Fetal Alcohol Syndrome: A Guide for Caregivers

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Purpose

The purpose of this thesis is to provide a comprehensive, reliable, and readable resource for caregivers of children with Fetal Alcohol Syndrome (FAS). Those with FAS suffer severe physical, emotional, and intellectual damage from infancy through adulthood. The impact of the syndrome on the life of the people involved can be lessened, but FAS must first be diagnosed. Once diagnosed, it is important to recognize general developmental patterns seen in people with FAS in order to plan appropriately. Also, resources must be tapped at various stages of development in order to help the child to grow into the most independent, emotionally stable adult possible. This thesis explores these aspects of FAS; providing developmental milestones and hurdles common to people with FAS, treatments that seem to be effective, and sources of support, both financial and emotional.
severity from the distinct facial characteristics of FAS to autism and epilepsy. For the natural or surrogate families, the effects of alcohol range from the emotional upheaval of dealing with a special child to the physical stress of twenty-four hour supervision. Some of these effects are obvious at birth; others do not surface until much later. No matter how many of its effects are evident, no matter how severe the syndrome, FAS does not go away. It has to be dealt with by the child and the family everyday, for life.

The permanence of FAS is the motivation behind this guide. The goal of this guide is to provide a comprehensive, reliable and readable resource for caregivers of children with FAS. It is to provide developmental milestones and hurdles common to children with FAS, treatments that seem to work, and sources of physical, financial and emotional support.
Diagnosis

On the playground . . . his classmates taunt him about his eerily flat face, with narrow, wide-set eyes and smooth upper lip. Although he will be thirteen on August twenty-seventh [1989], Jay . . . has difficulty reading and doing rudimentary arithmetic. And because he has trouble controlling his actions and emotions, the youngster cannot be left alone (Steacy, Brosnahan, Fraser, and Wolff, 1989, p. 48).

It would seem that the diagnosis of Fetal Alcohol Syndrome (FAS) could occur before conception, at least in the case of the chronically alcoholic mother. In many instances, however, whether it be due to the lack of knowledge of the mother's drinking history or the lack of awareness on the part of the physician, many children born with FAS are not diagnosed until much later. In addition, a large number of children are never diagnosed.

There are many reasons why an affected child might not be diagnosed with FAS. One reason that many physicians do not detect FAS is uncertainty regarding the mother's drinking history (Burgess and Streissguth, 1992). Another reason is that not all physicians are familiar with FAS. A physician may know what FAS is, but s/he may never have seen anyone with the syndrome. Some physicians do not believe that they will ever see a patient with FAS in their practice, whether it be due to bias based on the
size of the community, the socio-economic level of the area, or the ethnicity of their patients (Dorris, 1989). An additional reason for babies not being diagnosed is that the most distinct characteristic of FAS, the facial features, is difficult to distinguish in infancy, and is less pronounced in cases that are less severe (Rosett and Weiner, 1984). Although an infant cannot be diagnosed with FAS in utero, the physician's knowledge of the mother's drinking habits can greatly increase the likelihood of appropriate diagnosis shortly after birth.

There are specific signs to look for in the diagnosis of FAS in infancy. Some of the most obvious signs are those associated with alcohol withdrawal. In severe cases of FAS, infants show signs of withdrawal similar to those seen in adult alcoholics (Plunkett, 1990). They may sweat excessively, tremble, seem overly anxious, and have frightening hallucinations. This group of withdrawal effects, known as Delirium Tremens (DT's) are common among heavy drinkers who are suddenly cut off from alcohol (Streissguth, et al., 1988). Additional signs of alcohol withdrawal that are often seen in newborns with FAS include irritability, excessively rapid breathing (tachypnea), and extreme tension or spasticity of muscles (hypertona) (Beattie, 1992).

Regardless of whether or not an infant displays the signs mentioned above, there are three criteria that must be met at any age in order for a person to be diagnosed with FAS. These criteria include a growth deficiency, central nervous system
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(CNS) dysfunction, and the presence of two out of three distinct facial characteristics (Rosett and Weiner, 1984).

The first characteristic of FAS is the presence of a pre- or post-natal growth deficiency. This means that babies with FAS may be short in length. They may have a low birth weight. The average weight of an infant with FAS at birth (with correction for prematurity), is only 4 pounds and 8.5 ounces (Beattie, 1992) as compared to the average for the general population of 7 pounds and 7 ounces (Abel, 1990). They may have a small head circumference. The circumference of the baby's head must be at, or below, the third percentile, smaller than 97 out of 100 babies of the same age, as determined by national averages (Beattie, 1992). These measures are all relative to national averages for infants of the same age, given corrections for prematurity (Giunta and Streissguth, 1988).

The second criterion, CNS dysfunction, includes disorders of the brain (e.g. mental retardation and emotional disturbance), or the spinal cord (e.g. spina bifida and paraplegia). CNS dysfunction may or may not be detected at birth. Spinal cord disorders are generally recognizable, but brain dysfunction may only be evidenced subtly. Some examples of these subtle indicators include excessive crying, exaggerated mouthing behavior, irritability, fitful sleep and abnormal brain activity (seizures) as recorded on an electroencephalogram (EEG) (Beattie, 1992).
Newborns with FAS may suffer from withdrawal symptoms, such as periods of panic and agitation, and constant trembling (Beattie, 1992). In addition, they may be irritable and cry more often than other infants (Streissguth et al., 1988).

Rosett and Weiner (1984), in their book *Alcohol and the Fetus: A Clinical Perspective*, discussed some of the more common forms of CNS dysfunction found in patients with FAS. Autopsies revealed that people with FAS commonly have thin sheets of malformed neural tissue that cover part of the brain's surface (leptomeningeal neuroglia). Another common finding was the absence or immaturity of the corpus callosum, the part of the brain that connects the two cerebral hemispheres. This condition is called agenesis corpus callosum. Microcephaly, or small brain size, which is indicated by small head circumference, was also found to be very common in patients with FAS. Microcephaly is generally associated with mental retardation. Finally, Rosett and Weiner reported that neural tube defects, such as spina bifida, ranging from mild to severe are found in some patients with FAS.

The third criterion is the presence of at least two of the following three facial feature anomalies. One is the small head circumference mentioned earlier. The second anomaly is abnormally small eyeballs (microphthalmia) and/or shortened eye openings (palpebral fissures). The third diagnostic facial anomaly is a poorly developed area between the nose and upper lip.
(philtrum), a thin upper lip, and a flattened upper jaw (maxilla) (Giunta and Streissguth, 1988).

In addition to the three requirements of diagnosis listed above, most physicians will not diagnose FAS without knowing the mother's drinking history (Dorris, 1989). If this information is not obtainable, and the child meets the three criteria for diagnosis, the doctor may label the syndrome as possible Fetal Alcohol Effect (FAE) or Alcohol Related Birth Defects (Dorris, 1989). These are two categories of birth defects associated with parental alcohol consumption that are usually less severe than FAS, although many of the characteristics are similar.

Babies born with FAS enter the world with more physical problems than are considered during the initial diagnosis. These additional characteristics and associated problems are discussed throughout the remainder of the text, as they relate to the development of the child. In addition, a more detailed account of the more severe disorders that commonly accompany FAS can be found in Appendix A.
Development

The development of infants with Fetal Alcohol Syndrome (FAS) into adulthood is more challenging than that of other children. There are many obstacles that make the process more difficult, but there are also resources which may be utilized and people who may be contacted to make development less difficult for the child and the family. In the sections that follow, the development of individuals with FAS will be explored. General information in several areas, such as growth, behavior, and intellectual development, will be discussed through the stages of infancy, preschool, elementary school, adolescence, and adulthood. It is important to remember that while the following information reflects general tendencies among people with FAS, each person must still be regarded as an individual.
Infancy

An infant, or newborn, with Fetal Alcohol Syndrome (FAS), is not easily identifiable, except in the most severe cases. The facial features are not as distinct as they will become later in childhood. Unless the physician knows that the mother drank during pregnancy, or there are major immediate medical complications, there is no reason to suspect that something is wrong with the baby (Rosett and Weiner, 1984). The first sign of trouble may be difficulties with feeding or delays in reaching developmental milestones. This section discusses FAS in infant development from the perspectives of growth, behavior, feeding, and other characteristics.

Growth

At birth, babies with Fetal Alcohol Syndrome (FAS) are most easily identified by their "scrawny" appearance. These infants are significantly shorter in length than other newborns and their head circumference is usually smaller. In rare cases of FAS, a child is born with hydrocephaly, a condition in which there is excessive cerebral spinal fluid surrounding the brain. This causes the child's head to be abnormally large (Streissguth, LaDue, and Randels, 1988).

Infants born with FAS usually weigh less than other babies.
There is some evidence that birth weight is affected not only by maternal drinking during pregnancy, but also by paternal drinking at the time of conception (Robinson, 1988). Research, to date, has focused on parental drinking as independent variables and has not significantly differentiated children possibly affected by both parents' alcohol consumption. Thus, it is not known to what extent, if any, the combination compounds the problem.

Newborns with FAS often have hypotonia (weak muscle tone) that may make them appear more flabby than other babies (Streissguth et al., 1988). The muscles and skin may appear to hang limply from the bones or joints. This hypertonia adds to the impression of emaciation presented by these children.

Infants with FAS commonly experience "failure to thrive." This means that they continue to lose weight after delivery for longer periods of time than normal. "Failure to thrive" also prevents them from losing their emaciated appearance, even in the most ideal of home environments (Giunta and Streissguth, 1988). Babies with FAS are often required to stay in the hospital for an extended period of time in order to stabilize their weight (Streissguth et al., 1988).

**Behavior**

Newborns with FAS often have difficulty sleeping (Giunta and Streissguth, 1988). Their sleep patterns are usually erratic,
and it may be difficult to distinguish their sleep from their wake cycles (Streissguth et al., 1988).

Problems with sleep will continue throughout life. These sleep irregularities are highly significant. They result in decreased amounts of rapid eye movement (REM) or dream state sleep. REM sleep has been found to be "essential for the consolidation of memory; without it, learning does not take place" (Psychology Today, p. 18).

Babies with FAS have been found to be more easily distracted than their peers (Streissguth et al., 1988). The problem with this is that their attention is often quickly diverted from important learning activities. One learning activity which is interrupted by an increase in distractibility is interaction with others. While babies with FAS tend to have more interest in people than in objects, they are easily distracted from both. Constant interruption in attention to social interaction can have serious consequences to speech and language development. Another area that is significantly impacted by this distractibility is feeding (Randels and Streissguth, 1992).

**Feeding**

Newborns with FAS are likely to have very weak sucking reflexes. Some babies with FAS eat very little; one mother reported that her baby would eat only one and one half to two
ounces of formula at a time. As a result, she and her husband had to feed the infant every two hours (Randels and Streissguth, 1992).

One of the reasons that these infants often eat no more than a few ounces in one feeding is that eating requires the baby's attention. An infant with FAS may have difficulty focusing on eating due to environmental distractions. Some caregivers have successfully dealt with this problem by going into a quieter room, with less activity and fewer people. Leaving the lights off while feeding also reduces distractions in a room. Some caregivers have reported that swaddling (wrapping the infant up securely) has helped to reduce distractions while feeding their infants (Randels and Streissguth, 1992).

Feeding continues to be a problem for children with FAS as they mature. The transition from baby foods to more solid foods is very difficult for them. They continue to have poor appetites and they tend to be uninterested in food (Streissguth et al., 1988).

Other characteristics

As they get older, infants with FAS are generally delayed in reaching developmental milestones. These children may be late in starting to crawl, starting to walk, and developing speech and language. Their first words are often delayed beyond two years,
and they are usually slow to begin putting words together into phrases (Streissguth et al., 1988).

Giunta and Streissguth (1988) suggest that infants with FAS would benefit from "early mental and motor stimulation provided through infant stimulation programs." They feel that this concentrated stimulation might help to "offset some developmental delay." For more information on infant stimulation programs, see Appendix B.
Preschool Years

Preschool children with Fetal Alcohol Syndrome (FAS) are most readily identified by their hyperactivity and exceptionally outgoing personalities (Giunta and Streissguth, 1988). The world of the preschool child with FAS, from the perspective of growth, behavior, social interaction and speech and language development is unique in comparison to that of other children their age.

Preschoolers with FAS continue to be significantly smaller than their peers. They are usually very active and have short attention spans. Partly due to their attention deficits, children with FAS also have a great deal of difficulty interacting with others, particularly their peers. Because of this, they are at high risk for social isolation. The major potential problem for these preschoolers, however, is that their speech and language problems tend to mask the severity of their comprehension difficulties. In fact, many preschoolers with FAS are not diagnosed because of the deceptive nature of their speech and language difficulties (Giunta and Streissguth, 1988). This section of the text will explore this world of the preschool child with FAS more fully; examining characteristics in the areas of growth, behavior, social interaction, and speech and language development.
As babies with FAS develop into toddlers and preschoolers, the size difference between them and their peers continues. These children are often described as short, thin, petite, scrawny, or even emaciated. The size differences persist regardless of the quality of their environment (Burgess and Streissguth, 1992).

As the babies grow some changes in appearance naturally occur. The facial features that help in the diagnosis of children with FAS become more distinct. In fact, during this and their early school years, these diagnostic facial features are particularly clear (Rosett and Weiner, 1984).

Another important area in growth is motor development, that is, the ability to use the muscles as they grow. Children with FAS often have problems with fine and gross motor control. Some examples of gross (large or general) motor movements include running, jumping, and bending over. Fine (small or precise) motor movements include cutting with scissors, talking, and making a fist. As a result of this fine and gross motor skills problem, children with FAS often have difficulty with overall coordination. They are often more clumsy than their peers and may be more prone to accidents. They may fall frequently even after learning to walk. Poor coordination is usually exacerbated by their high level of activity (Streissguth
It is important to note that although poor coordination is common among children with FAS, it is also a side effect of some medications prescribed for problems accompanying FAS. For example, Dilantin, which is used in the reduction of some types of seizures, can cause unsteadiness and dizziness if dosages are too high. See Appendix C for more information on medications commonly prescribed to children with FAS.

**Behavior**

The behavior of many preschoolers with FAS is marked most predominantly by very high activity. These children often move from one person, activity, or topic to the next very suddenly and very rapidly, regardless of whether or not others move with them. It is their extremely high level of activity, coupled with their extreme distractibility that leads to some undiagnosed children being referred by teachers for psychological and/or neurological evaluation (Burgess and Streissguth, 1992).

Children with FAS are usually fearless. They lack an understanding of the concepts of danger or the ability to foresee consequences. They would play in traffic, hang from the roof of the house, or jump from the top of a tree if allowed or left unattended. These children usually do not respond well to verbal restrictions. A caregiver cannot simply tell the child not to
play in the road, hang from the roof, or jump from the tree, because a child with FAS is not likely to understand the danger involved and the possible consequences of their actions. If the child does get hurt s/he will often continue with the same activity, as if no harm had come to him/her (Streissguth et al., 1988). Intensive training and a consistent behavior intervention plan is often needed to teach the child to avoid everyday dangers. A good habilitative instructor can help caregivers to set goals for the child's behavior. S/he can also help to clarify appropriate and meaningful responses to the child's behavior that caregivers can consistently employ. For more information on behavior management and habilitative instructors, see Appendix B.

The extreme activity of children with FAS (often labeled "hyperactivity"), their fearlessness, and their lack of response to verbal restrictions means that they require closer supervision than other children. In fact they require constant supervision (Streissguth et al., 1988). This can quickly become exhausting for even the most active caregiver.

Very rarely a child with FAS will be found who is excessively fearful and withdrawn. Usually this is a reflection of the child's past or present living conditions. The behavior of these children usually improves as their living conditions improve or stabilize (Streissguth et al., 1988).

Overall, preschoolers with FAS are very endearing, happy,
active children, with little or no fear of the unknown. They are demanding in the attention that they require of their caregivers, but there are services available to help relieve some of this stress. These services are discussed in Appendix B.

**Social Interaction**

Preschool children with FAS are outgoing and excessively friendly, with an extreme need for body contact (Streissguth et al., 1988). A child with FAS would sit in the lap of any person who came along, distinguishing very little between strangers and friends. S/he may constantly request hugs or take them without request. S/he may grab others unexpectedly without regard as to where, on the other person's body, s/he is grabbing.

The concept of personal space is lost to the need for contact. These children, like many children their age, also have no idea about inappropriate touching. This is very dangerous for the child when combined with their need for contact and friendliness with strangers. Children with FAS are prone to abuse and exploitation (Giunta and Streissguth, 1988).

One might think that the outgoing, friendly nature of a child with FAS would make him/her many friends, but they are often viewed by others as intrusive. They have no idea about social cues or the rules of interaction. They have a great deal of trouble making friends, especially with children their own
These children run a very high risk of social isolation (Giunta and Streissguth, 1988).

**Speech and Language**

Children with FAS usually begin talking during their preschool years, although their expressive language is likely to be delayed (Giunta and Streissguth, 1988). These children have no greater incidence than other children for problems with articulation, once their expressive speech and language begin to emerge.

Children with FAS who have begun to talk, are often described as overly talkative, asking lots of questions, but with little or no thought and reduced grammatical complexity to their speech. Their talkativeness gives the impression that their speech and language skills are not impaired. Their small size may also be used as an excuse for their slow development and poor performance (Streissguth et al., 1988).
Elementary School Years

Elementary school children with Fetal Alcohol Syndrome (FAS) are most readily identified by their severe difficulty maintaining attention and extreme emotional lability (Streissguth, LaDue, and Randels, 1988). These children continue to differ from their peers in size and appearance. Their academic and social development is also vastly different from that of their peers.

In early elementary school children with FAS appear to do well academically. Then, as the material becomes more abstract and inferential thinking is required, they fall short of the expectations built up by their early successes. In addition to academic changes, social changes occur for the elementary school child with FAS. S/he may be acutely aware of the differences between him/herself and his/her peers (Trace, 1993). This section of the text will discuss the academic and social development of elementary school children with FAS.

Academics

The academic development of young children with FAS is very different from their peers. During their early elementary years many children with FAS are placed in special education classes. The children with the most obvious cognitive delays, those who
are having the most difficulty, are likely to be referred within the first two years. Others, however, may not be referred until much later (Streissguth et al., 1988).

Caregivers often choose to delay placement for a year, or have their child repeat kindergarten to allow the child to mature. According to Streissguth et al. (1988) children with FAS who repeat kindergarten or are not hyperactive tend to show no noticeable academic delays during their first two years of school. Whether or not a child repeats grades, or waits a year before starting, children with FAS generally have the least amount of trouble with their first few years of school (Streissguth et al., 1988). This is largely due to the concrete nature of the material taught and the rote methods of learning in these first few years of school. Children with FAS have greater difficulty with abstract ideas and concepts than with the concrete (Burgess and Streissguth, 1992).

There is a hidden problem with many of the success of children with FAS during their first few years of school. These successes mask underlying delays. A kindergartner or preschooler who can count to twenty or higher may not be regarded as having a problem. The question, however, is can the child recognize numbers? Does he/she understand what that number represents? In most cases the answer to these and many similar questions is no. The child can sing the alphabet song but he/she can not identify even one letter. It is nothing more than a memorized
tune. Children with FAS have a skill for memorization that can be very useful. It affords a basis from which to build academic and self-help skills. For example, the child can memorize answers to important questions regarding address and phone number. According to Burgess and Streissguth, (1992) it is very important for educators and caregivers to realize that being able to say something is not the same as understanding the statement.

Children with FAS usually have more difficulty with math than with spelling or reading (Streissguth et al., 1988). They often learn to read and write at the same pace as other children, but their comprehension of what they are reading and writing is very limited. Often educators, caregivers, and others get the impression that the child is achieving at a higher level than actually may be true (Giunta and Streissguth, 1988) based on successes with memorized or frequently repeated activities. This facade of higher achievement is reinforced by educators who compare the child's achievement with intelligence quotient (IQ) scores. These comparisons usually indicate higher levels of functioning based on performance, relative to his/her IQ, than the child comprehends (Streissguth et al., 1988).

One of the most important factors contributing to any child's success in the classroom is his/her ability to maintain attention. In early school years the attention deficit problems seen in preschool and infancy become worse. Not only is attention deficit worsening, but caregivers often find that
medications normally prescribed for attention deficit disorder (ADD) do not affect the problems of children with FAS (Dorris, 1989). See Appendix A for more information on ADD, and Appendix C for information on common medications prescribed for children with FAS.

Another important factor in classroom success is the ability to remember directions given by the teacher. Children with FAS have difficulty recalling even simple directions long enough to carry out the task requested. Such memory deficits compound problems for children with FAS, particularly in the regular classroom setting (Streissguth et al., 1988).

Another factor that influences the academic success of children with FAS is their extreme emotional lability. These children have a great deal of difficulty controlling their emotions during their elementary school years (Streissguth et al., 1988). In addition to emotional lability, children with FAS have poor control over their impulses. They tend to act upon impulses with no regard for the consequences of their behaviors. This lack of control over impulses is more than a detriment to learning. It is a health risk for the child and those around him/her, and it affects the child's social development (Burgess and Streissguth, 1992).

Children with FAS often have extreme difficulty in the regular classroom. There are several options, in terms of setting, for the education of children with special needs. There
is a range of involvement in normal class activities from full participation, to completely separate schooling. These options are discussed in detail in Appendix D under the heading "Least Restrictive Environment".

Giunta and Streissguth (1988) stress the importance of appropriate placement in special education classes for children with FAS beginning in early elementary school. They suggest that "a small classroom setting with clear guidelines and a great deal of individual attention to the students can help these patients maximize their intellectual capabilities" (p.456). Remedial education has not yet been proven to increase the intellectual level of children with FAS, but Giunta and Streissguth (1988) contend that it may help to keep them from regressing. In addition Giunta and Streissguth (1988) recommend periodic testing to help teachers meet each child's individual education needs; they stress that this is particularly important for children with FAS, as their skill levels vary widely.

It is very important for caregivers to be aware of their rights and their child's rights in the special education system. Appendix D discusses caregiver and children's rights and some procedures common in the special education system.
Social Interaction

Children with FAS have a great deal of trouble relating to and interacting with other people. Their outgoing nature and their difficulty detecting and interpreting social cues frequently cause these children to be perceived by others as intrusive. A child with FAS might ask inappropriate or poorly timed questions, change topics of conversation rapidly and without warning, or interrupt the person who is speaking (Trace, 1993).

Children with FAS often have trouble with the concept of personal space. Personal space is the area around each individual that allows one to be comfortable during conversation. The size of one's personal space usually decreases in proportion to how well they know or like someone (Giunta and Streissguth, 1988). Most children with FAS are totally unaware of personal space. They do not distinguish between strangers and friends, and therefore do not allow space accordingly. A child with FAS is likely to stand too close to others during conversation. He/she might touch others too frequently, for too long, or inappropriately during conversations, or sit on a stranger's lap. He/she will usually be in constant physical contact with his/her conversational partner (Trace, 1993).

The need for physical contact, while unnerving to the
child's conversational partner, can have more serious consequences for the child. Children with FAS generally are more openly interested in sexual exploration and are more easily influenced by others, than their peers. They have difficulty predicting and/or understanding the consequences of their behaviors, and they often have trouble distinguishing reality from fantasy (LaDue, 1988). Their inability to detect social cues, their poor ability to distinguish (socially) a stranger from a friend, their desire for bodily contact, and their interest in sexual exploration make children with FAS a unique high risk group for potential exploitation by adults and older children. Research indicates that the incidence of sexual abuse among children with FAS is higher than that of the general population (Giunta and Streissguth, 1988).

Many of the social and academic factors affecting children with FAS can combine with an awareness of being different, and lead to trouble with peer relations. This is especially true for higher functioning children. Difficulty making friends and maintaining relationships can quickly lead to social isolation and depression for the child. It is important for children with FAS to learn how to interact with other people. These skills, called pragmatic abilities can be dealt with by habilitative trainers and speech-language pathologists (Trace, 1993).

Occasionally a child with FAS is found to be excessively hostile and destructive. Streissguth et al. (1988) reported that
this hostility relates more to the child's current or previous living situation than it does to FAS.
Adolescence

A dramatic increase in the stress associated with school attendance is the most distinct trait of adolescents with Fetal Alcohol Syndrome (FAS). Adolescence is the time when children with FAS really begin to see the differences between themselves and their peers. Even children with normal Intelligence Quotients (IQ), who function at a relatively high level, begin to fall behind their peers more rapidly during adolescence (Streissguth, LaDue, and Randels, 1988).

Growth

As children with FAS grow older and reach adolescence, many of the physical characteristics of the syndrome become more subtle. The facial features that were so predominant in the child's younger years begin to change as the child's features mature. The diagnostic facial features become less distinct. The child's nose and chin usually become more coarse (Streissguth et al., 1988).

The emaciated appearance of the child with FAS also becomes less extreme during puberty. Height and small head circumference (microcephaly) separate adolescents with FAS from their peers, in terms of growth (Streissguth et al., 1988). While their height and head circumference continue to lag behind that of their
peers, the difference in overall size becomes less noticeable. This diminishing difference is due, in part, to the extreme variability in the weight of children with FAS as they pass through puberty and into adulthood. Many of these children will achieve normal weight in proportion to their height, decreasing the attention attracted by their size.

Changes in the physical characteristics from very distinct and readily identifiable to more subtle as the children develop through puberty makes diagnosis more difficult. Educators and other professionals are forced to rely more heavily on academic and behavioral characteristics to identify children who have reached adolescence without being diagnosed.

**Academics**

Individuals with FAS have very diverse IQ scores. Their scores range from profoundly mentally handicapped to within normal limits and do not appear to change as the child grows older (Beattie, 1992). Until adolescence, children with higher IQ's are generally able to function near the level of their peers, academically. The increase in abstract concepts and inferential thinking in middle school causes even the most highly functioning students with FAS to begin experiencing extreme difficulties. Academic successes become more difficult to obtain
as they struggle to keep up or catch up with their peers (Trace, 1993). According to Streissguth et al. (1988) it becomes more difficult for these children to learn new material in middle school. They seem to reach an academic peak, sometime between fourth and eighth grade. Children with FAS peak, on average, with a fourth grade reading level and third grade spelling and math levels (LaDue, 1988).

Stress associated with school attendance increases for children with FAS throughout middle school. Sparse academic success, increased difficulty learning new material, and inflated expectations built up by years of relative success in more concrete academics factor into the growing stress of school attendance. Continued trouble maintaining attention also increases the stress of school on these children.

This increased stress leads many middle school children with FAS, especially those who have yet to be diagnosed, to miss more and more school. According to Streissguth et al. (1988) this is especially true for children who do not have strong family support.

Even children with FAS who have normal IQ's will need a psychological evaluation and remedial placement in middle school according to Streissguth et al. (1988). They further warn that if the child's placement is not reevaluated, s/he runs an extremely high risk of dropping out of school all together.

Entrance into middle school is one of the most important
times in the life of a child with FAS. It is a time of change, a time for a shift in curriculum. Children with FAS reach a point when they can no longer intellectually handle the academic material (Burgess and Streissguth, 1992).

The child, who has been diagnosed with FAS, is at an extreme advantage over those who have not yet been diagnosed, as they enter middle school. A curriculum of daily living and prevocational skills can be developed before the student reaches middle school. This curriculum can then be integrated and built into the child's earlier academic career. This preparation can have enormous impact on the person's level of independence as an adult. Being able to develop an appropriate adaptive living curriculum before the child reaches middle school, so that he/she can move directly into this program may help to smooth the transition into middle school. The hope, with this preplanning, is to avoid much pain in the repeated failures inherent within the regular middle school curriculum for students with FAS. Children who are not diagnosed until middle school, or later, build up a history of academic failures that increases the stress of school attendance and can lead to severe depression and dropping out of school (Streissguth et al., 1988).

Like many of their developmentally disabled peers, students with FAS need to be taught many of the skills that other children seem to acquire effortlessly. They need to be taught a variety of skills from simple tasks, such as choosing weather appropriate
clothes, to more complex tasks, such as grocery shopping. They need intensive training in areas such as money management and how to structure free time (Dorris, 1989).

Adolescents with FAS need to learn very specific cause and effect relationships as they apply to the real world, especially to the world of law and order. Many children with FAS end up in jail. Their intentions are often misunderstood by others. They are perceived as intrusive and sometimes threatening. They actively explore sexuality and generally associate with younger children. In addition, the concepts of right and wrong are generally too abstract for them to comprehend, and they never learn the consequences of certain actions. As a result of these factors, many adolescents and young adults with FAS have difficulties with the law (Giunta and Streissguth, 1988).

The intense focus on daily living skills is necessary, even though ideally the child has had a curriculum with applications to daily life. Most students with FAS will still be far behind their peers in this area. They are usually so far behind, in fact, that it is rare for them to live completely independently. Many of these students, with or without this change in curriculum, find themselves still dependent upon others in adulthood, to help them with their daily living needs (Streissguth et al., 1988).
Adulthood

Adults with Fetal Alcohol Syndrome (FAS) face a multitude of challenges. They need assistance in many aspects of their lives, from finding a place to live, to parenting, to dealing with their own behavioral problems. Adults with FAS continue to have difficulty relating cause and effect; and therefore many continue to have legal problems. Adults with FAS need guidance and a strong support system in order to find success and a sense of purpose in their lives.

Housing

Many adults with FAS seek to find some measure of independence in their adult lives. Many caregivers cannot continue to provide for their children who have FAS. Through the services outlined in Appendix B, adults with FAS can find funding for and placement in an appropriate residential setting.

There are several housing options available for adults with FAS, varying according to the level of support needed by the individual. The needs of the adult as well as his/her abilities must be assessed to determine proper placement.

Adults who have the most difficulty taking care of themselves are often placed in state institutions or nursing homes. These people are usually placed in this setting before
they reach adulthood. Many spend the remainder of their lives there. Some, however, are able to move out to the next level of support (Ullum, 1994).

The second level of housing placement available to adults who function at a higher level is the group home setting. These settings range from basic developmental, for residents who can do the least on their own, through a range of higher and higher functioning homes with an ultimate goal of preparing the resident for assisted living. Many of the people who live in basic developmental homes come from institutional settings.

In group homes there is continuous training toward life skills and communication objectives. People in this setting are helped to live as normal a life as possible. Adults in group home settings often have an individualized program plan (IPP) which is similar to the individualized education plan (IEP) of their youth (Ullum, 1994). See Appendix D for more details on the IPP and IEP.

The next level of housing is assisted apartment living. This is where one or two adults share an apartment, with one person who comes in to help them throughout the day. Apartment living varies in the amount of support provided. Some adults in this situation require someone to be with them around the clock, while others need only daily or weekly visits. Adults in this setting are as independent as possible. Most have jobs within the community and a broad support system that they can call upon
when they have problems (Ullum, 1994).

Finally, there is totally independent living. Due to their inability to handle money and understand other basic abstract concepts, this never becomes a reality for most adults with FAS. For some who are unprepared the lack of structure and guidance of complete independence can lead to problems that eventually lead them to jail or prison. There are many resources available for adults with FAS who progress to the level of independent living (Ullum, 1994). These support services are discussed in Appendix B.

**Job training and placement**

Many adults with FAS begin their vocational or prevocational training in high school. Some are prepared to enter a sheltered workshop or the regular job market after high school. Others require more preparation. Sheltered workshops and job training facilities can provide excellent opportunities for adults with FAS to develop job skills that may one day allow them to work in the community. Sheltered workshops are places where adults with developmental disabilities can go during the day to learn very basic job-related tasks. They also learn appropriate behaviors for the job setting in these workshops. If an adult is learning at one of these sheltered workshops, he/she usually has an IPP (see Appendix D) and a final objective of moving from the
job situation is often very difficult for an adult with FAS to maintain. They generally have difficulty justifying their actions, or complain that others were responsible for a conflict. This is where the intervention of the supported job setting is most needed, and the major reason why adults with FAS, who continue without assistance or support often are unable to hold a job once they gain employment (Ullum, 1994).

Social integration

Adults with FAS, according to Giunta and Streissguth (1988), have a much higher incidence of emotional and psychological problems than their peers. LaDue (1988) cites depression and suicidal tendencies to be the most common of these.

The social isolation of their school years intensifies in adulthood for many people with FAS, particularly if they are on their own. Even adults in group settings often find themselves isolated from their peers. Their main contacts are usually other disabled adults who may or may not be aware of their presence and staff who are paid to spend time with them.

In addition to being isolated, many adults with FAS occupy highly repetitive jobs, or are unemployed. Unable to structure leisure time for themselves, they may find life unrewarding and pointless (Streissguth et al., 1988). This feeling of pointlessness combined with social isolation and recognition that
they are different from other people can lead many adults with 
FAS into deep depression and, not infrequently, to suicide 
(LaDue, 1988).

Adults with FAS continue to demand physical contact in 
excess of what is socially accepted. They also continue to 
explore sexually. This sexual exploration and desire for 
excessive physical contact can lead to charges from sexual 
harassment to rape. Adults with FAS are generally no better at 
understanding social boundaries now than they were as children. 
They often do not understand the cause-effect relationships 
involved, and finally, they do not understand the extremely 
abstract concept of right and wrong. It is extremely important 
for adults with FAS to continue to have guidance in the area of 
social interaction, as the judicial system does not yet recognize 
the difference between adults with FAS and other people who break 
the law.
Conclusion

Fetal Alcohol Syndrome (FAS), now recognized as the leading known cause of mental retardation in the Western World (Burgess and Streissguth, 1992), has devastating effects on its victims throughout their lives. From infancy through adulthood, people with FAS suffer severe physical, emotional, and intellectual challenges. The impact of the syndrome on the lives of the people involved can be lessened, but FAS must first be diagnosed. Once diagnosed, it is important to recognize the general developmental patterns seen in people with FAS in order to plan appropriately. Also, resources must be tapped at various stages of development in order to help the child to grow into the most independent, emotionally stable adult possible.
References


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APPENDICES
APPENDIX A
Appendix A

Conditions That May Accompany Fetal Alcohol Syndrome

Attention-Deficit Hyperactivity Disorder (ADHD):

A child must exhibit at least eight of the following characteristics for at least six months to be diagnosed with ADD.

1. Hand or foot fidgeting, squirming. (Adolescents may demonstrate this as extreme restlessness.)
2. Difficulty staying in seat when required to do so.
3. Easily distracted.
4. Trouble with waiting turn in games or conversation.
5. Gives answer before the whole question is asked.
7. Trouble attending to tasks or play activities.
8. Leaves one activity for another before completion.
9. Has difficulty playing quietly.
10. Exhibits excessive talking.
11. Interrupts or intrudes on others.
12. Does not seem to listen to what is being said.
13. Loses important elements of tasks or activities.
14. Engages in dangerous activities without regard for the consequences (Nicolosi, Harryman, and Kresheck, 1989.)

For more information on ADHD:


Autism:

Individuals with autism usually begin to exhibit the disorder within the first thirty months of life. They are usually extremely delayed in language development and when their speech does emerge, it is fraught with repetitions of what the speaker has said, excessive use of familiar phrases (i.e. "that's okay") and reversal of syntax (i.e. "go you" for "you go"). Individuals with autism are usually very resistant to change and become unusually attached to specific objects. There are several classifications of autism (Nicolosi, Harryman, and Kresheck, 1989).

Infantile Autism: This form of autism develops before age three. The child seems withdrawn or disinterested, has an obsession with keeping things the same, avoids eye contact, has obvious preferences of objects over people, and avoids communication. The child's appearance and coordination may be normal, but there is no "physical reaching out, imitation of gestures or sounds, or use of speech to communicate" (Nicolosi, Harryman, and Kresheck, 1989, p. 33) from infancy.

Primary Autism: This form of autism is considered "psychogenic in origin". There is no known cause for it, and it tends to have an early onset (Nicolosi, Harryman, and Kresheck, 1989).

Secondary Autism: Autism that is organic in nature, characterized by sudden, extreme regression, withdrawal and
rigidity following some form of trauma. There is usually some recovery (Nicolosi, Harryman, and Kresheck, 1989).

For more information on autism:

Journal of Autism and Childhood Schizophrenia

Journal of Autism and Developmental Disorders

Cerebral Palsy (CP):

CP is a disorder of movement resulting from oxygen deprivation during brain development. This can occur prenatally (before birth), perinatally (during birth), or postnatally (after birth). This disorder is not progressive, however, the symptoms may be. CP does not affect the cognitive ability of a person. CP is usually not diagnosed until the child is six to twelve months old when they start to have trouble moving around (Powers, 1986).

CP is described by physicians using three characteristics: place/location, type of involvement, and severity.

The place/location descriptors are:

- hemiplegia - two limbs on the same side of the body
- paraplegia - usually used when both legs are involved
- quadriplegia - all four limbs are involved
- monoplegia - only one limb is involved.

Types of involvement may be:

- spasticity - over-activity of the stretch reflex
- ataxia - tremors or discoordination when the person attempts to do something
- tremors - repetitive, uncontrolled body shaking at rest
- athetosis - involuntary squirming or writhing.

Severity is a subjective measure of the extent of the disability resulting from CP. It is described on a continuum from mild to profound and takes into consideration such aspects as the potential for development and medical costs (Powers, 1986).

For more information on CP:

Cleft Lip and Cleft Palate:

Cleft lip and cleft palate are congenital cosmetic disorders. Cleft lip is a deformity of the upper lip that can vary from notching to complete division of the lip into three parts. Cleft lip may occur on one side of the lip, on both sides of the lip, or in the middle of the lip. Cleft palate is a deformity of the hard and soft palates of the mouth, and is usually accompanied by cleft lip. A cleft palate is a fissure in the midline of the palate. This deformity varies in severity from a relatively small hole in the hard palate alone to complete separation of the lip, hard palate, and soft palate (Zemlin, 1988).

Cleft lip and palate result in temporary swallowing problems and extreme facial deformity. The hole in the palates can now be repaired surgically, as can the lip.

For more information on cleft lip and palate:


Epilepsy:

Epilepsy is a disorder that is characterized by chronic periods of abnormal brain wave activity, resulting in seizures of various kinds. Loss of consciousness and uncontrollable muscle spasms are generally associated with epilepsy (Nicolosi, Harryman, and Kresheck, 1989).

Petite Mal Seizures: These are less severe seizures which may consist of a "brief loss of consciousness, staring, and loss of continuity in activity," (Nicolosi, Harryman, and Kresheck, 1989, p. 196).

Grand Mal Seizures: This type of seizure results in extended loss of consciousness accompanied by involuntary muscle contractions and convulsions (Nicolosi, Harryman, and Kresheck, 1989).

Convulsions: These are violent, involuntary series of contractions of voluntary muscles (Nicolosi, Harryman, and Kresheck, 1989).

For more information on Epilepsy and seizure disorders:


APPENDIX B
Appendix B

Resources Available

There are many services available to people with special needs that can facilitate changes in the person's life. There are educational, medical, psychological, legal, and financial resources available for both the person involved and the caregivers.

Educational Resources

Titles for educational resources vary from state to state. A great deal of information on these resources and information on where to find them in various communities can usually be obtained from local Associations for Retarded Citizens (ARC).

Infant Language Stimulation - Programs available in the community, sometimes offered through a center for the developmentally disabled, at which infants and toddlers are worked with in groups by trained staff, to stimulate language development. Some of the methods generally incorporated include the use of functional language through self and parallel talk and play (Ullum, 1994).

Sensory Stimulation Programs - Programs designed to help infants and toddlers with disabilities to experience their environment more fully through various types of sensory stimulation (Ullum, 1994).
Head Start - federally funded early intervention programs designed to introduce economically disadvantaged and at-risk preschool children to a positive, responsive environment that encourages thinking and communication (Smith and Luckasson, 1992).

Educational Diagnostician & School Psychologist - professionals trained to assess individual's eligibility and needs within the special education system (Smith and Luckasson, 1992).

Qualified Mental Retardation Professional (QMRP) - an individual with at least a bachelor's degree in special education or a related field and at least two years experience providing direct care to individuals with intellectual disabilities. These individuals are usually found in management at group homes or state institutions, and also frequently serve as individual case managers (Ullum, 1994).

Case (Service) Manager - a person who assists caregivers in the coordination of services for individuals with disabilities. This person also often acts as an advocate and advisor for parents, usually a QMRP. Case managers can be located through the State Department of Health or by contacting the Association for Retarded Citizens.

Habilitative Instructor - a life skills trainer who helps to teach people skills that they need to function at various age levels in society. Habilitative trainers are very important in helping the child to increase independence more quickly and with less strain on the caregivers. A
habilitative trainer may work in the child's home, may take them out into the community (for example to the library or a restaurant), or may see them in the trainer's own home, depending on the needs of the child and the family. Habilitative instructors can also be located by contacting the Association for Retarded Citizens.

Speech-Language Pathologist (SLP) - a professional who works with people of all ages who have communication disorders. SLP's are found in a wide variety of settings, including hospitals, private clinics, schools, nursing homes, and centers for the developmentally disabled.

Medical Resources

Audiologist - a professional who works with people of all ages in the evaluation, habilitation and rehabilitation of various types of hearing loss.

Neurologist - a professional who works with people of all ages in the diagnosis and treatment of neurological problems.

Occupational Therapist - a professional who conducts activities with the goals of improving muscle control and developing self-help skills (Smith and Luckasson, 1992).

Ophthalmologist - a medical doctor whose specialty is eye disorders.

Optician - a professional who fills eyewear prescriptions.
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Optometrist – a professional who measures vision and may prescribe corrective eyewear.

Personal Care Attendant – an individual hired to assist in hygiene, mobility, household maintenance, child care, and various other aspects of life management. The county public health nurse can usually provide information on locating personal care attendants.

Physical Therapist – a professional who works in muscular, connective tissue, and joint rehabilitation through nonmedical means, such as exercise and massage (Smith and Luckasscn, 1992).

Respiratory Therapist – a professional who works towards the rehabilitation and habilitation of disorders of the respiratory system.

Psychological Resources

The county public health nurse or office of social services can usually provide information on locating various mental health professionals.

Behavior Specialist – a professional who specializes in the management of inappropriate behaviors. This professional can often offer many options to behavior management that may be alternatives to drug therapy.

Psychiatrist – a medical professional who specializes in the treatment of mental disorders and diseases. A psychiatrist
Psychologist - a professional who specializes in human behavior and the human mind. Psychologists can provide counseling and alternatives to medication, but cannot prescribe medications.

Respite Worker: an adult who takes responsibility for an individual for periods of time, affording caregivers a break. For example, a "respite worker" may come into the home of the child and watch him/her for several hours or an evening, or even over a weekend, while the caregivers relax around the house, go out to dinner, or take a weekend trip. Respite workers often may take the children out on activities, such as to the park or bowling, to get them out of the house for a short period of time. These arrangements vary for each individual, they are set up by the caregivers and the respite workers to best meet the needs of the family.

Often children with FAS require a special waiver for eligibility for respite services. This is because many states do not recognize Fetal Alcohol Syndrome (FAS) as a disability that requires 24 hour supervision. In some states a child with FAS must be diagnosed with autism, even if they only demonstrate autistic-like behaviors, before the child is eligible to receive services such as respite. Respite is a service that is paid for by Medicaid. To find out more about respite services and how to become
eligiblE~, contact your local chapter of the Association for Retarded Citizens.

Other Resources

These resources can often be accessed through the public school system.

Advocate - an individual, parent, friend, or professional, who works to promote the best interests of an individual with disabilities within the community.

Job Coach - one who works along side a person with a disability, helping them to learn all aspects of the job.

Job Developer - one who looks for and creates job opportunities in the community for people with disabilities.

Organizations

Alcoholics Anonymous (AA) - contact your local chapter

Association for Retarded Citizens (ARC) - contact your local chapter

Children of Alcoholics Foundation - (212) 980-5394
540 Madison Avenue New York, NY 10022

Early Intervention System - an Indiana program to help coordinate intervention programs for families of children with disabilities. (317) 232-2291 / (800) 441-7837
402 W. Washington St., E-414 PO Box 7083
Indianapolis, IN 46207-7083

FAE/FAS Support Group - nationwide support group for parents and caregivers of children affected by Fetal Alcohol Effects and Fetal Alcohol Syndrome (717) 769-6092 or (717) 769-6289
PO Box 68 Woolrich, PA 17779
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FAS Adolescent Task Force - 20508 Cypress Way Lynnwood, WA 98036
Fetal Alcohol Education Program - (617) 739-1424
   Boston University School of Medicine
   7 Kent St. Brookline, MA 02146
Fetal Alcohol Network (FAN) - nationwide newsletter, CARELINE,
   and support group. (215) 384-1133
   158 Rosemont Ave. Coatsville, PA 19320
Greater Indianapolis Council on Alcoholism - (317) 542-7128
   2511 E. 46th St. Building 0 Indianpolis, IN 46205
Growing With FAS - a publication of a non-profit coalition on
   Fetal Alcohol Syndrome
   7802 SE Taylor Portland, OR 97215
ICEBERG - non-profit educational newsletter concerning Fetal
   Alcohol Syndrome and Fetal Alcohol Effects
   PO Box 95597 Seattle, WA 98145-2597
March of Dimes Birth Defects Foundation - for more information
   contact your local chapter
National Association for Native American Children of Alcoholics -
   (206) 322-5601
   PO Box 18736 Seattle, WA 98118
National Black Alcoholism Council - (202) 296-2696
   1629 K St., NW, Suite 802 Washington, DC 20005
National Clearinghouse for Alcohol and Drug Information -
   (301) 468-2600 or (800) 729-6686
   PO Box 2345 Rockville, MD 20852
National Coalition for Hispanic Health and Human Services -
   (202) 371-2100
   1030 15th St., NW, Suite 1035 Washington, DC 20005
National Council on Alcoholism and Drug Dependence (NCADD) -
   (212) 206-6770 12 W. 21 St. New York, NY 10010
National Organization on Fetal Alcohol Syndrome (NOFAS) -
   (202) 785-4585 or (800) 666-6327
   1815 H St., NW Suite 750 Washington, DC 20006
Step Ahead - an Indiana program to help make a wide spectrum of
   family services available to all. (317) 232-1144
   402 W. Washington St. Rm W386 Indianapolis, IN 46204
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Women for Sobriety - (800) 333-1606
PO Box 618 Quakertown, PA 18951-0618

American Speech-Language-Hearing Association - (800) 638-6868
ASHA 10801 Rockville Pike Rockville, MD 20852
APPENDIX C
Appendix C

Commonly Prescribed Medications

Behavior Management:

Carbamazepine (Tegretol)

Indications: control of certain psychological or behavioral disorders

Adult Dosage Range: 400-1200mg daily

Onset of Effect: within four hours

Duration of Action: 12-24 hours

Possible Adverse Effects:

- common - dizziness, unsteadiness, nausea, vomiting, blurred vision.
- rare - ankle swelling, rash.

Notify physician if blurred vision, ankle swelling, or rash occur.

Stop taking medication immediately if a rash occurs.

Interactions: reduces the effectiveness of anticoagulants. may reduce the effectiveness of oral contraceptives. causes a sedative effect when combined with alcohol. reduces effectiveness of quinidine, a drug that helps to reduce arrhythmia.

Prolonged Use: slight risk of blood abnormalities.

Monitoring: periodic blood tests to monitor level of medication in blood stream and blood composition (Physicians' Desk Reference, 1994).
Haloperidol (Haldol)

Indications: reduction of violent, aggressive aspects of mental illnesses in which hallucinations occur. Control behavior disorders in children.

Adult Dosage Range: starts at 1.5-6mg daily increases to 10-20mg daily

Onset of Effect: 20-30 minutes with injection 2-3 hours by mouth

Duration of Action: 6-24 hours

Possible Adverse Effects:
- common - drowsiness, lethargy, weight gain, abnormal movements in face and limbs (parkinsonism), dizziness, fainting.
- rare - rash, high fever, convulsions.

Notify physician if symptoms of parkinsonism, dizziness, fainting, rash occur.

Stop taking medication immediately if a rash, high fever, or convulsions occur.

Call physician immediately if high fever or convulsions occur.

Interactions: any drug with a sedative effect will increase the sedative effect of haloperidol. may counter the beneficial effects of anti-parkinson medications. may cause an increase in side effects of anticholinergic drugs. anticonvulsant dosages may need to be adjusted when taken in conjunction with haloperidol.

Prolonged Use:
USE OF HALDOL FOR MORE THAN A FEW MONTHS MAY CAUSE TARDIVE DYSKINESIA. (Tardive dyskinesia is a disorder characterized by abnormal involuntary movements of the eyes, face and tongue). Jaundice may occur.

Monitoring: periodic blood tests to monitor level of medication in blood stream (Clayman, 1988).
Methylphenidate (Ritalin)

Indications: to reduce symptoms of Attention Deficit Disorder.

Adult Dosage Range: 10-60mg daily

Onset of Effect: within one hour

Duration of Action: unknown

Possible Adverse Effects:

common - insomnia, nervousness.

rare - rash, headache, dizziness, rapid/forceful heart beat, loss of appetite, nausea, abdominal discomfort, aggressive and erratic behavior, low red/white blood cell counts.

Notify physician if rash, rapid and forceful heart beat, loss of appetite, abdominal discomfort, aggressive and erratic behavior, abnormally low red and white blood cell counts occur.

Stop taking medication immediately if severe rash, abnormal behavior patterns, or drastic changes in heart beat occur.

Interactions: foods rich in tyramine can cause excessively high blood pressure in conjunction with this medication. increases the effects of tricyclic antidepressants, and enhances their toxic side effects. decreases the effects of some medications that lower blood pressure. when taken with anticonvulsant, seizure patterns and severity may change.

Prolonged Use: This medication can produce a tolerance and cause serious psychological dependence. Suppression of weight and height in children.
**Dexedrine (Dextroamphetamine)**

**Indications:** reduction of symptoms of Attention Deficit Disorder

**Adult Dosage Range:** 2-500mg

**Onset of Effect:** 2 hours

**Duration of Action:** 48 hours

**Possible Adverse Effects:**
- **common** - palpitations, elevated blood pressure, restlessness, dizziness, discoordination, headaches, dry mouth.
- **rare** - psychotic episodes, tremors, anorexia, weight loss, impotence.

Notify physician if palpitations, increases in blood pressure, psychotic episodes, or dramatic weight loss occur.

**Interactions:** acidic substances, such as fruit juices, decrease the effectiveness of this medication.
- Inhibit androgenic blockers.
- Antacids increase the effects of this medication.
- Increase the effects of most antidepressants.
- Counteracted by antihistamines.
- Inhibited by Haloperidol.
- Delays absorption of Phenobarbital and Phenytoin, taking either of these medications with Dexedrine may increase seizure frequency.

**Prolonged Use:** may exacerbate behavior, thought, or motor disorders. May inhibit growth in children.

**Monitoring:** periodic blood tests to monitor level of medication in blood stream (Physicians' Desk Reference, 1994).
Thioridazine (Mellaril)

Indications: control of certain behavioral disorders and anxiety/depression associated with serious mental disorders.

Adult Dosage Range: 50-800mg daily

Onset of Effect: 2-3 hours

Duration of Action: 4-10 hours

Possible Adverse Effects:

common - drowsiness, dry mouth, stuffy nose.

rare - blurred vision, muscle stiffness, unsteadiness, dizziness, fainting.

Notify physician if stuffy nose, blurred vision, muscle stiffness, unsteadiness, dizziness, or fainting occur.

Stop taking medication immediately if dizziness or fainting occurs.

Interactions: increases effects of all sedatives. may counter the beneficial effects of drugs prescribed for parkinsonism. increases the side effects of anticholinergic drugs.

Prolonged Use: may lead to eye problems.

USE OF MELLARIL FOR MORE THAN A FEW MONTHS MAY CAUSE TARDIVE DYSKINESIA. (Tardive dyskinesia is a disorder characterized by abnormal involuntary movements of the eyes, face and tongue) (Clayman, 1988).
Seizure Control:

Carbamazepine  (Tegretol)

See previous description on page 61.

Phenobarbital  (Barbita, Luminal, Solfoton, PBR-12)

Indications: anticonvulsant, prevention and treatment of epileptic seizures.

Adult Dosage Range: 15-120mg daily (up to 300mg to control seizures)

Children's Dosage: adjusted based on age and weight.

Onset of Effect: 30-60 minutes (by mouth)

Duration of Action: 24-48 hours

Possible Adverse Effects:

common - drowsiness, clumsiness, unsteadiness, dizziness, faintness.

rare - confusion

Notify physician if confusion or rash occur.

Stop taking medication immediately if a rash occurs.

Interactions: increases effects of all sedatives.
may reduce the effects of corticosteroids.
may reduce the effectiveness of oral contraceptives.
may reduce the effects of anticoagulants.

Prolonged Use: risk of build up of sedative effect leading to excessive drowsiness and lethargy. A tolerance may develop, however, that reduces these effects. may cause vitamin D deficiency.

Monitoring: periodic blood tests to monitor level of medication in blood stream (Physicians' Desk Reference, 1994).
Phenytoin (Dilantin, Dyphenylan)

Indications: seizure control

Adult Dosage Range: 300-400mg

Children's Dosage: adjusted based on age and weight.

Onset of Effect: 7-10 days

Duration of Action: 24 hours

Possible Adverse Effects:

common - slurred speech, dizziness, confusion, overgrowth of gums.

rare - increased body hair, rash.

Notify physician if overgrowth of gums or rash occur.

Stop taking medication immediately if rash occurs.

Interactions: many drugs interact with phenytoin, reducing its anticonvulsant effect.

may reduce the effectiveness of oral contraceptives.

may increase the effects of all sedative drugs.

increases the sedative effect of alcohol.

alcohol, overtime, may reduce phenytoin's anticonvulsant effect.

Prolonged Use: slight risk of blood abnormalities, damage to skin, gums, and bones.

disruption of diabetes control.

Monitoring: periodic blood tests to monitor level of medication in blood stream, blood composition, and chemistry (Clayman, 1988).
APPENDIX D
Appendix D

Rights and Responsibilities

Individuals with Disabilities Education Act (IDEA):

1975 - PL 94-142: Education for All Handicapped Children Act (EHA)

1. Free Appropriate Public Education - every child with a handicap is entitled to receive educational services appropriate to his/her individual needs without cost to the child or the family.

2. Notification and Procedural Rights of Parents -
   a. right to examine their child's records
   b. right to obtain an independent evaluation of their child's needs.
   c. right to receive clearly written notes in the language that the parents read best, stating the results of school evaluations.
   d. right to agree or disagree with this notice of evaluation results.
   e. right to issue formal complaints.
   f. right to peruse a due process hearing.
   g. right to peruse a judicial hearing (with this comes the right to legal counsel and rights concerning witnesses, written evidence, verbatim documentation of the hearing, and appeals).

3. Identification and Services for all Children - States must actively seek out and identify all children who require special education services.

4. Necessary Related Services - developmental, corrective, and other support services that are necessary to
allow the child to benefit from special education must be provided.

examples: transportation, speech-language pathology, audiology, psychology, physical and occupational therapy, recreation, and some medical and counseling services.

5. Individualized Assessment - determination of eligibility for special services and placement must be made on an individual basis by trained professionals.

6. Individualized Education Program (IEP) Plans - written statements of short and long term educational goals and procedures developed at a meeting to be attended by at least the following:

   A qualified representative of the school (usually the special education teacher), the child's classroom teacher, the parent(s), the child (if appropriate).

   Other professionals may be present, and the parents have the right to bring any additional personnel to the meeting.

   It is the responsibility of the school to notify parents of the meeting and to make the meeting place and time convenient for both parents to attend if they wish.

   It is the school's responsibility to provide any interpreters that are necessary for the parents or the child to understand the meeting.
It is the school's responsibility to ensure that parents understand the proceedings of the meeting and their rights in the IEP process.

7. Least Restrictive Environment (LRE) - The environment in which the child learns best. This environment is one which allows for as much interaction with non-handicapped children as possible for the individual child.

Amendments:

1986 - PL 99-457

1. Expanded Age Range of Special Education to Include Infants and Toddlers

2. Individualized Family Services Plans (IFSP) - a written program plan for children under the age of three who receive special education services. This plan should identify and organize resources to assist families in reaching goals with their child (Smith and Luckasson, 1992).

3. Individualized Transition Plans (ITP) - a written plan identifying skills and services needed by an individual to function in the community after the completion of their schooling (Smith and Luckasson, 1992).

1986 - Handicapped Children's Protection Act

Guarantees payment of legal fees for parents who win disputes over special education issues.
1990 - PL 101-476

1. Changed name to Individuals with Disabilities Education Act (IDEA)
2. Changed wording from "handicapped children" to "children with disabilities"
3. Created categories of Autism and Traumatic Brain Injury (TBI) in special education
4. Required transition services be provided no later than age sixteen
5. Called for further definition of Attention Deficit Disorder in the law
6. States may be sued in federal courts for special education law violations.

Other Legislation:

1968 - PL 90-247 Bilingual Education Act
1973 - Vocational Rehabilitation Act, Section 504
1988 - Technology-Related Assistance for Individuals with Disabilities Act
1990 - Americans with Disabilities Act (ADA)

Bars discrimination in employment, transportation, public accommodations, and telecommunications. Guarantees access to all private and public facilities, not only those that are federally funded.

For more information on Special Education Law:
