violence

"Individuals with FAS who do not experience abusive households or become involved in youth violence are much less likely to develop secondary conditions than children who have had such negative experiences" (National Center on Birth Defects and Developmental Disabilities).

Secondary disabilities can be difficult for individuals with Fetal Alcohol Syndrome and their families. However, the protective factors can help to eliminate or lessen this set of secondary disabilities.

Bibliography - See page 23.



Prevention

Given that Fetal Alcohol Syndrome is 100% preventable, it may seem a given that prevention would figure in any discussion of not only Fetal Alcohol Syndrome but also of women's health issues. However, it is sometimes a very fine line that researchers studying Fetal Alcohol Syndrome, physicians treating women, and public health officials must walk. Alcohol is a legal drug and anyone, including women, who are legally of age are allowed to use alcohol. "The use and abuse of alcohol have long been centered in emotional and moral debate. Women who use alcohol or other substances are particularly stigmatized" (Institute of Medicine, page 112). For this reason it is helpful to establish a model of prevention that focuses not only on the woman who is or may become pregnant, but also on her spouse or significant other, her physician, her community, and her society.

Ann Streissguth, Ph.D., a noted researcher in the area of Fetal Alcohol Syndrome, has developed what she terms the "Five P's of Prevention."

- 1. Public Education
- 2. Professional Training
- 3. Public Policy
- 4. Programs and Services
- 5. Parent and Citizen Activism (Streissguth, page 250)

Stresissguth's "Five P's of Prevention" work together to affect not only women who are or may be come pregnant but also the society around them.

- 1. **Public Education** is focused on educating the public at large about the dangers of drinking during and even before pregnancy. Public education can take many forms. Posters, lectures, brochures and media attention are all forms of public education.
- 2. **Professional Training** is focused on teaching healthcare and social service professionals about Fetal Alcohol Syndrome. But beyond that, teaching them how to discuss with women the effects drinking can have on a fetus. Professionals should be given concrete suggestions for introducing the topic of drinking during pregnancy and they should be familiarized with ways to help women stop drinking.
- 3. **Public Policy** refers to the way government on every level deals with the issue of drinking during pregnancy. Public policy is seen in the United States Surgeon General's warning urging women to stop drinking while they are planning to become pregnant. It is also seen in the laws in some states requiring individuals to report to the state women they know to be drinking during pregnancy.
- 4. **Programs and Services** refers to programs which intervene even briefly with women who are drinking during pregnancy and services which support the women while they are pregnant and after.
- 5. **Parent and Citizen Activism** is simply what its name says. Parents and citizens taking and active role in the prevention of Fetal Alcohol Syndrome.

Ann Streissguth's "Five P's of Prevention" are only one of several popular models of prevention. No matter which model of prevention is used. It is important to remember that Fetal Alcohol Syndrome is 100% preventable.

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Introduction to Educational Techniques

The following pages of this handbook contain articles describing educational techniques that may be helpful to teachers and parents of individuals with Fetal Alcohol Syndrome. The articles are:

- Educational Techniques for Preschool Children with Special Needs and/or Developmental Disabilities on page 26,
- Educational Techniques for Elementary School Children with Special Needs and/or Developmental Disabilities on page 31, and
- Educational Techniques for Junior and Senior High School Children with Special Needs and/or Developmental Disabilities on page 37.

As was noted in the Secondary Disabilities article on page 18, disrupted schooling is one of the most common secondary disabilities encountered by individuals with Fetal Alcohol Syndrome. The Secondary Disabilities article discussed some of the behaviors which may lead to school disruption.

However, there may also be underlying causes for the behaviors that lead to school disruption as well as other contributing factors. Some of the possible contributing factors to school disruption may be:

- Arithmetic Disabilities
- ♦ Attention Deficits
- belayed Reaction Time Students with Fetal Alcohol Syndrome may process information slower and less efficiently than their peers.
- ♥ Difficulties with Abstraction Often seen as a difficulty understanding consequences.
- ♥ Difficulties Transitioning Between Two Activities.
- ♥ Difficulties with Verbal Learning Students with Fetal Alcohol Syndrome may learn fewer words.
- Difficulties with Visual-Spatial Learning Students with Fetal Alcohol Syndrome often have difficulty replacing objects in their original position.
- ♦ Disorientation in Time and Space Often seen as a difficulty in perceiving social cues.
- \$ Impulsivity Often seen as poor frustration tolerance.
- ♦ Memory Impairments

The following lists some of the focus areas that teachers and parents might consider when discussing the education of the student with Fetal Alcohol Syndrome. Also listed are some basic recommendations for each of the areas. This recommendations will be expanded on in the following articles.

- Structions Environment Free of Distractions and Organized
- Transitional Periods Establish and use clearly defined cues to begin and end transition period.
- Solution of the Contraction of t
- Increasing Attention Use eye contact and touch when giving directions and have the student repeat the directions.
- Controlling Impulsivity Model and Rehearse Social Skills Require student to wait for an established signal before beginning a task.
- Discipline Ignore negative behavior whenever possible.

- Hyperactivity Teach Substitute Behaviors Have a respite plan for when the student is overwhelmed.
- Memory Teach Memory Strategies and Repeat Information Continuously- Have the student repeat information back to you.

The following articles will provide further information on strategies for helping students with Fetal Alcohol Syndrome. While every student with Fetal Alcohol Syndrome will not encounter every problem discussed in these articles, most will experience at least some difficulties with school and/or learning. Not every student will respond to every technique included in the following articles, but the suggestions provided here may help the teacher or parent to better help the student learn and succeed in school.

Five words to remember when teaching a student with Fetal Alcohol Syndrome.

- **Structure**
- **Solution** Consistency
- **Brevity**
- **♦ Variety**
- **Persistence**

Information in this article was provided by Judy Struck, M.A.



Educational Techniques for Preschool Children with Special Needs and/or Developmental Disabilities

Prepared by Valborn Kvigne, M.B.A.; Judy Struck, M.A.; Ellen Englehard, Ed.D.; and Tracy West, M.A.

Alphabet



jello."

- Make letters with paper and glue other objects to the letter.
- Match letters.
- Match words.
- Use the sounds of the letters repeatedly "J", juice, jump, jacket, etc.
- Teacher cuts a letter out of sandpaper and has the child follow the sandpaper letter with his/her finger.
- Teacher writes a letter on the blackboard and has the child trace the letter on the blackboard.
- Teacher makes dots on a paper in the shape of the letter and has the child connect the dots to make the letter, gradually decreasing the number of dots to connect to make the letter.
- ♦ Make letters with jiggler jello.
- When a child is learning to write his/her name, it may be easier for the child if the child uses all capital letters at the beginning.

Environment

- ♦ Calm and quiet.

 - Tone down classroom so rooms are not overly stimulating.
 - ☼ Keep a minimal number of objects hanging from the ceiling and on the walls.
 - Use calm colors of paint on the walls.
- Structure.
 - Same rules are enforced the same way.
- \$\transition from one activity to another activity.
 - Tell the child what they will be doing "We'll finish painting then we'll eat a snack."
 - * "When we finish our snack, we will brush our teeth." The teacher may need to give the child his/her toothbrush at this time so the child has an easier time making the transition.
 - The child could carry the book to story time or carry the puppet to the puppet story.

Evaluations

- The following evaluations may be helpful in learning more about the child's development and assist in planning the teacher's activities.

 - Psychological Evaluations.

 - Adaptive Behavior.



Children with special needs and/or developmental disabilities usually need more one-to-one teaching. The number of staff available for the number of children with special needs and/or developmental disabilities needs to be a consideration.

Eye-Hand Coordination Activities

- Use puzzles with knobs on the pieces.
- ♦ Lace cards.

 - The lace for the lace card may need masking tape on the end to make it easier for the child to lace the card.
- Squeeze clothes pins.
- The teacher may need to show the child how to do the activity, guide the child through the activity, and then encourage the child to do the activity on his/her own.
 - The teacher could pick up the puzzle piece for the child to put in the right place in the puzzle.
 - The teacher could lace the first two holes of a lacing card.
- Putting pegs in a board.
- Pounding a peg board.



Language Development

- \$\to\$ Children who are not talking.
 - ⇔ Begin with simple story books.
 - The teacher can touch an object and name the object for the child, the teacher touches a table and says to the child "table."
 - ♦ Use real objects like "trees, cars, dog" and name the object.
- \$\to\$ Children who are using single words.
 - Fig. If the child says "drink" say to the child "more drink" to stimulate more words in the child's vocabulary.
 - Expand the child's vocabulary slowly when the child starts using two words, start using three words "want more drink."
 - Talk with the child at the child's level use short sentences avoid using long sentences.
- ♦ Poor articulation.
 - A speech therapist would be a good resource for child and teacher.
 - The teacher needs to use proper pronunciations a good role model is important.
 - ☆ Go around the classroom, touch objects and name the object have the child do the same thing.
 - Meal time have the child say what he/she wants rather than just giving the child what one thinks the child wants.
 - Music activities can help children learn vocabulary.
 - ♦ Good morning song.
 - Song before the children eat.
 - ♦ Name songs.
 - \$\times\$ Circle game songs sit down, stand up, name games.

- Sign language.
 - Sign language may be helpful to teach children with special needs and/or developmental disabilities even when they do not have a hearing loss.
 - Sign language is concrete and visible which can be used along with verbal language.

Managing Hyperactivity

- ☼ Keep the environment structured.
- ♦ Make a picture calendar.
 - A Make a board with hooks.
 - A Laminate pictures of activities for the whole day.
 - \(\bar{\pi} \) Have a picture of a child taking jacket off and hanging up the jacket.
 - Have a picture of a child putting puzzle together.
 - As the child completes each activity during the day, the child would take the picture off the hook, turn it over, and hang the picture back on the hook. The child knows that he/she has completed the activity.
- \$\\$Give the child a choice from 2 or 3 toys.
 - Give the child plenty of time to make a choice.
 - If the child seems to be having difficulty making a choice, watch the child to see if he/she looks longer at a particular toy or makes a movement toward a certain toy.
- Place each activity in two baskets.
 - Have two baskets for a puzzle, two baskets for a pegboard, two baskets for a matching activity, two baskets for lacing cards, two baskets for scissors and paper activity, etc. Having one activity in one set of baskets will help keep the child's attention on the activity for a longer period of time.
 - Take the activity out of the "start" basket and when the child has finished the activity, the child puts the activity in the "finish" basket.
- Keep the designated activities in the same place. The child will know where to return the activity when he/she is finished with the activity.
- \(\bar{\parameters}\) Hyperactive children should sit on a chair rather than the floor.
 - The chair keeps the child from leaning backward, forward, and sideways.
 - The chair helps keep the child in a specific space.
 - The teacher may need to show the child how to sit in the chair.
 - ♦ Feet flat on the floor.
 - \(\bar{\psi} \) Hands on the side.
 - ♦ Sitting straight up.
 - Have the activity at the table ready for the child when the child is sitting properly the child probably will not sit at the table very long waiting for the teacher to bring an activity.
- Structure the day alternating quiet time, active time, quiet time, etc.
- ♥ Tantrums.
 - Take the child to a different room. Lullaby music playing in the room may help calm the child.

 - Teachers body language should not get the child excited. Talk in a calm voice, walk slowly. If the teacher is relaxed, this will help the child relax.

- Determine what happened before the tantrum occurred.
 - \$\took \text{ Look for antecedents to the behavior.}
 - Antecedents are the events/things that happen which help the child lose his/her temper.
- Another way of reducing the likelihood of the child having a tantrum is to teach the child new ways of dealing with his/her stress. Teach the child to say "I'm mad."
- The child's diet could be a contributing factor for the behavior.
- \$\to\$ Observe the child for any health problems.

 - Ask the child to "show me where you hurt."
- Ignore negative behavior whenever possible. Avoid overreacting to negative behavior.
- ⇔ Build a positive reinforcement.
 - As the child finished each activity on the picture calendar, hug the child.
 - ♦ When the child does a good job on a project, let the child know he/she will get a hug.
- If the child does not need sleep at nap time, the child may benefit from having active activities like riding a tricycle in the hall.

Math



- Memorized counting from one to ten does not mean the child understands numbers.
- Teach the child to learn what the number "one" means before any more numbers are taught to the child.
 - ⇔ "Give me one crayon."
 - Put one napkin on the table."
- Ut the numbers out of paper glue oatmeal, rice, glitter, etc. to the number the child can see, feel and hear the number.
- ♥ Touch and count objects.

Sensory Stimulation

- Use as much sensory stimulation as possible to teach each concept.
 - Example teaching the color "orange."
 - ♥ Wear orange clothes
 - Paint with orange paint.
 - Use orange construction paper for projects.
 - Serve oranges for a snack.
- Use objects as much as possible to teach concepts.
 - - \$\text{Laminate polka dot fabric.}
 - Use a cookie cutter to cut circle sandwiches.
 - Ut circles from construction paper and glue Cheerios to the paper.
- ☼ Teaching activities must be "concrete."
 - Example child is told to stay in the yard.
 - \$\text{Child continuously wanders into street.}
 - Parents obtained 4 large orange cones and the child stays inside the 4 cones.
 - Parents gradually expanded the cones.



"Serve oranges for a snack" when teaching the color orange.

- ★ Example "What do you want?"
 - \$\triangle\$ This question is very abstract.
 - Give child choices he/she can see, feel, touch and hear.

Short Attention Span

- Determine how long the child is working on an activity.
- ∜ "One more."
 - ☆ If the child is drawing circles on a paper and the child decides to quit, have the child draw "one more" circle.
 - The teacher should never make the child do the activity more than once if the teacher said "draw one more circle."
 - This approach should increase the child's attention span over time.

Social Behavior

- Show the child how to share toys may need to use a timer to share the most popular toy.
- Teach the child how to be a friend.
 - Teach the child how to sit with a friend at the table.
 - Pair children for a week so the child with special needs and/or developmental disabilities can work/play with child who do not have special needs and/or developmental disabilities.



"Use a timer to share the most popular toy.



Educational Techniques for Elementary School Children with Special Needs and/or Developmental Disabilities

Prepared by Valborn Kvigne, M.B.A.; Judy Struck, M.A.; Ellen Englehard, Ed.D.; and Tracy West, M.A.

Environment

- ♦ Calm and quiet.
 - Soft music may relax the environment during breaks.
 - - Skeep a minimal number of objects hanging from the ceiling and on the walls.
 - Use calm colors of paint on the walls.
 - Reduce classroom clutter.
 - Use bulletin boards as teaching tools, use soft colors. (Bulletin boards could be covered if they are not in use.)



- Establish a few simple rules.

- Transition from one activity to another activity.
 - ☆ Give the student reminders for ending and beginning activities. Use tactile signal touch should, tap elbow, say "The bell will ring in five minutes, you need to finish up." "We will go to lunch when the bell rings."
 - The is important for the student to have a fairly consistent routine that is followed every day.
 - Provide notebooks for the students which have all their classroom activities in order for the day.
 - This gives the student a concrete item with which to structure his/her day.
 - \$\text{Class periods should not exceed 20 minutes.}
 - The student can carry the book to the reading area. Students can carry puppets to the puppet story.
 - Students with special needs and/or developmental disabilities need several breaks during the day.
 - Students may need sleep during the day.
 - Students may need to get up and move around more frequently than other students.
 - Plan activities to facilitate movement and creativity between seat work assignments.
 - Students with special needs and/or developmental disabilities may need food snacks during the day.

Evaluations

- The following evaluations may be helpful in learning more about the child's development and assist in planning the teacher's activities.

 - Psychological Evaluations.

 - Adaptive Behavior.

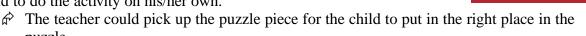


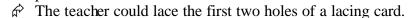
during breaks."

Children with special needs and/or developmental disabilities usually need more one-to-one teaching. The number of staff available for the number of children with special needs and/or developmental disabilities need to be a consideration. The students with special needs and/or developmental disabilities usually need repetition of the information.

Eye-Hand Coordination

- Use puzzles with knobs on the pieces.
- ♦ Lace cards.
 - The teacher may need to make a larger lace card from cardboard.
 - The lace for the lace card may need masking tape on the end to make it easier for the child to lace the card.
- Let student help with tasks that require sorting, stapling, putting things in place, etc.
- The teacher may need to show the child the object, show the child how to do the activity, guide the child through the activity, and then encourage the child to do the activity on his/her own.







stapling, putting

things in place, etc."

Language Development

- Talk with the student at the student's level. Use short sentences. Avoid using long sentences.
- ♥ Poor Articulation.
 - A speech therapist would be a good resource for child and teacher.
 - The teacher should use proper pronunciation a good role model is important.
 - Articulation errors are common, accept their communications without correcting them. Repeat their sounds correctly.
 - Music activities can help children learn vocabulary.
 - ⇔ Good morning song.
 - Song before the children eats.
 - Stricle game songs sit down, stand up, name games.
- \$\text{ Quantity verses quality of speech.}
 - Students with special needs and/or disabilities often use a large quantity of speech. Be aware that quantity does not indicate quality.
 - À Listen for the numbers of words per sentence.
 - Listen for the number of new words that the student uses.
 - Stress concept development through concrete examples encouraging the student to demonstrate understanding. Example temperature child would know what to wear on hot day and what to wear on cold day.
- Sign language.
 - Sign language may be helpful to teach children with special needs and/or developmental disabilities even when they do not have a hearing loss.
 - Sign language is concrete and visible which can be used along with verbal language.

Managing Hyperactivity

- ☼ Keep the environment structured.
- Have as few rules as possible and enforce rules consistently. (Never make a rule you do not plan to enforce. Avoid threats.)
- Make a picture calendar.
 - A Make a board with hooks.
 - Laminate pictures of activities for the whole day.
 - \(\beta\) Have a picture of a child taking jacket off and hanging up the jacket.
 - Have a picture of a child putting puzzle together.
 - As the child completes each activity during the day, the child would take the picture off the hook, turn it over, and hang the picture back on the hook. The child knows that he/she has completed the activity.
- Make lists for the student to follow during the day.
 - * "Read story starting on page 30 in the Reading Book."
 - "Do worksheet on page 10 in the Reading Workbook."
 - * "Read about rocks starting on page 15 in the Science Book."
 - Students may need to have the list taped to their desk.
 - Some students with special needs and/or developmental disabilities may have difficulty relating chalk board instructions to their own behavior.
- ♥ Place each activity in two baskets.
 - Have two baskets for a puzzle, two baskets for a pegboard, two baskets for a matching activity, two baskets for lacing cards, two baskets for scissors and paper activity, etc. Having one activity in one set of baskets will help keep the child's attention on the activity for a longer period of time.
- 1. Read story on page 30.
 2. Draw a picture of the story.

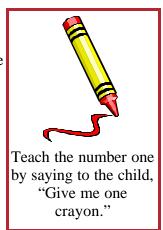
 "Make lists for the student to follow."
 - "Make lists for the student to follow during the day."
- ☆ Take the activity out of the "start" basket and when the child has finished the activity, the child puts the activity in the "finish" basket.
- Keep the designated activities in the same place. The child will know where to return the activity when he/she is finished with the activity.
- \$\Begin{align*} \text{Shelves and bookcases should be enclosed if possible to eliminate visual distraction.} \end{align*}
- Use vivid colors to emphasize important concepts. Emphasize with sound and movement the factors that complement the learning objectives.
- During organized activities, hyperactive students need structure.
 - Students need sequence of activity.
 - Students need to know what behaviors will be acceptable.
 - \(\subseteq \) Examples "During this activity we will stay in our chairs."
 - "There will not be any talking."
 - ∜ "Keep your eyes on your own paper."
 - "If you want help, raise your hand and I will come to you."
- Loosely structured activities must be balanced with highly structured activities to give the student opportunity to move about, visit, relax, etc.
- Structure the day alternating quiet time, active time, quiet time, active time, etc.
- **♥** Tantrums.
 - Remain calm and quiet. Teacher's body language should not get the student excited. Talk in a clam voice, walk slowly. If the teacher is relaxed, this will help the student relax.
 - ★ Let the student know there is a protocol for loss of control.
 - Taking the student's hand and holding it a short time will give the student a signal

- that the teacher thinks the student is losing control.
- \$\forall \text{ If restraint is necessary, the teacher needs to exercise care and control.}
- Talk to the student, telling him/her that you are helping him/her to control his/her behavior.

 - ☆ "Are you feeling better?"
 - *Let me know when you are ready for me to let go."
- - Soft music and soft colors in a room may help calm the student.
 - \$\to\$ Talk to the student in a calm, soft voice.
 - Ask the student to tell the teacher when he/she is ready to go back to the classroom.
- Determine what happened before the tantrum occurred.
 - \$\to\$ Look for the antecedents to the behavior.
 - Antecedents are the events/things that happen which help the student lose his/her temper.
- Look at different ways to eliminate the chances of the student throwing a tantrum.
 - If the student has an extremely difficult time with loud noises and lots of activity, the student should be taught in a relatively quiet and calm area.
- Another way of reducing the likelihood of the student having a tantrum is to teach the student new ways of dealing with his/her stress. Teach the student to say "I'm mad."
- \$\times\$ Child's diet could be a contributing factor for the behavior.
- \$\to\$ Observe the child for any health problems.
 - Ear infections, child may pull at his/her ears.
 - Ask the child to "Show me where you hurt."
 - - ♦ Abnormal head posturing.
 - Squinting.
 - ♦ Holding paper close to face.
 - \$\to\$ Obvious errors made when working from the chalk board.
- \$\text{ Ignore negative behavior whenever possible. Avoid overreacting to negative behavior.}
- Build a positive reinforcement.
 - As the child finishes each activity on the picture calendar, give student positive reinforcement for his/her efforts in completing the activity.
 - When the child does a good job on a project, tell the student what he/she did right. "I really like the way you wrote your k's."

Math

- Memorized counting from one to ten does not mean the child understands numbers. Stress concept development of numbers encouraging students to demonstrate knowledge.
- Teach the child what the number "one" means before any more numbers are taught to the child.
 - ☆ "Give me one crayon."
 - Put one card on the table."
- Ut the numbers out of paper glue oatmeal, rice, glitter, etc. to the number the child can see, feel, and hear the number.
- ♥ Touch and count objects.
- Teach functional math money, time, addition subtraction.



- Using the student's fingers for addition and subtraction or a calculator may assist in teaching students with special needs and/or developmental disabilities.
 - These techniques should not be the first choice but should not be ruled out if they can benefit the student's ability to learn math.
 - A calculator may be necessary for the student to do multiplication and division.

Reading



pictures."

Some students may have difficulty focusing their eyes on the left side of the page and moving their eyes to the right.

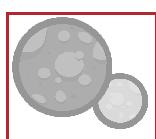
- if student uses a piece of paper to follow the line across the page, the student may have an easier time reading.
- Use colored arrows to signal starting points and direction from right to left.
 Use books with simple, plain pictures. Small detailing marks in a picture can distract the student.

Provide the student with books that follow student's interest and independent reading levels. Independent reading levels means the student can read 90% of the words in the book.

Read aloud to the students daily and provide uninterrupted silent reading periods.

Sensory Stimulation

- Use as much sensory stimulation as possible to teach each concept.
 - Example teaching the color "orange."
 - ♦ Wear orange clothes
 - ♦ Paint with orange paint.
 - Use orange construction paper for projects.
 - Serve oranges for a snack.
- Use objects as much as possible to teach concepts.
 - Example teaching the child about "circles."
 - Laminate polka dot fabric.
 - Use a cookie cutter to cut circle sandwiches.
 - Ut circles from construction paper and glue Cheerios to the paper.
- ☼ Teaching activities must be "concrete."
 - Example child is told to stay in the yard.
 - \$\triangle\$ Child continuously wanders into street.
 - Parents obtained 4 large orange cones and told the child stay inside the 4 cones.
 - Parents gradually expanded the cones.
 - Teacher sets a work-play schedule using pictures, nesting cups, etc.
 - Teacher would set out 6 nesting cups to show the student he/she has 6 activities to complete before taking a break.
 - Example "What do you want?"
 - \$\triangle\$ This question is very abstract.
 - Give child choices he/she can see, feel, touch and hear.



"Laminate polka dot fabric when teaching about circles."

Short Attention Span

- Determine how long the child is able to work on a given activity.
- Once the teacher has determined the attention span for an activity, expand it by one more try and reinforce the student.
- Determine what activity the student can attend to longest.
 - What is it about the activity that allow him/her to attend.

Social Behavior

- Show the student how to share playground equipment may need to use a timer to share the most popular playground equipment.
- Teach the child how to be a friend.

 - Emphasize feelings of others.
 - Practice using manners, consideration statements and apologies.
- Teach the child how to sit with a friend at the table.
 - Emphasize interaction, sharing, courtesy, etc.
- Use peer tutoring.
 - Pair children for a week so the child with special needs and/or developmental disabilities can learn from children who do not have special needs and/or developmental disabilities.
 - Allow students with special needs and/or developmental disabilities to help other students.
 - She gets to your desk."
 - A Capitalize on academic strengths of the student with special needs and/or developmental disabilities.



"Show the student how to share playground equipment."



Educational Techniques for Junior and Senior High School Children with Special Needs and/or Developmental Disabilities

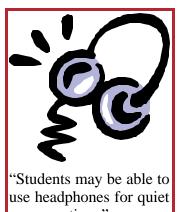
Prepared by Valborn Kvigne, M.B.A.; Judy Struck, M.A.; Ellen Englehard, Ed.D.; and Tracy West, M.A.

Environment

- Calm and quiet.
 - Soft music may relax the environment during breaks.
 - Tone down classroom so rooms are not overly stimulating.
 - Reep a minimal number of objects hanging from the ceiling and on the walls.
 - Use bulletin boards as teaching tools, use soft colors. (Bulletin boards could be covered if they are not in use.)
 - Students may be able to use headphones for quiet time.
 - Students with special needs and/or developmental disabilities are not always able to block out other noises.
 - The ticking of the clock can distract students with special needs and/or developmental disabilities.
 - Teacher talking with another student can distract students with special needs and/or developmental disabilities.



- Establish a few simple rules.
- Same rules are enforced the same way.
- \$\to\$ Transition from one activity to another.
 - Give the student reminders for ending and beginning activities. Use tactile signal touch shoulder, tap elbow, say "The bell will ring in five minutes, you need to finish up." "We will go to lunch when the bell rings."
 - The is important for the student to have a fairly consistent routine that is followed every day.
 - Provide notebooks for the students which have all their classroom activities in order for the dav.
 - This gives the student a concrete item with which to structure his/her day.
 - \$\text{Class periods should not exceed 30 minutes.}
 - ♦ Students with special needs and/or developmental disabilities need several breaks during the day.
 - \$\text{\$\\$Students may need sleep during the day.}
 - Students may need to get up and move around more frequently than other students.
 - Plan activities to facilitate movement and creativity between seat work assignments.
 - Students with special needs and/or developmental disabilities may need food snacks during the day.



time."

Evaluations

- The following evaluations may be helpful in learning more about the child's development and assist in planning the teacher's activities.

 - Motor Evaluations.
 - Adaptive Behavior.
- Children with special needs and/or developmental disabilities usually need more one-to-one teaching. The number of staff available for the number of children with special needs and/or developmental disabilities need to be a consideration. The students with special needs and/or developmental disabilities usually need repetition of the information.

Language Development

- Recognize that students with special needs and/or developmental disabilities may have delayed language development.
 - Use concrete basic language when giving instructions. Use simple sentences. Avoid giving more than one instruction per sentence.
 - ☆ Check with the student to make sure he/she understands directions given.
 - Refer to speech pathologist.
- Sign language.
 - Sign language may be helpful to teach children with special needs and/or developmental disabilities even when they do not have a hearing loss.

Managing Hyperactivity and Attention Deficit

- Provide structure and predictable routine.
- Implement as few rules as possible and only the rules you are willing to enforce.
- Allow students to sit in their chairs as comfortably as possible. Rapidly growing students are unable to maintain strict posture and enforcing it can be frustrating for both teachers and students.
- Limit time frames for one activity to no more than 30 minutes if possible.
- \(\bar{\sqrt{e}} \) Keep the environment structured.
- ♦ Make a picture calendar.
 - Make a board with hooks.
 - A Laminate pictures of activities for the whole day.
 - Have a picture of a child taking jacket off and hanging up the jacket.
 - ₩ Have a picture of a child putting puzzle together.
 - As the child completes each activity during the day, the child would take the picture off the hook, turn it over, and hang the picture back on the hook. The child knows he or she has completed the activity.
- Make lists for the student to follow during the day.
 - ☆ "Read story starting on page 30 in the Reading Book."
 - "Do worksheet on page 10 in the Reading Workbook."
 - Read about rocks starting on page 15 in the Science Book."



- Students may need to have the list taped to their desk.
- ⇔ Some students with special needs and/or developmental disabilities may have difficulty relating chalk board instructions to their own behavior.
- ♦ Place each activity in two baskets.
 - Have two baskets for a puzzle, two baskets for a pegboard, two baskets for a matching activity, two baskets for lacing cards, two baskets for scissors and paper activity, etc. Having one activity in one set of baskets will help keep the child's attention on the activity for a longer period of time.
 - Take the activity out of the "start" basket and when the child has finished the activity, the child puts the activity in the "finish" basket.
- Skeep the designated activities in the same place. The child will know where to return the activity when he/she is finished with the activity.
- \$\triangle\$ Shelves and book cases should be enclosed if possible to eliminate visual distraction.
- Use vivid colors to emphasize important concepts. Emphasize with sound and movement the factors that complement the learning objectives.
- During organized activities, hyperactive students need structure.
 - Students need sequence of activity.
 - Students need to know what is expected of them.
 - Students need to know what behaviors will be acceptable.
 - Examples "During this activity we will stay in our chairs."
 - \$\times\text{"There will not be any talking."}
 - ∜ "Keep your eyes on your own paper."
 - "If you want help, raise your hand and I will come to you."
- \$\text{Loosely structured activities must be balanced with highly structured activities to give the student opportunity to move about, visit, relax, etc.
- Structure the day alternating quiet time, active time, quiet time, active time, etc.
- ♥ Tantrums.
 - Remain calm and quiet. Teacher's body language should not get the student excited. Talk in a calm voice, walk slowly. If the teacher is relaxed, this will help the student relax.
 - Let the student know there is a protocol for loss of control.
 - Taking the student's hand and holding it a short time will give the student a signal that the teacher thinks the student is losing control.
 - \$\forall \text{ If restraint is necessary, the teacher needs to exercise care and control.}
 - Talk to the student, telling him/her that you are helping him/her to control his/her behavior.

 - Are you feeling better?"
 - ☆ Take the student to a different room if necessary.
 - Soft music and soft colors in a room may help calm the student.
 - ♥ Talk to the student in a calm, soft voice.
 - Ask the student to tell the teacher when he/she is ready to go back to the classroom.
 - Determine what happened before the tantrum occurred.
 - \$\to\$ Look for the antecedents to the behavior.
 - Antecedents are the events/things that happen which help the student lose his/her temper.
 - Look at different ways to eliminate the chances of the student throwing a tantrum.
 - If the student has an extremely difficult time with loud noises and lots of activity, the student should be taught in a relatively quiet and calm area.

- Another way of reducing the likelihood of the student having a tantrum is to teach the student new ways of dealing with his/her stress. Teach the student to say "I'm mad."
- \$\to\$ Observe the child for any health problems.
 - Ear infections, child may pull at his/her ears.
 - Ask the child to "Show me where you hurt."
 - - ♦ Abnormal head posturing.
 - ♥ Squinting.
 - ⇔ Holding paper close to face.
 - \$\to\$ Obvious errors made when working from the chalk board.
- Ignore negative behavior whenever possible. Avoid overreacting to negative behavior.
- ♥ Build a positive reinforcement.
 - As the child finishes each activity, give student positive reinforcement for his/her efforts in completing the activity.
 - When the child does a good job on a project, tell the student what he/she did right. "You read the whole story."

Math

- Math seems to be the more difficult subject for students with special needs and/or developmental disabilities.
- Memorizing the multiplication table may not be successful with all students who have special needs and/or developmental disabilities. Division may also be a difficult concept.
- Teach functional math money, time, addition, subtraction.
- Encourage student to use strategies for counting fingers, counting tools, etc.
 - A calculator may assist in teaching students with special needs and/or developmental disabilities.
 - These techniques should not be the first choice but should not be ruled out if they can benefit the student's ability to learn math.

Reading

- Some students may have difficulty focusing their eyes on the left side of the page and moving their eyes to the right.
 - ★ If a student uses a piece of paper to follow the line across the page, the student may have an easier time reading.
- Use books with simple, plain pictures. Small detailing marks in a picture can distract the student.
- \$ Encourage reading for enjoyment and developing independence.
 - incorporate popular magazines, newspapers, school paper, etc. into reading program.
 - Emphasize reading as a means to communications. Note writing, letter writing, memos, posters, etc.



Sensory Stimulation

- Use as much sensory stimulation as possible to teach each concept.
- ☼ Teaching activities must be "concrete."
 - Provide hands on materials whenever possible.

 - Allow students to make concrete choices. Example "Which one do you want?"
 - - ♥ This question is very abstract.
 - Give student choices he/she can see, feel, touch and hear.

Social Behavior

- Teachers need to consult the school counselor. It is important that teachers work together using complimentary techniques to serve the student in the following areas:
 - inappropriate sexual behavior,
- Be emphatic, firm and realistic about expectations and performance from students.
- Treat students with special needs and/or developmental disabilities as valuable, worthwhile human beings with gifts to share. All students see teachers and other school personnel as role models and will follow the examples they set.

Vocational Education

- \$\times\$ Continue practicing the basic skills necessary to live independently as adults.
 - Academics.

 - Survival skills.
- Basic skills should be generalized to a variety of settings.
 - Use a variety of stimulus to elicit behavior.

 - Use a variety of personnel.
- Curriculum should focus on recognizing and coping with being labeled as "different."
- Urriculum should focus on assisting student to function as social human beings.

 - A Taking on responsibilities.
 - A Making decisions and realizing their consequences.
- Developing and practicing independent living skills within a group setting getting along with others in the same living space, sharing responsibilities, cooking, personal hygiene, etc.
- Urriculum should focus on assisting students to function in the world of work.
 - A Identify individual interests and aptitudes.
 - Develop self scheduling skills, community mobility skills, rule governed behavior, etc.



Websites

The ABC's of FAS/FAE: Teacher's Guide and Resource Booklet http://www.lcsc.edu/education/fas/

Al-Anon/Alateen

http://www.al-anon-alateen.org

Alcohol Related Birth Injury (FAS/FAE) Resource Site http://www.arbi.org

Alcoholics Anonymous

http://www.alcoholics-anonymous.org

The Arc of the United States

http://thearc.org

American Association on Mental Retardation http://www.aamr.org

The Arc's Fetal Alcohol Syndrome Resource Guide http://www.thearc.org/misc/faslist.html

Arium

http://www.arium.org

Center for Disabilities

http://www.usd.edu/cd

Centers for Disease Control and Prevention (CDC)

http://www.cdc.gov

Center for Substance Abuse Prevention (CSAP)

http://www.prevention.samhsa.gov

Family Empowerment Network (FEN)

www.dcs.wisc.edu/pda/hhi/fen/

Family Village - Waisman Center - University of Wisconsin, Madison http://www.familyvillage.wisc.edu/index.htmlx

FASlink - Fetal Alcohol Syndrome Information, Support & Communication Link http://www.acbr.com/fas/index.htm

FAS World

http://www.fasworld.com

Fetal Alcohol and Drug Unit at the University of Washington, Seattle http://depts.washington.edu/fadu

Fetal Alcohol Syndrome and Adoption Implications http://www.adopting.org/rwfas.html

Fetal Alcohol Syndrome at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control http://www.cdc.gov/ncbddd/fas/

Fetal Alcohol Syndrome Community Resource Center http://www.come-over.to/FASCRC

Fetal Alcohol Syndrome Diagnosis & Prevention Network at the University of Washington, Seattle http://depts.washington.edu/fasdpn

Fetal Alcohol Syndrome Family Resource Institute (FAS*FRI) http://www.fetalalcoholsyndrome.org

Fetal Alcohol Syndrome at National Center On Birth Defects and Developmental Disabilities part of the Centers for Disease Control http://www.cdc.gov/ncbddd/fas/default.htm

Four-State Consortium on Studies in the Prevention of Fetal Alcohol Syndrome/ Fetal Alcohol Effect http://www.usd.edu/fourstatefasconsortium

March of Dimes Birth Defects Foundation http://www.modimes.org

Medical Mailbox - Children's Health http://www.medicalmailbox.com/childrens_health.htm

MEDLINE Plus at the National Library of Medicine - Fetal Alcohol Syndrome http://medlineplus.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html

Minnesota Organization on Fetal Alcohol Syndrome http://www.mofas.org

National Center for Education in Maternal and Child Health (NCEMCH) http://www.ncemch.org

National Clearinghouse for Alcohol and Drug Information (NCADI) http://www.health.org

National Institute on Alcohol Abuse & Alcoholism (NIAAA) http://www.niaaa.nih.gov

National Organization on Fetal Alcohol Syndrome (NOFAS) http://www.nofas.org

The National Women's Health Information Center http://www.4woman.gov

The Office on Women's Health in the United States Department of Health and Human Services http://www.4woman.gov/owh/index.htm

South Dakota Division of Drug and Alcohol Abuse http://www.state.sd.us/dhs/ada/index.htm

South Dakota Office of Special Education http://www.state.sd.us/deca/SPECIAL/special.htm

Substance Abuse and Mental Health Services Administration (SAMHSA) http://www.samhsa.gov

Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers from the British Columbia Ministry of Education http://www.come-over.to/SpecialEdFAS/contents.htm

"What is Fetal Alcohol Syndrome?" - State University of New York, Potsdam http://www2.potsdam.edu/alcohol-info/FAS/FAS.html

Please Note: Inclusion of websites in the *Fetal Alcohol Syndrome Handbook* does not imply endorsement by the Center for Disabilities, The University of South Dakota (USD), the USD School of Medicine, or the USD School of Medicine Department of Pediatrics. Content of the websites listed in the *Fetal Alcohol Syndrome Handbook* is the sole responsibility of the authors of the website.



Organizations

Al-Anon/Alateen

1200 Corporate Landing Parkway Virginia Beach, Virgina 23454-5617 Phone - (757) 563-1600 For Meeting Information - (888) 425-2666 Website - www.al-anon-alateen.org The purpose of Al-Anon/Alateen is "to help families and friends of alcoholics recover from the effects of living with the problem drinking of a relative or friend. Similarly, Alateen is our recovery program for young people. Alateen groups are sponsored by Al-Anon members."

Alcoholics Anonymous (AA)
Grand Central Stations
P.O. Box 459
New York, New York 10163
Phone - (212) 870-3400
Website - www.alcoholics-anonymous.org
Or check your local Yellow Pages for AA.

"Alcoholics Anonymous (AA) is a fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism. AA is not allied with any sect, denomination, politics, organization or institution; does not wish to engage in any controversy; neither endorses nor opposes any causes. Our primary purpose is to stay sober and help other alcoholics to achieve sobriety."

American Association on Mental Retardation (AAMR)

444 North Capitol Street, NW, Suite 846 Washington, DC 20001-1512 Phone - (202) 387-1968 or (800) 424-3688 Website - www.aamr.org The American Association on Mental Retardation "(AAMR) promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities."

The Arc of the United States 1010 Wayne Avenue, Suite 650 Silver Spring, Maryland 20910 Phone - (301) 565-3842 Website - www.thearc.org "The Arc of the United States works through education, research and advocacy to improve the quality of life for children and adults with mental retardation and related developmental disabilities and their families and works to prevent both the causes and the effects of mental retardation."

Canadian Centre on Substance Abuse

75 Albert Street, Suite 300 Ottawa, Ontario, Canada K1P 5E7 Phone - (613) 235-4048 Website - <u>www.ccsa.ca</u> "A non-profit organization working to minimize the harm associated with the use of alcohol."

Center for Disabilities Department of Pediatrics The University of South Dake

The University of South Dakota School of Medicine 1400 West 22nd Street Sioux Falls, South Dakota 57105 Phone - (605) 357-1439 Toll-Free - (800) 658-3080 Website - www.usd.edu/cd The Center for Disabilities works with others creating opportunities that improve the lives of persons with disabilities and those they consider their families. The Center for Disabilities creates opportunities through training, technical assistance, services, information and research.

Center for Substance Abuse Prevention (CSAP)

Substance Abuse and Mental Health Services Administration 5600 Fishers Lane Rockville, Maryland 20857 Phone - (301) 443-0365 Website - www.prevention.samhsa.gov "The Center for Substance Abuse Prevention (CSAP) is the sole Federal organization with responsibility for improving accessibility and quality of substance abuse prevention services. The Center provides national leadership in the development of policies, programs, and services to prevent the onset of illegal drug use, underage alcohol and tobacco use, and to reduce the negative consequences of using substances."

Family Empowerment Network (FEN)

610 Langdon St., Room 517 Madison, Wisconsin 53703-1195 Phone - (800) 462-5254 or (608) 262-6590 Website - www.dcs.wisc.edu/pda/hhi/fen/ The Family Empowerment Network (FEN) is "a national organization serving families affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects as well as the professionals involved in their lives."

Fetal Alcohol Syndrome Family Resource Institute (FAS*FRI)

P.O. Box 2525
Lynnwood, Washington 98036
Phone - (253) 531-2878 or
in Washington state (800) 999-3429
Website - www.fetalalcoholsyndrome.org

"The mission of the FAS Family Resource Institute, a non-profit organization, is to identify, understand and care for individuals disabled by prenatal alcohol exposure and their families, and to prevent future generations from having to live with this disability."

Join Together

441 Stuart Street 7th floor Boston, Massachusetts 02116 Phone - (617) 437-1500 Website - <u>www.jointogether.org</u> "Join Together, founded in 1991, supports community-based efforts to reduce, prevent, and treat substance abuse across the nation."

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue White Plains, NY 10605 Phone - 888-MODIMES (663-4637) Website - www.modimes.org "The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. [They] support this vital mission through four programs: community services, advocacy, education and research."

National Center for Education in Maternal and Child Health (NCEMCH)

2000 15th Street North Suite 701 Arlington, Virginia 22201-2617 Phone - (703) 5247802 Website - www.ncemch.org "The National Center for Education in Maternal and Child Health [NCEMCH] provides national leadership to the maternal and child health community in three key areasprogram development, education, and state-of-the-art knowledge--to improve the health and well-being of the nation's children and families."

National Clearinghouse for Alcohol and Drug Information (NCADI) P.O. Box 2345

Rockville, Maryland 20847-2345 Phone - (800) 729-6686 or (301) 468-2600 Website - www.health.org "Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Clearinghouse for Alcohol and Drug Information (NCADI) is the Nation's one-stop resource for the most current and comprehensive information about substance abuse prevention and treatment. NCADI is one of the largest Federal clearinghouses, offering more than 500 items to the public, many of which are free of charge."

National Institute on Alcohol Abuse & Alcoholism (NIAAA) 6000 Executive Boulevard

Willco Building
Bethesda, Maryland 20892-7003
Website - www.niaaa.nih.gov

"The National Institute on Alcohol Abuse and Alcoholism (NIAAA) [an institute of the National Institutes of Health] supports and conducts biomedical and behavioral research on the causes, consequences, treatment, and prevention of alcoholism and alcohol-related problems"

National Organization on Fetal Alcohol Syndrome (NOFAS) 216 G Street, North East Washington, DC 20002 Phone - (202) 785-4585 Website - www.nofas.org

The National Organization on Fetal Alcohol Syndrome (NOFAS) "is committed to raising public awareness of Fetal Alcohol Syndrome (FAS)—the leading known cause of mental retardation—and to developing and implementing innovative ideas in prevention, intervention, education and advocacy in communities throughout the nation."

South Dakota Division of Alcohol and Drug Abuse

East Highway 34, Hillsview Plaza c/o 500 East Capital Avenue Pierre, South Dakota 57501 Phone - (605) 773-3123 Website - www.state.sd.us/dhs/ada/index. htm The mission of the South Dakota Division of Alcohol and Drug Abuse is "to reduce the prevalence of substance abuse disorders through prevention and treatment services." If you don't live in South Dakota, please contact the Division of Alcohol and Drug Abuse or similar agency in your state.

South Dakota Office of Special Education

700 Governors Drive Pierre, South Dakota 57501-2291 Phone - (605) 773-3678 Website - <u>www.state.sd.us/deca/SPECIAL/special.htm</u>

"The Office of Special Education, located in the South Dakota Department of Education and Cultural Affairs, advocates for the availability of the full range of personnel, programming, and placement options, including early intervention and transition services, required to assure that all individuals with disabilities are able to achieve maximum independence upon exiting from school." If you don't live in South Dakota, please contact the Office of Special Education in your state.

Substance Abuse and Mental Health Services Administration (SAMHSA) 5600 Fishers Lane Rockville, Maryland 20857 Website - www.samhsa.gov The Substance Abuse and Mental Health Services Administration (SAMHSA) "is the Federal agency charged with improving the quality and availability of prevention, treatment, and rehabilitative services in order to reduce illness, death, disability, and cost to society resulting from substance abuse and mental illnesses."

Please Note: Inclusion of organizations in the *Fetal Alcohol Syndrome Handbook* does not imply endorsement by the Center for Disabilities, The University of South Dakota (USD), the USD School of Medicine, or the USD School of Medicine Department of Pediatrics. Actions of the organizations listed in the *Fetal Alcohol Syndrome Handbook* are the sole responsibility of the organization and its employees.



Books

- Adoption and Prenatal Alcohol and Drug Exposure: Research, Policy and Practice editors R. Barth, M. Freundlich and D. Brodzinsky, 2000
- <u>Alcoholism Sourcebook</u> editor Karen Bellenir, 2000 (Includes information on Fetal Alcohol Syndrome)
- <u>Alcohol, Pregnancy and the Developing Child</u> editors Hans-Ludwig Spohr and Hans-Christoph Steinhausen, 1996
- American Indian Health: Innovations in Health Care, Promotion, and Policy editor Everett R. Rhoades, 2000 (Includes information on Fetal Alcohol Syndrome)
- Assessing Students with Special Needs by John Venn, 2000
- Assessment & Resource Guide for FAS/FAE * by Mary Wegman, et al., 1995
- <u>Assessment in Special Education: A Practical Approach</u> by Roger Pierangelo and George A. Guilianai, 2002
- The Best I Can Be: Living with Fetal Alcohol Syndrome or Effects by Liz Kulp with Jodee Kulp, 2000
- The Broken Cord * by Micheal Dorris, 1989
- Born Hooked: Poisoned in the Womb editor Gary E. McCuen, 1994
- Bruised Before Birth: Parenting Children Exposed to Parental Substance Abuse by Amy Bullock, Elizabeth Grimes and Joan McNamara, 1995
- <u>Building Cultural Reciprocity with Families: Case Studies in Special Education</u> by Beth Harry, Maya Kalyanpur and Monimalika Day, 1999
- <u>The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities</u> editors Ann Streissguth and Jonathan Kanter, 1997
- <u>Children with Fetal Alcohol Syndrome: A Handbook for Caregivers</u> developer Lisa Gerring, 1993
- <u>Children with Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption</u> by Susan B. Edelstein with contributions from Judy Howard, 1995

- <u>Collaborative Strategies for Accommodating Diverse Learning Styles</u> by Alice Udvari-Solner and Julie Fentz, 1997
- <u>Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services</u> * by Beverly Rainforth and Jennifer York-Barr, 1997
- Commonsense Methods for Children with Special Needs: Strategies for the Regular Classroom by Peter Westwood, 1997
- Congenital Disorders Sourcebook: Basic Information About Disorders Acquired During Gestation editor Karen Bellenir, 1997
- Coping with a Learning Disability by Lawrence Clayton, 1999
- Creating Collaborative IEPs: A Handbook * editor Kate Wallace McCoy, 1998
- <u>Curriculum Adaptations for Students with Learning and Behavior Problems: Principles and Practices</u> * by John J. Hoover and James R. Patton, 1997
- <u>Developing and Implementing IDEA-IEPs: An Individualized Education Program (IEP)</u>

 <u>Handbook for Meeting Individuals with Disabilities Education Act (IDEA)</u>

 Requirements by Edward Burns, 2001
- <u>Does the Owl Still Call Your Name? Paths of Struggle and Renewal</u> by Bruce Brand, 2000 (Includes the chapter "Do the Effects of Fetal Alcohol Syndrome Still Haunt You?")
- <u>Effective Instruction for Special Education</u> by Margo A Mastropieri and Thomas E. Scruggs, 2002
- Everything You Need to Know About the Dangers of Binge Drinking by Magdalena Alagna, 2001
- Exceeding the Boundaries: Understanding Exceptional Lives by Judy W. Wood and Andrea M. Lazzari, 1997
- <u>Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome</u> editors Judith Keinfeld with Barbara Morse and Siobhan Wescott, 2000
- <u>Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome</u> * editors Judith S. Kleinfeld and Siobhan Wescott, 1993
- FAS: Parent and Child * by Barbara A. Morse and Lyn Weiner, 1993
- FAS: Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living by Sara Gaefe, 1998

- Fetal Alcohol Syndrome * by Ernest L. Abel, 1990
- Fetal Alcohol Syndrome by Amy Nevitt, 1996
- <u>Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Profesionals</u> by Diane Malbin, 1993
- <u>Fetal Alcohol Syndrome and the Criminal Justice System</u> by Julianne Conry and Diane K. Fast, 2000
- <u>Fetal Alcohol Syndrome and Other Alcohol-Related Birth Defects</u> by Kathy Huebert and Cindy Raftis, 1996
- <u>Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment</u> *
 Committee to Study Fetal Alcohol Syndrome, Division of Biobehavioral Science and Mental Disorders, Institute of Medicine, 1996
- Fetal Alcohol Syndrome: From Mechanism to Prevention editor Ernest L. Abel, 1996
- <u>Fetal Alcohol Syndrome: A Guide for Families and Communities</u> * by Ann Streissguth, 1997
- Getting Comfortable with Special Education Law: A Framework for Working with Children with Disabilities by Dixie Snow Huefner, 2000
- Group Activities to Include Students with Special Needs: Developing Social Interactive Skills by Julia Wilkins, 2001
- Guide to Writing Quality Individualized Education Programs: What's Best for Students with Disabilities? by Gordon S. Gibb and Tina Taylor Dyches, 2000
- A History of Childhood and Disability * by Phillip L. Safford and Elizabeth J. Safford, 1996
- Improving the Implementation of the Individuals with Disabilities Education Act:

 Making Schools Work for All of America's Children * National Council on Disability,
 1995
- <u>Inclusion: 450 Strategies for Success: A Practical Guide for All Educators Who Teach</u>
 <u>Students with Disabilities</u> by Peggy A. Hammeken, 1995
- <u>Interactive Teaming: Enhancing Programs for Students with Special Needs</u> by Carol Chase Thomas, Vivian Ivonne Correa and Catherine Voelker Morsink, 2001
- <u>Issues in Educating Students with Disabilities</u> editors John Wills Lloyd, Edward J. Kameenui and David Chard, 1997

- The LD Child and the ADHD Child: Ways Parents and Professionals Can Help by Suzanne H. Stevens, 1996
- <u>The Least Restrictive Environment: Its Origins and Interpretations in Special Education</u> by Jean B. Crocket and James M. Kauffman, 1999
- <u>The Mother's Survival Guide to Recovery: All About Alcohol, Drugs & Babies</u> by Laurie L. Tanner, 1996
- <u>The Paraprofessional's Guide to the Inclusive Classroom: Working as a Team</u> * by Mary Beth Doyle, 1997
- <u>Parental Involvement: A Practical Guide for Collaboration and Teamwork for Students</u> <u>with Disabilities</u> by George Taylor, 2000
- <u>Prenatal Exposure to Drugs/Alcohol: Characteristics and Educational Implications of Fetal Alcohol Syndrome and Cocaine Polydrug Effects</u> by Jeanette M. Soby, 1996
- Reaching Out to Children with FAS/FAE: A Handbook for Teachers, Counselors, and Parents Who Work with Children Affected by Fetal Alcohol Syndrome & Fetal Alcohol Effect by Diane Davis, 1994
- Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook by Brenda McCreight, 1997
- Socialization and Sexuality: A Comprehensive Training Guide for Professionals Helping
 People with Disabilities that Hinder Learning * by Winifred Kempton with Toni Davies and
 Lynne Stiggall-Muccigrosso, 1998
- Students with Mild Disabilities in General Education Settings: A Guide for Special Educators by Ada L. Vallecorsa, Laurie U. deBettencourt and Naomi Zigmond, 2000
- <u>Teaching Children Affected by Prenatal Drug Exposure</u> * editor Barbara J. Seitz de Martinez, 1995
- <u>Understanding Fetal Alcohol Syndrome</u> * editor Barbara J. Seitz de Martinez, 1995
- What Do I Do When? The Answer Book on Special Education Law * by Susan Gorn, 1997
- Women and Alcohol: Contemporary and Historical Perspectives by Moira Plant, 1997
- Women and Alcohol: Issues for Prevention Research by Jan M. Howard, et. al., 1996
- Women and Alcohol, A Private Pleasure or a Public Problem? by E. Ettorre, 1997

Young Children with Special Needs by Warren Umansky and Stephen R. Hopper, 1998

* - Books marked with an "*" are available from the Wegner Health Science Information Center. The Center for Disabilities is a partner in the Wegner Health Science Information Center. For information on borrowing one of these books, call the Center for Disabilities at (800) 658-3080 (Voice/TTY) or (605) 357-1439 or stop by the Wegner Health Science Information Center at 1400 West 22nd Street, Sioux Falls, South Dakota or contact your local library.

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Videos

Adolescence and Future * "Focuses on two young people with FAS - a 13-year old boy and a 22-year old woman. examines the skills and attitudes parents need in order to work with FAS/FAE children." Alcohol and Other Drugs * Produced by the Wisconsin Counseling Association Alcohol and Pregnancy * "Through candid interviews, it presents a realistic look at the daily struggles of the FAS/FAE child and his parents or caregivers. The interviews, featuring a diverse group of children, teenagers, biological parents and foster parents, create a developmental overview of FAS/FAE." Assessment and the Early "A discussion of the symptoms and characteristics of FAS as well as appropriate help and possible interventions." Years * A Challenge to Care "This video addresses prenatal care, labor, delivery and neonatal and postpartum care for women substance abusers." The Broken Cord * "Bill Moyers interviews writers Louise Erdrich and Michael Dorris who talk about their work, their American Indian Heritage, fetal alcohol syndrome, and parenthood." A Different Way of Learning: "Presents an overview of workplace challenges faced by young The Employee with a Learning people with learning disabilities. Explains how disabilities can affect job performance and how to make adjustments." Disability * The Fabulous F.A.S. Quiz Written by Nancy White and Ruth Francis. A video and activities for middle school students to understand Fetal Alcohol Syndrome Show * and Fetal Alcohol Effects Faces Yet to Come * "Designed for American Indian students in the 6th through 8th grade. The program focuses on the prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects." Family Perspectives on "The purpose of this videotape is to bring forward the experiences and wisdom gained by families as they have confronted a rapidly Inclusion Across the changing social milieu for individuals with developmental Lifespan * disabilities."

F.A.S. Series *

"Viewers spend a day with the family and learn what life is like for them. An expert explains why children with FAS/FAE behave in certain ways and offers advice on the best way to handle a typical situation."

Fetal Alcohol Syndrome *

"This video describes aspects of FAS related to the Native Americans of the northern plains."

Fetal Alcohol Syndrome *

"Examines the cause and effect of Fetal Alcohol Syndrome. Profiles an eight-year-old Apache boy with FAS"

Fetal Alcohol Syndrome and Effects: What's the Difference? *

"Presents the physiological effects of fetal alcohol syndrome or fetal alcohol effects as well as the behavioral problems that can arise."

High School Inclusion: Equity and Excellence in an Inclusive Community of Learners *

"Committed to the idea that a school is for all students, the people of Amherst, New Hampshire restructured their concept of education. This program shows the results of their efforts, and give the viewer an insider's perspective on how to make inclusive education work."

How Difficult Can This Be? Understanding Learning Disabilities: Frustration, Anxiety, Tension * "A group experiences life the way a student with a learning disability does and learns methods of teaching and helping such students."

The IEP: A Tool for Realizing Possibilities *

"Highlights the importance and use of the IEP as the basic tool in designing and delivering supports and services for students with disabilities. Useful for building confidence in family members about their vital role in the IEP meeting."

Last Call: The Sobering Truth About FAS/FAE

"This video uses individual interviews showing children with FAS and FAE to encourage women not to drink at all if they are pregnant or even considering becoming pregnant."

Living with FAS/FAE: The Early Years Birth to 12 *

"Explains characteristics of, and disabilities associated with, children from birth to 12 years who are affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects. Describes problems that face their caregivers and educators, and tells of coping and classroom strategies."

Parents' Perspective: Living with a Child who has FAS *

"This video was part of a fetal alcohol training workshop which included reports from parents whose children have Fetal Alcohol Syndrome."

A Pregnant Woman Never Drinks Alone *

Produced by the Bowman Gray School of Medicine, Wake Forest University. Featuring Alice Bell.

Preventing FAS *

"Explains how drinking during pregnancy affects the fetus. Discusses how the mother's drinking may be related to her social environment."

Sebastian *

"Shows the day to day medical care provided by the foster parents of a small boy born with Fetal Alcohol Syndrome."

Students Like Me: Teaching Children with Fetal Alcohol Syndrome "Written, produced and directed by Betsy Anderson for Vida Health Communications to provide assistance to teachers who instruct children with Fetal Alcohol Syndrome."

Living with FAS/FAE: The Early Years Birth to 12 *

"Explains characteristics of, and disabilities associated with, children from birth to 12 years who are affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects. Describes problems that face their caregivers and educators, and tells of coping and classroom strategies."

What is FAS? *

"Describes the possible effects of a woman drinking alcohol during pregnancy and, specifically, Fetal Alcohol Syndrome."

Worth the Trip: Raising and Teaching Children with Fetal Alcohol Syndrome "This comprehensive video resource about the health, development and learning styles of children with Fetal Alcohol Syndrome and Fetal Alcohol Effects is full of practical information and interactive demonstrations."

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Journal Articles

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Medical Science Monitor September-October 2000, Volume 6, Issue 5, Page 1031 J.D. Chaudhuri

"Alcohol and Pregnancy: Highlights from Three Decades of Research" * Journal of Studies on Alcohol September 2001, Volume 62, Issue 5, Page 554 Carrie L. Randall

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Seminars in Neonatalogy August 2000, Volume 5, Issue 3, Page 243 J.H. Hannigan, D.R. Armant

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- * Journal articles marked with an "*" are available from the Wegner Health Science Information Center. The Center for Disabilities is a partner in the Wegner Health Science Information Center. For information on borrowing one of these items, call the Center for Disabilities at (800) 658-3080 (Voice/TTY) or (605) 357-1439 or stop by the Wegner Health Science Information Center at 1400 West 22nd Street, Sioux Falls, South Dakota or contact your local library.

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Glossary of Terms

- **abstract -** 1. An idea or an image of a situation, symbol, or object that can be selected from any specific attributes in an environment. 2. Sometimes used to refer to complex ideas, generally of symbolic origin, that tend to be difficult to understand.
- **aberrant** Wander or deviating from the usual or normal course.
- **acetaldehyde** A compound formed by the action of enzyme systems on ethanol when it is metabolized by the body. It is further metabolized to acetic acid.
- **anomalies** Marked deviations from the normal standard especially as a result of congenital or hereditary deficits.
- **assessment -** 1. A collecting and bringing together of information about a child's learning needs, which may include social, psychological, and educational evaluations used to determine assignment to special programs or services; a process using observation, testing, and test analysis to determine an individual's strengths and weaknesses to plan, for example, his or her educational services. Also referred to in some instances as "evaluation". 2. As related to early childhood programs, assessment is the ongoing observations and monitoring of progress by qualified personnel throughout the period of a child's eligibility to identify the child's unique needs; the family's strengths and needs related to development of the child; and, the nature and extent of early intervention services that are needed by the child and the child's family to meet the needs of the child.
- **assessment team** A team of people from different areas of expertise who observe and test a child to determine his or her strengths and weaknesses.
- **apnea** Cessation of breathing.
- **Attention Deficit** (**Hyperactivity**) **Disorder** (**ADD**, **ADHD**) The classification of the DSMIII-R System; inattention, and impulsivity are present before age 7. Attention Deficit Hyperactivity Disorder is the same as Attention Deficit Disorder except emphasis is placed on the hyperactivity. Either ADD or ADHD is acceptable language.
- **Attention Deficit Hyperactivity Disorder (ADHD) -** A condition in which a child exhibits signs of developmentally inappropriate hyperactivity, impulsivity, and inattention. These characteristics are usually present before the age of 7. ADHD is similar to "Attention Deficit Disorder", except emphasis is placed on the hyperactivity.
- **Attention Deficit Disorder (ADD)** A condition characterized by when a person is easily distracted and has difficulty staying focused on an individual activity for any period of time. ADD affects 3-5% of all students, and is not recognized as a separate category of disability under federal educational legislation (IDEA). See also "Attention Deficit Hyperactivity Disorder" as these terms are often used interchangeably.

- **basal ganglia** A group of structures deep inside the brain that are involved in movement and cognition.
- **camptodactyly** One or more fingers constantly flexed at one or more joints. Permanent bending of fingers and toes.
- **caregivers -** Any persons who have input into the care of the child: babysitter, extended family, day care workers, hospital workers (nurses, aides, etc.).
- **cent ral nervous system (CNS)** The brain and spinal cord.
- **cerebellum** The largest portion of the brain; involved in controlling consciousness, voluntary processes, and cognition.
- **clinodactyly** Abnormal bending of fingers and toes. Permanent bending either medial or lateral, of one or more fingers and toes.
- **cognitive -** A term that describes the process people use for remembering, reasoning, understanding, problem solving, evaluating, and using judgment. Cognition more simply, is what a person or child knows and understands, or the process of knowing.
- **cognitive development -** The development of skills necessary for understanding and organizing the world, including such perceptual and conceptual skills as discrimination, memory, sequencing, concept formation, generalization, reasoning, and problem solving.
- **cognitive functioning -** Refers to the level of proficiency in thinking, processing information, and knowledge.
- **concrete -** Describes an idea or an image of a situation, symbol or object that can be perceived by the senses and derives from an experience that makes it familiar.
- **concrete mode** A person's learning or cognitive style characterized as learning most efficiently by use of objects and tangible items.
- **corpus callosum -** The central tract inside the brain that connects the right and left halves, or hemispheres, of the brain.
- **cyanosis** A bluish discoloration of skin and mucus membranes due to excessive concentration of reduced hemoglobin in the blood.
- congenital Existing at, or dating from, birth.
- **development -** Growing both physically and mentally.
- **developmental** Having to do with the steps or stages in growth and development before the age of 18.
- **diagnosis** 1. Naming the cause of a disorder by looking at its symptoms. 2. The process of identifying specific mental or physical disorders. Some use the term more broadly to refer to a comprehensive evaluation not limited to the identification of specific disorders.

- **dysmorphology** The study of birth defects or malformation in a species.
- **dysmorphologist** One who is knowledgeable about deviations from the physical patterns of development in humans.
- early intervention programs or services Programs or services designed to meet the developmental needs of each eligible infant or toddler and their family under Part H and also to meet the needs of the family as they relate to enhancing the child's development. Such services are designed to (A) identify, assess, and treat developmental disabilities at the earliest possible time to prevent more serious disability; (B) ensure the maximum growth and development of the child; and to (C) assist families in raising a child with a developmental disability.
- **embryo** The fertilized ovum that eventually becomes the offspring during the period of most rapid development. In humans this period is from two weeks after fertilization until the end of the 7th or 8th week, after which time the offspring is known as a fetus.
- **epicanthal folds** A vertical fold of skin on either side of the nose, sometimes covering the inner corner of the eye. It is present as a normal characteristic in persons of certain races and sometimes occurs as a congenital anomaly in others.
- **epidemilogy** The study of the occurrence of a disease in a population and factors which influence it, in order to find ways to prevent the disease.
- **ethanol** Alcohol; a transparent, colorless, mobile, volatile liquid, C2 H2 OH, obtained by the fermentation of carbohydrates with yeast.
- evaluation 1. As applies to educational settings: A way of collecting information (includes testing, observations, and parental input) about a student's learning needs, strengths, and interests. The evaluation is part of the process of determining whether a student qualifies for special education programs and services. 2. A process conducted by mental health professionals that results in an opinion about a child's mental or emotional capacity, and may include recommendations about treatment or placement. See "assessment".
- **facies** The term used in anatomical nomenclature to designate (a) the face; and (b) a specific surface of a body structure, part, or organ.
- **failure to thrive (FTT)** A chronic disorder of infancy and childhood characterized by growth failure, malnutrition and variable degrees of the delay in motor and social development. Possible causes of FTT are varied; illness, oral-motor feeding and swallowing disorders, inadequate food resources and problems with parent-child interaction.
- **fetus** The unborn offspring in the postembryonic period, after major structures have been outlined in humans, from the 7th or 8th week after fertilization until birth.

free appropriate public education (FAPE) - A key requirement of the federal legislation, Public Law 94-142, which requires that special education and related services are provided to all eligible children, and meet the following requires: (a) Are provided at public expense, under public supervision and direction, and without charge; (b) Meet the standards of the state board of education and the laws pertaining thereto; (c) Include preschool, kindergarten, elementary school, and secondary school education; and (d) Are provided in conformity with an individualized educational program (IEP).

gestation - The period of development from the time of fertilization of the ovum until birth.

hirsutism- Abnormal hairiness, especially in women.

hyperactivity - Constant and excessive movement and motor activity.

hypoplastic - Having incomplete development of an organ so that it fails to reach adult size.

hypovolemia - Diminished blood supply.

IEP goals and objectives - The long and short-term behaviors that are the targets of special education or therapeutic intervention. IEP objectives are almost always written in behavioral terms.

IFSP outcomes - Statements of the changes families want to see for their children or themselves.

impulsivity - Acting or speaking too quickly (upon impulse) without first thinking of the consequences.

incidence - The number of new cases of a condition that have been identified within a specific period of time (e.g., one year).

Individualized Educational Program (IEP) - A written education plan for a school-aged child with disabilities developed by a team of professionals (teachers, therapists, etc.) and the child's parents. IEP's are based on a multidisciplinary evaluation of the child, describes how the child is presently doing, what the child's learning needs are, and what services the child will need. They are reviewed and updated yearly. IEP's are required under Public Law 94-142, the Individuals with Disabilities Education Act (IDEA). For children ages birth through 2 years, an IFSP is written.

Individualized Family Service Plan (IFSP) - A plan of intervention for an eligible child (age birth through 2) and his/her family, similar in content to the IEP, which has been developed by a team of people who have worked with the child and family. IFSP's must contain: statements regarding the child's present development level, strengths, and needs; the family's strengths and needs; major outcomes of the plan, a description of the specific interventions and delivery systems to accomplish outcomes, statement of natural environments, name of service coordinator, dates of initiation and duration of services, dates for evaluation of the plan, and a transition plan.

Individuals with Disabilities Education Act (IDEA) - Mandates that states and local divisions provide special education for children with disabilities.

intelligence quotient (IQ) - A score obtained from an intelligence test that provides a measure of mental ability in relation to age.

interdisciplinary team - A team whose members come from multiple disciplines, who interact and rely on the others for information and suggestions.

interdisciplinary - Involving 2 or more academic, scientific or artistic disciplines.

intervention - Action taken to correct, remediate, or prevent identified or potential medical or developmental problems.

maxillary hypoplasia - Incomplete development of the bone of the upper jaw.

mental retardation (MR) - Having significantly subaverage general intellectual functioning (refers to scores obtained on intelligence tests) existing concurrently with deficits in adaptive behavior (refers to a person's adjustment to everyday life) and manifested during the development period, which adversely affects a child's educational performance. Difficulties may occur in learning communication, social, academic, vocational, and independent living skills.

microcephaly - Abnormal smallness of the head, usually associated with mental retardation.

microphthalmos - Abnormal smallness of the eyes.

motility - The ability to move spontaneously.

multidisciplinary evaluation/assessment (MDE) - An evaluation of a child's strengths and weaknesses from a variety of professional vantage points using a number of different sources of information, and involving the child's parents. Typically, the child's present levels of physical, neurological, cognitive, speech and language, psychosocial development, and self-help skills are assessed.

multidisciplinary - Refers to 2 or more professionals (like educators, psychologists, and others) working together and sharing information in the evaluation, assessment, and development of an IFSP or IEP.

neonatal - The first four weeks after a child's birth.

neonate - A newborn under 28 days of age.

palmar crease - Any of the normal grooves across the palm which accommodates flexion of the hand. In certain congenital anomalies there is only a single transverse crease.

palpebral fissure - The longitudinal opening between the eyelids.

parity - The number of live births that a woman had delivered.

pathogen - A specific causative agent of the disease.

perinatal - The period shortly before and after birth, generally considered to begin with completion of 28 weeks of gestations and ending 1 to 4 weeks after birth.

- **phenotype** The environmentally and genetically determined observable appearance of an individual especially when considered against all other possible genetic possibilities.
- **philtrum** The vertical groove in the middle of the upper lip.
- **placenta** An organ surrounding the fetus during pregnancy which joins the mother and offspring and supports growth and development during gestation.
- postnatal Occurring after birth.
- **prenatal:** The time before birth, while a baby is developing during pregnancy. The period of time between the conception and birth of an infant.
- **prevalence:** The number of persons in any given population who exhibit a condition or problem at a specific point in time.
- **ptosis** Drooping of the upper eyelids.
- **strabismus** Deviation of the eye which the patient cannot overcome without treatment. The inability of both eyes to focus on one object.
- **syndactyly** Fingers or toes joined together. A fusion of two or more toes or fingers.
- **syndrome** A group of symptoms that characterize a disease or pathological entity.
- **tachycardia** Accelerated pulse. Abnormal rapidity of heart action.
- **teratogen** An agent or factor that causes physical defects in the developing embryo.
- **toxemia** A metabolic disturbance in pregnancy characterized by hypertension, albuminuria, and edema.
- **trimester** The three terms or periods of three months each into which the nine months of pregnancy can be divided.
- **vermilion** A bright red pigment.

For more definitions, check out the <u>Dictionary: For Parents of Children with Disabilities</u> available on the Center for Disabilities website. The dictionary contains definitions for words related to testing/evaluation, early intervention, special education and related services, medical and therapeutic services, family supports and resources, vocation training, independent living, guardianship and insurance. Visit the Center for Disabilities website and check out the <u>Dictionary: For Parents of Children with</u> Disabilities at www.usd.edu/cd/dictionary>.