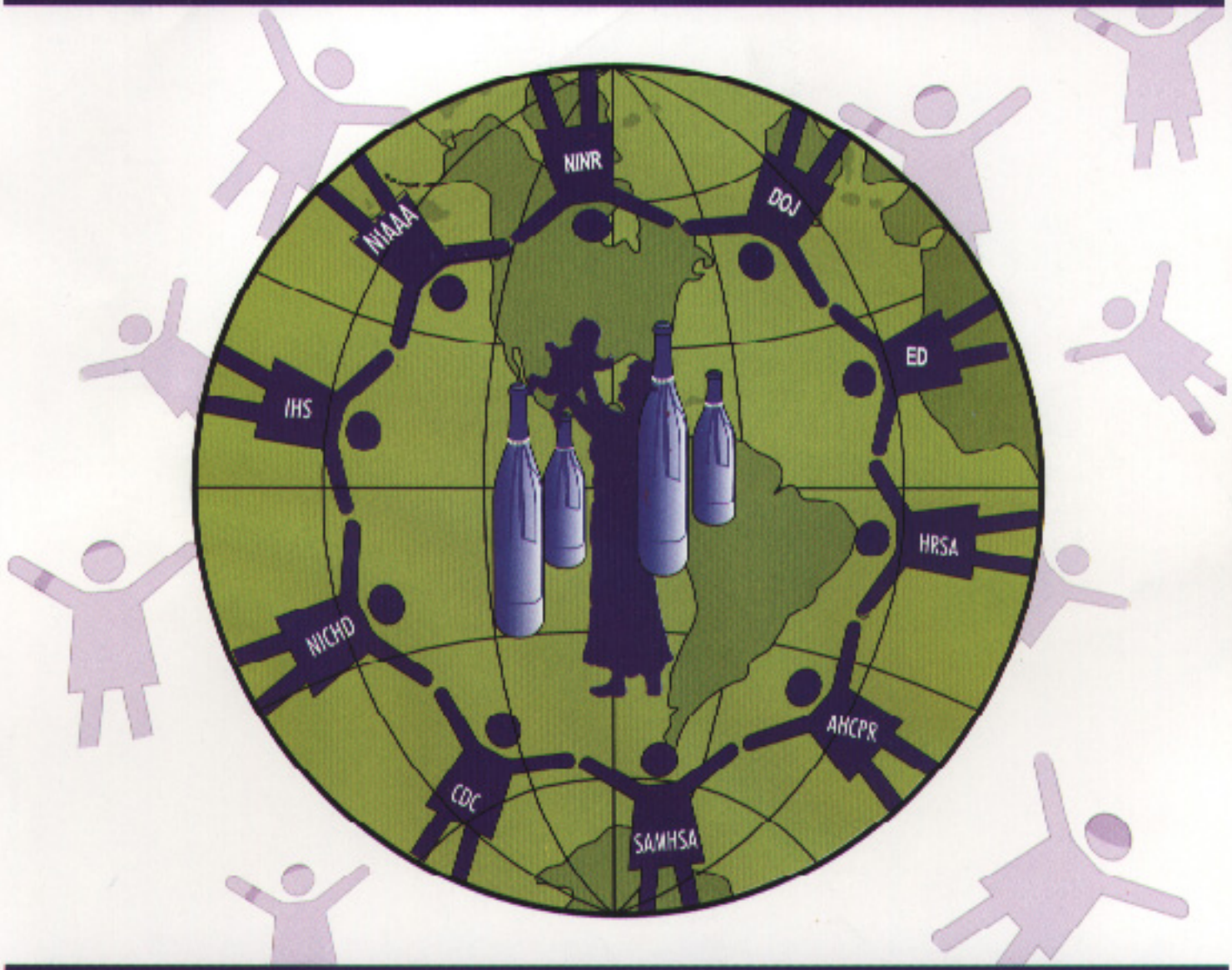
# INTERVENING WITH CHILDREN AFFECTED BY PRENATAL ALCOHOL EXPOSURE

## Proceedings of a Special Focus Session of the Interagency Coordinating Committee on Fetal Alcohol Syndrome




September 10-11, 1998

## PREFACE

This document, *Intervening With Children Affected By Prenatal Alcohol Exposure*, was developed as a summary of the papers presented at a special focus session of the Interagency Coordinating Committee on Fetal Alcohol Syndrome. This meeting was held in Chevy Chase, Maryland on September 10-11, l998. The primary objectives of the Interagency Coordinating Committee are to foster the exchange of information and to promote collaborative efforts between member organizations and between member organizations and other organizations interested in issues related to fetal alcohol syndrome and the effects of prenatal alcohol exposure. The committee identified this topic as critical and a sub-committee was formed to organize this special focus session. The committee is grateful for the work of Dr. Louise Floyd, Centers for Disease Control and Prevention; Dr. Ralph Nitkin, National Institute of Child Health and Human Development and Drs. Kenneth Warren and Faye Calhoun, National Institute on Alcohol Abuse and Alcoholism.

The papers presented cover a wide range of topics related to the behavior, social, and health impacts of prenatal alcohol exposure. The committee is appreciative of the participation and contributions from the FAS Family Institute and the representatives of FAS programs in several states. Many of the scientists whose work is represented have been actively pursuing research in this area for years and the focus session presented an opportunity to review a broad range of research and activities representing many perspectives. While much progress has been made in characterizing the problems resulting from prenatal alcohol exposure and in identifying desired outcomes, it is clear that an expanded effort is needed.

The recommendations and opinions expressed in this summary are those of the presenters and do not necessarily reflect the official position of the Interagency Coordinating Committee or its member organizations.

We commend this summary to you as a document to foster discussion and to promote additional research and activities around these important issues.

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National Institute on Alcohol Abuse and Alcoholism (NIAAA)

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## SUMMARY OF PROCEEDINGS

### INTRODUCTION

DR. FAYE CALHOUN,
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Dr. Calhoun welcomed the participants to the workshop meeting that focused on intervening with children affected by prenatal alcohol exposure. She reviewed the history and activities of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS). The Congress-mandated Institute of Medicine (IOM) report, *Fetal Alcohol Syndrome-Diagnosis, Epidemiology, Prevention, and Treatment* (1995) recommended the creation of an interagency committee to coordinate a national effort addressing FAS. NIAAA was designated as the lead agency due to its long history in addressing prenatal alcohol exposure. Since the inaugural meeting in October 1996, ICCFAS has held five meetings, in which member agencies presented a portfolio of FAS-related programs and activities. In addition, three workshop meetings were held that addressed recommended topics from the IOM report.

### OVERVIEW AND MEETING OBJECTIVES

DR. LOUISE FLOYD,
CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)
AND
DR. RALPH NITKIN,
NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD), NIH

Dr. Floyd stated that the objective of the meeting was to determine how Federal agencies could work with parents, educators, and the scientific community to prevent or ameliorate secondary disabilities among children affected by prenatal alcohol exposure. She reported the 1997 findings of an AD HOC meeting of participants from the Research Society on Alcoholism, which addressed "Future Directions for Intervention Research for Children Affected by Prenatal Alcohol Exposure." The participants reached three consensus points—(I) intervention and treatment of children affected by prenatal alcohol exposure should be a priority issue within CDC and other Federal agencies; (2) characteristics and diagnostic criteria of alcohol-related neurodevelopmental disorders (ARND) require delineation, particularly of cognitive, linguistic, and social attributes; and (3) sufficient animal and human FAS research exists to support development of initial intervention frameworks and protocols.

Dr. Ralph Nitkin remarked that intervention approaches must consider biological and environmental factors. To design successful interventions, it is important to know what regions of the brain are affected by prenatal alcohol exposure, the child's strengths and weaknesses, and confounding home environment factors, such as nutritional deficiencies or history of abuse.

# BRAIN AND BEHAVIOR IN CHILDREN WITH HEAVY PRENATAL ALCOHOL EXPOSURE: STRUCTURAL AND FUNCTIONAL RELATIONSHIPS

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## BACKGROUND

Since the identification of the fetal alcohol syndrome (FAS) thirty years ago (Jones & Smith, 1973; Jones, Smith, Ulleland, & Streissguth, 1973; Lemoine, Harousseau, Borteyru, & Menuet, 1968), it has been known that heavy prenatal alcohol exposure could cause structural defects in the brain. Initially, what was known about these alcohol-related brain anomalies came from human autopsy reports. These autopsies generally showed a wide range of severe and diffuse neuropathological changes. Abnormalities included microcephaly, holoprosencephaly, anencephaly, cerebral dysgenesis, hydrocephaly, ventricular abnormalities, agenesis of the corpus callosum or anterior commissure, migration anomalies, and abnormalities of the basal ganglia, diencephalon, cerebellum, brainstem, optic nerve, and olfactory bulbs (for review, see Mattson & Riley, 1996). It was concluded that a "specific pattern of neurological, behavioral, or intellectual deficit" related to prenatal alcohol exposure was unlikely because of the diffuse nature of the damage (Clarren, 1986). However, those FAS cases coming to autopsy were primarily infants whose deaths were a consequence of their severe prenatal alcohol exposure. Thus, autopsy reports might not be representative of the surviving alcohol-exposed child. Despite the limitations with these autopsy reports, it is important to note that while they may not be representative, there are similarities between the autopsy findings and more recent findings using noninvasive imaging techniques, such as MRI. Furthermore, case reports and behavioral studies on humans and studies using animal models of fetal alcohol effects have been fairly convergent (e.g., Driscoll, Streissguth, & Riley, 1990), showing similar types of effects. This consistency across studies and species indicates a potential pattern or profile of behavioral and neuroanatomical changes related to prenatal alcohol exposure.

Animal models have been essential in elucidating the effects of prenatal alcohol exposure on brain and behavior. Importantly, there are many similarities between the behavioral effects seen in humans and those demonstrated with animal models, underscoring the importance of this type of work. In terms of brain alterations, studies of rat models have included anomalies in neuronal migration (Miller, 1986; Miller, 1993), reduced Purkinje cell numbers in the cerebellum (Bonthius & West, 1991; Pierce, Goodlett, & West, 1989), and alterations in the hippocampus (Barnes & Walker, 1981; Bonthius & West, 1990; Morrisett, Martin, Wilson, Savage, & Swartzwelder, 1989; West & Hodges-Savola, 1983), among others.

Additionally, behavioral similarities comparing human and animal data have been noted and include feeding problems, motor deficits, learning and memory problems, developmental delays, and deficits in attention and increased activity (Driscoll et al., 1990).

Given the findings from both human and animal studies, our laboratory initiated a multidisciplinary project to investigate both brain and behavior in children exposed to large amounts of alcohol prenatally. This multidisciplinary approach has encompassed comprehensive neuropsychological examinations, brain imaging work using magnetic resonance imaging (MRI) done in collaboration with Dr. Terry Jernigan, and electrophysiological investigations done in collaboration with Dr. Cindy Ehlers. The

pediatric dysmorphologist on this project, Dr. Kenneth Lyons Jones, examines all alcohol-exposed children and determines whether children meet criteria for alcohol-related diagnoses, if at all. In the following sections, we will detail some of our behavioral and neuroanatomical findings and integrate them with other findings in the field.

### MICROCEPHALY

One of the most commonly reported structural abnormalities following prenatal alcohol exposure is microcephaly, an overall reduction in the size of the head. In the autopsy reports of children exposed to alcohol prenatally, microcephaly is well-documented (Clarren, Alvord, Sumi, Streissguth, & Smith, 1978; Coulter, Leech, Schaefer, Scheithauer, & Brumback, 1993; Jones & Smith, 1973; Kinney, Faix, & Brazy, 1980; Peiffer, Majewski, Fischbach, Bierich, & Volk, 1979; Ronen & Andrews, 1991; Wisniewski, Dambska, Sher, & Qazi, 1983). This condition is reflective of smaller brains in alcohol-exposed children and is consistent with a decrease in brain weight in animal studies (Diaz & Samson, 1980; West, Goodlett, Bonthius, & Pierce, 1989). It is not surprising then, that across our studies involving MRI, microcephaly was found to be a common feature in individuals with prenatal alcohol exposure (Mattson et al., 1992; Mattson et al., 1994; Mattson et al., 1996b). Additionally, in other MRI studies of children with FAS, microcephaly was reported in the majority of cases (Johnson, Swayze, Sato, & Andreasen, 1996; Swayze et al., 1997).

The presence of microcephaly emphasizes the importance of accounting for overall brain size reduction when evaluating individual brain structures. It stands to reason that a reduction in overall brain size indicates similar reductions of structures within the brain. The presence of such "proportional" reductions would indicate that the whole brain is reduced in volume equally. In contrast, "disproportionate" reductions in specific brain regions (i.e., regional reductions greater than those seen in overall brain volume) suggest that alcohol affects some brain areas more than others. By accounting for overall brain size in the measurement of specific brain regions or structures, region-specific reductions may be identified. For example, in assessing the size of the various lobes of the cerebrum, we found that alcohol reduced most of the cerebral lobes equally, although there was a tendency for the parietal lobe to be disproportionately smaller than expected.

### CEREBELLUM

The cerebellum has also been implicated in studies of FAS, by both human autopsy studies (Clarren et al., 1978; Coulter et al., 1993; Peiffer et al., 1979; Wisniewski et al., 1983) and animal studies (Bonthius & West, 1991; Pierce et al., 1989). In the initial MRI case reports, the overall volume of the cerebellum was significantly reduced in comparison to non-exposed controls (Mattson et al., 1992; Mattson et al., 1994). When results from six additional children with FAS were reported, four had significantly reduced cerebellar volumes (Mattson et al., 1996b), although overall group averages were

not significantly different. An additional study of the cerebellar vermis revealed disproportionate size reductions in the anterior portion (lobules I-V) of this structure, whereas other regions were spared (Sowell et al., 1996). These findings are in agreement with previous reports of anterior vermal abnormalities noted in a rat model of heavy alcohol exposure (Goodlett, Marcussen, & West, 1990). However, whether or not vermal size reductions in alcohol-exposed children are attributable to Purkinje cell death remains to be established.

The main function of the cerebellum is to coordinate limb movement, and maintain balance and posture (Ghez, 1991), although it has also been linked with specific aspects of attention (Courchesne et al., 1994). Recently, we reported deficits in the ability to maintain balance as measured by computerized dynamic posturography (Roebuck, Simmons, Mattson, & Riley, 1998c). This procedure systematically alters somatosensory, visual, and vestibular information and measures changes in the degree of body sway under different permutations of sensory challenge. Balance deficits were noted in children with prenatal alcohol exposure and specifically, alcohol-exposed children were less able than controls to maintain balance when somatosensory feedback was unreliable. These deficits, as well as motor deficits noted in animal models of perinatal alcohol exposure (Goodlett, Thomas, & West, 1991; Meyer, Kotch, & Riley, 1990; Thomas, Wasserman, West, & Goodlett, 1996) suggest that the cerebellum is especially sensitive to such exposure.

### CORPUS CALLOSUM

The corpus callosum is the main band of fibers, which connects the two hemispheres of the brain and allows for interhemispheric transfer of information and bimanual coordination of motor activity. A smaller fiber band, the anterior commisure, also serves this purpose, but plays a much smaller role in interhemispheric transfer than that of the corpus callosum. Autopsy reports of callosal anomalies have described observations ranging in severity from complete absence of the structure (agenesis) to a marked thinning (Clarren et al., 1978; Coulter et al., 1993; Jones & Smith, 1973; Kinney et al., 1980; Peiffer et al., 1979; Wisniewski et al., 1983). Additionally, the anterior commisure was noted as missing (Peiffer et al., 1979) or underdeveloped (Coulter et al., 1993) in some of these reports. This autopsy evidence clearly documents callosal anomalies in children prenatally exposed to alcohol although surviving children with prenatal alcohol exposure may be less affected than those in the aforementioned reports.

Corpus callosum anomalies, including agenesis, have also been reported in MRI studies of FAS. The first case report involving MRI results documented one child with callosal agenesis and one child with a hypoplastic corpus callosum (Mattson et al., 1992). In a subsequent MRI study (Riley et al., 1995), two additional cases of callosal agenesis were documented, resulting in an incidence of 3/44 or 6.8 percent in this sample. Other research groups have also confirmed significant corpus callosum abnormalities in individuals with FAS, including callosal hypoplasia and partial and complete agenesis (Johnson et al.,

1996; Swayze et al., 1997). It has been suggested that the incidence of agenesis found in children with FAS exceeds that of other developmentally disabled populations and of the general population (Jeret, Serur, Wisniewski, & Fisch, 1986; Jeret, Serur, Wisniewski, & Lubin, 1987). Additionally, it has been suggested that FAS may be the most common syndrome associated with agenesis of the corpus callosum (Jeret & Serur, 1991).

Although the rate of agenesis of the corpus callosum is high compared to other groups, even in FAS it is a fairly unusual finding. Thus, we (Riley et al., 1995) evaluated callosal area in 10 children with histories of heavy prenatal alcohol exposure. Disproportionate reductions were found in the most anterior and the two most posterior regions of the corpus callosum. Interestingly, this is a similar pattern found in children with attention deficit hyperactivity disorder (Hynd et al., 1991).

There is some indication that deficits in psychosocial functioning, social abilities, and behavior may be related to the integrity of the corpus callosum. In a group of adolescents with normal IQ, but with agenesis of the corpus callosum, abnormal psychosocial functioning was reported. Specifically, these teens had difficulty in perceiving and understanding social situations correctly and in displaying age appropriate social behavior (Warren Brown, personal communication). Interestingly, evidence of psychosocial deficits has been reported in children with FAS. We reported that social skills, as measured by the Vineland Adaptive Behavior Scales, were impaired in children with FAS in comparison to non-exposed children, including those matched for IQ scores. Children with FAS scored lower than both control groups on social ability measures and demonstrated the most notable impairments in interpersonal relationship skills (Thomas, Kelly, Mattson, & Riley, 1998). We also reported that alcohol-exposed children were significantly impaired relative to controls in psychosocial functioning using the Personality Inventory for Children (Roebuck, Mattson, & Riley, 1998b) and behavior using the Child Behavior Checklist (Mattson & Riley, 1998).

### BASAL GANGLIA

The basal ganglia are a collection of nuclei lying deep within the brain and are composed of two main regions: the caudate nucleus and the lenticular nuclei. These nuclei are implicated in motor, cognitive, and emotional functioning (Masterman & Cummings, 1997). Results from both autopsy (Peiffer et al., 1979; Ronen & Andrews, 1991; Wisniewski et al., 1983) and MRI (Mattson et al., 1992; Mattson et al., 1994; Mattson et al., 1996b) studies have revealed abnormalities or size reductions in this brain region. The first of the case reports (Mattson et al., 1992) noted volumetric reductions in the basal ganglia of two children with FAS. In a subsequent case report of two alcohol-exposed children without the diagnosis of FAS, disproportionate volumetric reductions in the basal ganglia were again noted (Mattson et al., 1994). In a more recent study, six additional children, all of whom had FAS, displayed overall volumetric reductions in the basal ganglia, and in particular the caudate (Mattson et al., 1996b). Animal work has also found a reduction in the size of the caudate following prenatal alcohol exposure (Mattson et

al., 1994). The basal ganglia are strongly implicated in circuitry linking subcortical brain areas to the frontal lobes. These frontal-subcortical circuits are involved in a number of complex systems, including cognitive, affective, and motor functioning (Masterman & Cummings, 1997). The dorsolateral prefrontal circuit has been cited as the circuit involved in carrying out executive functions, such as planning or goal-directed behaviors (Mega & Cummings, 1994). Past studies of children with prenatal alcohol exposure have revealed impairments on separate tasks measuring various aspects of executive function such as planning, working memory, verbal fluency, response inhibition, and cognitive estimation (Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995; Kopera-Frye, Dehaene, & Streissguth, 1996). In a recent study, we (Mattson, Goodman, Caine, Delis, & Riley, 1998a) examined executive functioning using the Delis-Kaplan Executive Function Scale (D-KEFS). This study revealed deficits in the areas of cognitive flexibility, selective inhibition, planning, and abstract thinking. For example, a task involving planning and response inhibition required children to build a pictured "tower" by manipulating five disks of varied size and color between three pegs. However, two rules were imposed: only one disk may be moved at a time using only one hand and a larger disk may never be placed on top of a smaller disk. Alcohol-exposed children could not successfully complete as many "tower" patterns as non-exposed controls and interestingly, had many more cases of rule violations.

We as well as others have also tested children exposed to alcohol prenatally on the Wisconsin Card Sort Test. This task measures cognitive flexibility and response inhibition and presumably involves frontal systems. As expected we found that children exposed to alcohol prenatally are impaired on this task, making more perseverative responses than controls (Mattson, Roebuck, & Riley, 1996c). Importantly, we have preliminary data linking the size of the caudate nucleus to deficits on this task.

On the D-KEFS, executive impairments on measures of flexibility and inhibition were not explained by basic processing deficits such as counting or reading. Notably, deficits in all areas were found in children exposed to heavy amounts of alcohol prenatally with or without a diagnosis of FAS and who were not mentally retarded.

In another test of executive functioning from the D-KEFS, verbal and nonverbal fluency was measured. For example, the child would have to say as many words as he or she could produce beginning with the letter "F," or connect dots to produce as many unique designs as possible in a given period of time. Children exposed to alcohol prenatally performed at a level significantly below non-exposed controls on both verbal and nonverbal domains, suggesting a global fluency deficit (Goodman, Mattson, Lang, Delis, & Riley, 1998). Similar executive functioning deficits are also seen in patients with Huntington's disease, a disease with reductions in the size of the caudate, albeit to a more significant degree than in FAS. When patients with Huntington's disease were studied with positron emission tomography (PET) and MRI, the basal ganglia were linked to executive function impairments (Bäckman, Robins-Wahlin, Lundin, Ginovart, & Farde, 1997). This finding supports the suggestion that the

disproportionate volume reductions in caudate are related to the executive function deficits seen in alcohol-exposed children.

Another main frontal system circuit, the lateral orbitofrontal circuit, has been implicated in the display of social skills mediating "empathic, civil, and socially appropriate behavior" (Mega & Cummings, 1994, p. 362). Our studies on psychosocial functioning may also have implications for the state of the lateral orbitofrontal circuit in prenatally exposed children. As previously mentioned, children with FAS have displayed impairments on measures of social skills functioning and interpersonal relations (Thomas et al., 1998), and psychosocial (Roebuck et al., 1998b) and behavioral functioning (Mattson & Riley, 1998). As noted earlier, corpus callosum abnormalities might be linked to deficits in psychosocial functioning. However, it is also possible that the basal ganglia, as well as the corpus callosum, are implicated in social and emotional deficits prevalent in this disorder.

A third frontal-subcortical circuit, the anterior cingulate circuit, has been linked to response inhibition and display of appropriate affect (Mega & Cummings, 1994). Importantly, in the context of executive function reports, children in our study have demonstrated problems with response inhibition (Mattson et al., 1998a), a finding which has been reported by other research groups as well (Kodituwakku et al., 1995). However, one of the hallmark features of individuals with anterior cingulate damage is emotional indifference (Mega & Cummings, 1994), a finding not often described in individuals with FAS. Additionally, the anterior cingulate is less well studied than the other frontal system circuits (Cummings, 1993) and warrants further investigation. Given the basal ganglia's integral role in the frontal-subcortical circuits relating to cognitive and affective domains, the reductions seen in this structure are likely to be involved in alcohol-related deficits observed in these areas.

We recently reported that children with prenatal alcohol exposure display deficits in a reflex used to maintain equilibrium in responses to rapid "toe-up" disturbances of balance. Using electromyography (EMG), we found that children with prenatal alcohol exposure had slower responses on a "long-latency" reflex thought to involve central processing at the level of the brain. Other responses, which are regarded as spinal reflexes that are not processed at this central level, were not different from non-exposed controls (Roebuck, Simmons, Richardson, Mattson, & Riley, 1998). This long-latency deficit may be linked to basal ganglia function, specifically via motor circuits. A study of patients with Huntington's disease reported delays in this same long latency reflex and suggested a relationship between this reflex and their basal ganglia abnormalities (Huttunen & Hömberg, 1990).

Although it is well documented that the caudate nucleus is an active participant in the frontal system circuits (Cummings, 1993; Masterman & Cummings, 1997; Mega & Cummings, 1994; Stuss, Alexander, & Benson, 1997), the exact relationship between these structures and neurobehavioral outcome in children with prenatal alcohol exposure is not entirely clear. Additional studies involving such techniques as PET or functional MRI (fMRI) may help elucidate this relationship.

## OTHER NEUROPSYCHOLOGICAL FINDINGS

**Intellectual Functioning**. In our laboratory, we have studied IQ in both FAS children and in a group of children with documented exposure to high levels of alcohol but who were not dysmorphic, microcephalic, or growth retarded (Mattson, Riley, Gramling, Delis, & Jones, 1997). We designate these latter individuals as having prenatal exposure to alcohol (PEA). Both the FAS and PEA groups displayed significant deficits in overall IQ as well as deficits on most of the subtest scores in comparison to normal controls. The PEA subjects generally had slightly higher IQ scores than the children with FAS, but few significant differences were found between the two alcohol-exposed groups. Thus, high levels of prenatal alcohol exposure resulted in intellectual deficits both in children with FAS and in those without the physical features required for this diagnosis.

**Visuospatial Abilities**. One interesting finding from our laboratory is a deficit in local processing of hierarchical stimuli (Mattson, Gramling, Delis, Jones, & Riley, 1996a). Children with FAS were impaired in recalling and copying local (details) but not global (configural) features of a complex stimuli. These deficits were not due to the size of the stimuli or to deficits in memory, and suggested a specific impairment in processing local features of hierarchical visual information. Similar deficits have been noted in other developmental (Bihrle, Bellugi, Delis, & Marks, 1989) and dementing (Delis et al., 1992) disorders. Although very speculative, these data might implicate differences between hemispheric involvement in fetal alcohol effects, since the loss of local features has been related to functions traditionally thought to involve the left hemisphere.

**Learning & Memory**. We have recently compared performances between children with FAS and non-exposed controls on comparable tests of verbal and nonverbal learning and memory: the California Verbal Learning Test-Children's Version and the Biber Figure Learning Test, respectively (Mattson & Roebuck, 1998). On both tasks, children with FAS were impaired on all learning and free recall trials but demonstrated relatively spared recognition memory. In addition, when corrected for differences in initial learning, savings scores were similar to controls, consistent with intact retention of the learned material. These results indicate that the learning deficits seen in children with FAS occur in both verbal and nonverbal domains and that, importantly, retention for this material may be relatively spared. These results add to the body of literature documenting deficits in learning or memory in alcohol-exposed children (Streissguth, Bookstein, Sampson, & Barr, 1989; Uecker & Nadel, 1996) and animals (Gianoulakis, 1990; Lochry & Riley, 1980; Reyes, Wolfe, & Savage, 1989).

**Language**. Verbal ability was assessed within a comprehensive study of neuropsychological functioning that compared children with FAS, PEA, and non-exposed controls (Mattson, Riley, Gramling, Delis, & Jones, 1998b). Both receptive (naming ability) and expressive (word comprehension) language were impaired in children with FAS and PEA when compared to non-exposed controls. However,

performance on these tests did not differ between the alcohol-exposed groups. These results further underscore that lack of an FAS diagnosis does not imply a lack of neurobehavioral deficits in other alcohol-exposed groups.

## CONCLUDING REMARKS

It is well documented that heavy exposure to alcohol prenatally can result in both structural and functional anomalies, and the aim of this report has been to provide the reader with a greater appreciation of these deficits. Structurally, the corpus callosum, the cerebellum, and the basal ganglia appear to be especially sensitive to prenatal alcohol exposure. Whereas a comprehensive review of the behavioral problems in these children would have been outside of the scope of this paper, we hope to have emphasized that these children suffer from behavioral deficits in such domains as motor functioning, executive functioning, and social functioning, among others. Additionally, these findings may be related to observed brain structural anomalies. Thus, in several cases, we tried to draw a link between the structural and functional changes, although much of these associations are still speculation. With the growth of new and advanced technologies such as MRI, we should begin to obtain a much better understanding of the relationship between brain structure and behavior in these children. This is clearly the direction in which the study of alcohol related birth defects should progress. With results from neuropsychological and neuroimaging studies such as those mentioned in this report, researchers will be able to devise the most appropriate approaches for future investigations integrating brain structure and function. Furthermore, understanding these relationships will help us to devise the strategies most appropriate for maximizing strengths and minimizing weaknesses in the neurobehavioral functioning of these children.

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## ABBREVIATED SUMMARY OF PRESENTATION AND PARTICIPANT DISCUSSION

Brain Structures Affected by In Utero Alcohol Exposure and Critical Periods of Exposure

DR. ED RILEY,
SAN DIEGO STATE UNIVERSITY

Dr. Riley explained that the human brain consists of approximately 20 billion nerve cells that come into existence by the fourth month of gestation. By 40 days postconception, 50,000 nerve connections are formed per minute. An enormous potential exists for damage to brain development due to prenatal alcohol exposure. Animal studies demonstrated that in utero exposure to alcohol prevents the normal migration of nerve cells in the developing brain. Additionally, the number of Purkinje cells is altered, depending on the timing of exposure.

Dr. Riley's human subject research used a multidisciplinary approach, consisting of neuropsychological testing, brain imaging with magnetic resonance imaging (MRI), and electrophysiological studies. The MRI studies found that FAS children demonstrate size reductions in the basal ganglia, cerebrum, cerebellum (particularly the anterior vermis), corpus callosum (in some cases, agenesis of the corpus callosum), and overall brain size.

The pattern of size reduction in the corpus callosum is similar to reductions in children with attention deficit hyperactivity disorder (ADHD). The corpus callosum reduction may be related to difficulty in processing complex social stimuli (e.g., facial expressions). Reduced basal ganglia volume may be responsible for some behavioral problems displayed by FAS children, such as poor spatial memory, goal-directed behavior, or inhibitory behavior. As the basal ganglia also participates in the dorsolateral prefrontal circuit, its reduced size may explain decreased verbal and nonverbal fluency, decreased learning ability, decreased memory retrieval, and impaired problem solving observed in FAS children.

The neuropsychological tests included IQ, language performance, visuospatial ability, fine motor skills, verbal learning and memory, nonverbal learning, and academic achievement. Test outcomes revealed that heavy prenatal alcohol exposure is associated with a wide range of neurobehavioral deficits including visuospatial functioning, verbal and nonverbal learning, and executive functioning. Children prenatally exposed to alcohol, with or without the physical features of FAS, display qualitatively similar deficits. A specific pattern of relative strengths and weaknesses may exist that would support interventions based on maximizing the strengths and minimizing the weaknesses.

The type and magnitude of alcohol-related effects depends on the stage of organ development exposed to alcohol. For example, mouse fetuses exposed to alcohol on gestation day 8 (for a single day) will display facial anomalies. If exposure is delayed for 2 days, facial anomalies are not observed. Rats that ingest alcohol on postnatal days 4 and 5 (analogous to the human third trimester), when the cerebellum is developing, exhibit reduced cerebellum weight and performance in balance tests. Delaying

exposure decreases the difference between the control animals and the exposed animals. Different behavioral and physical characteristics have different critical periods for alcohol exposure.

**Discussion**

Dr. Nitkin asked if Dr. Riley had determined at what stage the human study subjects were prenatally exposed to alcohol. Dr. Riley replied that most of the subjects were exposed throughout gestation. In a few cases, the mother stopped or reduced consumption at the end of the second trimester. Larger collaborative projects might examine the timing of exposure.

Dr. Kiernan O'Malley commented that recent research demonstrated that stress or medication might cause pseudohypertrophy in the hippocampus. Dr. Riley noted that these factors are relevant to FAS patients and warrant further exploration.

Dr. Ann Anderson asked if the neuropsychological tests used in Dr. Riley's study could be applied in an educational setting. Dr. Riley explained that the neuropsychological evaluation for the study involved specific tests that are not used in a general education setting. Dr. Anderson inquired as to what tests should be used to determine whether a child has learning problems related to alcohol exposure. Dr. Riley stated that a test battery for executive function does not exist to discriminate children with a history of alcohol exposure from those with no alcohol exposure. Studies using IQ-matched controls indicate that many of the neuropsychological deficits may be related to general IQ deficits.

Dr. Kenneth Warren questioned whether the prenatal exposure to alcohol (PEA) subjects (with no characteristic FAS facial anomalies) were identified through the mother's history of alcohol abuse or the child's behavioral deficits. Dr. Riley responded that most of the PEA children were identified through the California Teratogen Registration Service. Some children were identified through clinics noting a chart entry of heavy maternal alcohol abuse. Dr. Warren asked if PEA children have normal IQs. Dr. Riley explained that the average IQ score for these children is in the 80s, while some scores are as high as 100. Their normal IQ range adds to the difficulty in identifying PEA children.

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# THE COGNITIVE, SOCIAL, AND HEALTH IMPACTS OF PRENATAL ALCOHOL EXPOSURE: INTERVENTION ISSUES FOR REASONABLE STANDARDS OF COMMUNITY CARE

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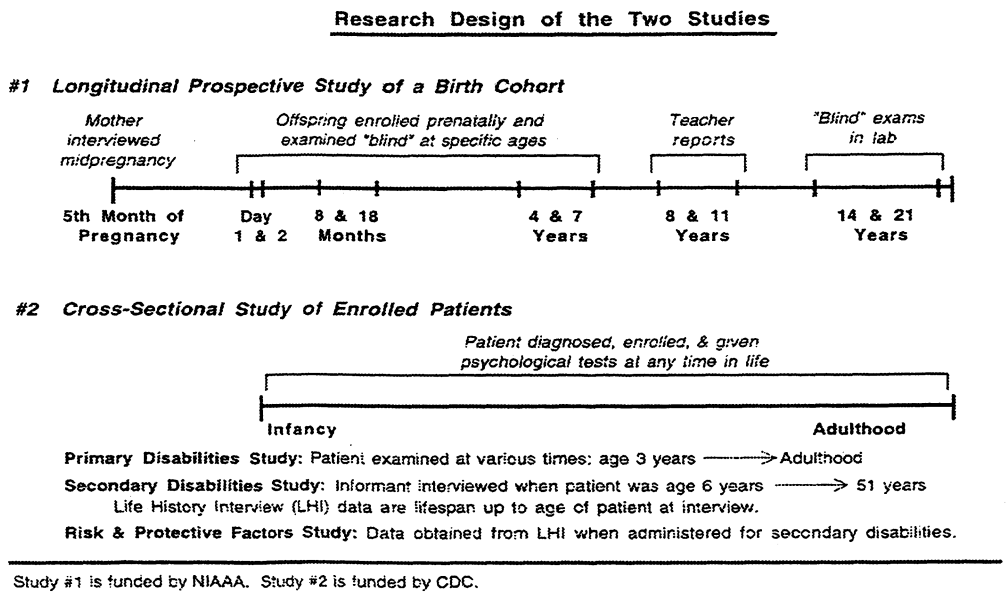
## INTRODUCTION

In considering how to design appropriate interventions and develop reasonable standards of care for people with Fetal Alcohol Syndrome and other Fetal Alcohol Effects, three separate issues are important. First, these disorders are birth defects, caused by prenatal alcohol exposure, and they have lifespan implications for the cognitive functioning, social interactions, and mental health of affected individuals. Second, there are postnatal environmental factors associated with maternal alcohol abuse and its household consequences that can exacerbate the prenatal insults. Third, there are policy issues pertaining to service delivery that can further handicap the lifespan struggles of affected individuals. Understanding the pertinent research findings on these topics that have accrued over the past 24 years can guide intervention research, community action, and public policy.

This paper reviews the findings from two major Federally funded research projects relevant to the social, cognitive, and mental health impacts of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) or Alcohol Related Neurodevelopmental Disorders (ARND). The first, the Seattle Longitudinal Prospective Study on Alcohol and Pregnancy is a birth cohort study funded since 1974 by the National Institute on Alcohol Abuse and Alcoholism (NIAAA). The goal of the study is to evaluate the long-term influences of prenatal alcohol exposure across the whole range of exposures, on the health and development of the offspring. By careful research design and covariate control, an epidemiologic study such as this can shed light on the etiologic role of alcohol in the cognitive impairment of infants and children and the lifetime course of cognitive disability.

The second study, on Primary and Secondary Disabilities in Patients With Fetal Alcohol Syndrome and Fetal Alcohol Effects, is a cross-sectional study of people of various ages who had previously been diagnosed with FAS or FAE, who were enrolled in a fetal alcohol follow-up study. The mother of each patient had abused alcohol during pregnancy. This latter study was funded by the Centers for Disease Control and Prevention (CDC) from 1992–1997. This large clinically based study examines the relationship between primary and secondary disabilities, and those risk and protective factors that can exacerbate or ameliorate secondary disabilities.

Figure 1 presents a graphic representation of the two studies. Together, they provide special insights for intervening with fetal alcohol-affected individuals and for developing appropriate standards of care.




## STUDY 1

The Seattle Longitudinal Prospective Study (Grant # R01/AA01455-01-23, referred to here as the NIAAA study) is a population-based study ongoing since 1974 which demonstrates broad CNS effects of prenatal alcohol in a primarily low-risk population conceived before general awareness of alcohol's adverse effects on pregnancy outcome and the later lives of those who are exposed.

Two hospitals were selected for study with demographic characteristics representative of the Seattle area. In order to study alcohol effects in the absence of competing risks, only women enrolled in prenatal care by the 5th month of pregnancy were eligible. The screening interviews from 1529 consecutive consenting women revealed a fairly low-risk lifestyle in relation to a variety of factors that could relate to offspring health, including diet, drugs, medications, caffeine, alcohol, smoking, family

history, and environment. The follow-up birth cohort of approximately 500 infants represented an over sampling of the heavier drinkers and smokers from the original 1529, along with others representing a variety of drinking patterns including abstinence. In this sample, 18 percent used marijuana, 2 percent used other street drugs, 12 percent had not graduated from high school and 8 percent were on welfare.

The primary independent variable, alcohol, was assessed via a Quantity-Frequency-Variability interview with additional questions about higher levels of drinking, intoxications, and problems with drinking. Drinking during two time periods was assessed: During pregnancy (D) and Prior to pregnancy or pregnancy recognition (P). see Streissguth et al. (1993, 1994a) for details. Although 86 percent of the mothers reported drinking during one or another of these time periods, only 1 percent reported any problems with alcohol. The majority of mothers were white, married, middle class, and well educated, although a broad range of socioeconomic and racial groups was represented. Heavier drinking mothers did not differ from the rest of the mothers in terms of nutrition, maternal weight gain, prenatal care, or other pregnancy risk factors such as diabetes, renal disease, thyroid abnormality, or rubella.

Children in the follow-up birth cohort were examined on days 1 and 2 of life, at 8 and 18 months, and at 4, 7, and 14 years; (see Figure 1). Parents were interviewed at each examination; teacher evaluations were obtained at 8 and 11 years. All examinations were conducted blind, without the examiner knowing subjects' exposure history, living conditions, or previous performance on tests. Follow-up has been excellent, with at least 82 percent of the original follow-up birth cohort at each assessment. There has been no differential loss of heavily exposed subjects. (The cohort was also examined at 21 years, but analyses are not available at this writing.)

Data analyses from the first 4 years of life involved multiple regression analyses of single outcomes against single alcohol predictor variables. Analyses from 7 years onward have incorporated Partial Least Squares (PLS), a method of data analysis that permits the simultaneous assessment of the relationship among multiple alcohol predictor scores and multiple outcome scores. PLS is better suited than multiple regression or other alternatives to the complex multifactorial data generated in human behavioral teratology studies such as ours (Bookstein et al., 1996). PLS analyses yield Latent Variables (LVs) for both dose (Alcohol LVs) and response (Outcome LVs) that demonstrate the salience of prenatal alcohol scores for the outcomes under consideration (Sampson et al., 1989; Streissguth et al., 1993, 1994a, 1989a). The Alcohol LV is computed as a linear combination of all the prenatal dose measures, each one nonlinearly transformed according to a scatterplot smoother applied to its relationship with the Outcome LV. This permits consideration of possible threshold effects. The Alcohol LV is very stable over the whole range of outcome ages examined in the present study.

Data on possible confounds were obtained prospectively, prenatally, and at each succeeding examination. More than 150 in number, these variables include maternal nutrition and use of all drugs and medications during pregnancy, socio-demographic and education characteristics of the family,

mother/child interactions, major life stresses in the household, childhood accidents, hospitalizations and illnesses, education experiences of the child, family history of alcoholism, and many others (Baer et al., 1998; Streissguth et al., 1993, 1994a).

All findings reported here have been evaluated in terms of potential confounds. Correlations between the many covariates in the database and the Outcome LVs were examined, and then covariates associated with both the Alcohol LV and Outcome LVs were examined in regression analyses to see the extent to which they alter the estimated effects of alcohol dose. Scatterplots and partial residual plots are routinely examined.

**FINDINGS: STUDY 1**

Prenatal alcohol exposure, after covariate control, was related to infant outcomes on day 1 of life. These include: poor habituation to redundant stimuli and poor response modulation measured on the Brazelton Scale (Streissguth et al., 1983); other CNS effects measured with naturalistic observations including increased head-turning to the left, tremulousness, hand-to-face movements, time with eyes open, and decreased bodily activity (Landesman-Dwyer et al., 1978); and both hyper-responsive reflexes (Incurvation, Passive Arms reflex) and weak or delayed reflexes (Stepping reflex, Moro) (Streissguth et al., 1993). On day 2 of life, prenatal alcohol was significantly related to longer latency to suck and lower sucking on a pressure-transducer measure of non-nutritive sucking (Martin et al., 1979). At 8 months (but not at 18 months) prenatal alcohol was related to subtle decreases in mental and motor development on the Bayley Scales and to increased feeding problems (Streissguth et al., 1980; 1993). Prenatal alcohol was also related to IQ decrements on the WPPSI at 4 years (Streissguth et al., 1989b) and on the WISC-R (particularly Arithmetic and Digit Span subtests) at 7 years (Streissguth et al., 1990; 1993; Sampson et al., 1989). At 4 years, prenatal alcohol was also related to more "time in error" (suggesting slower central processing time), poorer fine motor performance on the Wisconsin Motor Steadiness Battery, and poorer gross motor performance (especially balance) (Barr et al., 1990).

Attentional deficits, assessed by vigilance tests, were associated with prenatal alcohol exposure at 4, 7, and 14 years. Errors of omission (failing to respond to the target stimulus), errors of commission (responding to the wrong stimulus), and high variability of reaction time were the strongest prenatal alcohol-related attentional deficits (Streissguth et al., 1984, 1995, Sampson et al., 1989). Many other neurobehavioral, phonological, and memory tests were also related to prenatal alcohol at 7 years (Streissguth et al., 1989b, 1993) and at 14 years (Streissguth et al., 1994a, 1994b).

Academic problems were associated with prenatal alcohol from the first grade on, particularly problems with arithmetic (Sampson et al., 1989; Streissguth et al., 1993, 1994b). By the end of the 2nd grade, prenatal alcohol was associated with higher frequency of participation in special programs and classes in school, and with teacher ratings of poor organization, poor attention, poor grammar and word recall, and less tactfulness (Streissguth et al., 1990, 1995). By the 11th grade, prenatal alcohol was

associated with lower functioning on standardized school-administered tests of arithmetic and overall achievement and with teacher ratings of distractibility, poor persistence, and restlessness as well as with problems with information processing and reasoning skills (Carmichael Olson et al., 1992). By age 14, poor academic performance was reported both by the adolescents themselves and by their parents (Carmichael Olson et al., 1997).

Prenatal alcohol exposure was related to examiners' ratings of poor goal directedness, short attention spans, frequent verbal interruptions, excessive talking, general hypertonia, distractibility, poor organization, and a rigid inflexible approach to problem solving at 7 years (Streissguth et al., 1989b, 1993). At 14 years prenatal alcohol was related to examiner ratings of high impulsivity and poor organization under stress (Carmichael Olson et al, 1997). A surprising new finding from the 14-year examination is that prenatal alcohol exposure is a significant predictor of adolescent alcohol problems and use, in fact, a stronger predictor than family history of alcohol abuse (Baer et al., 1998).

The neurobehavioral effects of prenatal alcohol summarized here have been measured in this study from the first day of life through 14 years. New effects were detected at each new age of assessment, as the developing child accrued more testable behaviors (Streissguth et al., 1993). The observed alcohol effects on offspring are dose-dependent, generally without a threshold, and are more salient for binge-type maternal alcohol use. Self-reported drinking prior to pregnancy recognition is generally more salient for these outcomes than drinking in mid-pregnancy, but the two are highly correlated. The results reported are not attributable to such potential confounds as other drug exposures, smoking, or social/demographic factors (Streissguth et al., 1993, 1994a). They are also not mediated by low birth weight in this generally low risk group. In fact prenatal alcohol effects on height and weight in this group are undetectable after 8 months of age (Sampson et al., 1994). For details of specific analyses, see the original scientific papers from which this overview derives. Streissguth et al., 1993 lists all publications prior to 1993. A full listing of published papers from this study is available from the author.

This study, and other prospective studies of prenatal alcohol exposure, carried out in other countries and with other populations, demonstrates the short and long-term impacts of prenatal alcohol exposure, particularly on CNS functioning. See, for example, Aronson et al., 1985; Coles et al., 1992; Day et al., 1994; Halmesmäki et al., 1988; Jacobson et al., 1993; 1994; and Larroque et al., 1995. These research findings, revealing the breadth of neurobehavioral effects associated with prenatal alcohol even below alcoholic levels, are replicated in almost all instances by experimental animal studies (Driscoll et al., 1990; Goodlett and West, 1992; Riley and Vorhees, 1986; West 1986). In many animal studies, the behavior can be clearly linked to offspring brain damage. Mechanisms for ethanol-induced teratogenesis include excessive cell death, reduced cell proliferation, migrational errors in brain development, inhibition of nerve growth factor, and neurotransmitter disruption, among others (Goodlett and West, 1992; West, 1986). There is no doubt that alcohol is teratogenic (Randall et al., 1990; Schenker et al., 1990) and that

CNS damage can be produced at lower levels of exposure and more variable periods of exposure than the more obvious physical birth defects.

Two children from our longitudinal prospective NIAAA study were diagnosed FAS at birth in blind examinations of most of the children with the highest levels of prenatal alcohol exposure from among the singleton births. Accounting for less than complete assessment of all the highly exposed infants, this translates into an approximate FAS incidence rate of 3 per 1,000 live births, a figure that is compatible with the very few other comparable studies that have been carried out. The prevalence rate of ARND, according to an operational definition involving the full history of alcohol-related deficits from birth through 7 years, is approximately twice that of FAS, and the combined rate of FAS and ARND was estimated to be nearly 1 per 100 live births (Sampson et al., 1997).

Our NIAAA study demonstrates the many subtle and not-so-subtle types of birth defects caused by prenatal alcohol exposure. Our CDC study demonstrates what happens to patients with Fetal Alcohol Syndrome and Fetal Alcohol Effects in real life.

**STUDY 2**

The Study of Primary and Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects (Grant R04/CCR008515, referred to here as the CDC study) is a cross-sectional study of patients of various ages who had been diagnosed by dysmorphologists associated with David W. Smith and the University of Washington and who were referred to the Fetal Alcohol Syndrome Follow-up Study between 1973 and 1995 (Jones et al., 1973; Jones & Smith, 1973). The goals of this study were twofold:

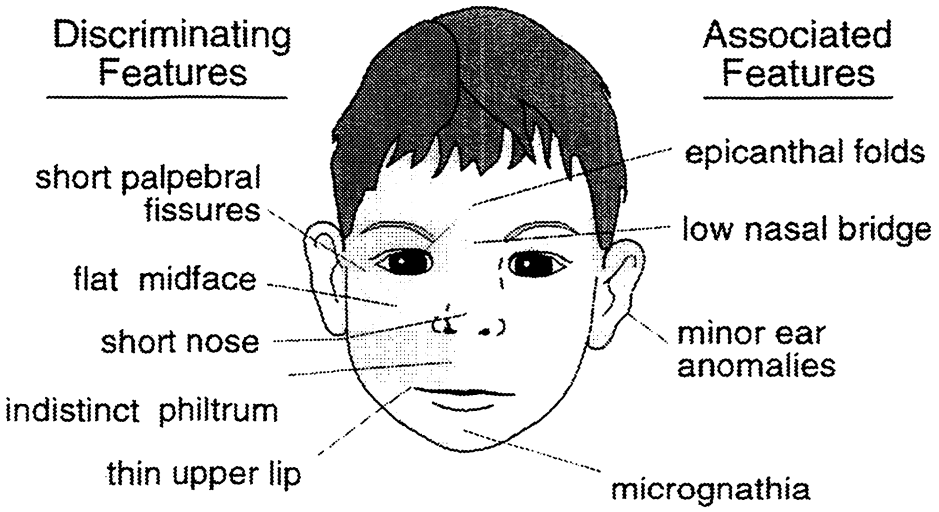
1. To document the occurrence and range of secondary disabilities that are associated with FAS and FAE. These include: 1) mental health problems, 2) disrupted school experiences, 3) trouble with the law, 4) confinement, 5) inappropriate sexual behavior, and 6) drug/alcohol problems.

2. To determine the risk and protective factors associated with these secondary disabilities. A risk factor is a characteristic or condition that is related to increased odds of a particular disability occurring. A protective factor is a characteristic or condition that is related to decreased odds of a secondary disability occurring. Universal risk or protective factors are those that apply to all six of the secondary disabilities in which we are most interested. Specific risk or protective factors are those that apply to only some of the six, or that are related to increased odds of some secondary disabilities, but to decreased odds of others. A full description of the study is available in Streissguth, A.P. et al., 1996 and a brief description in Streissguth et al., 1997.

Fetal Alcohol Syndrome (FAS) is diagnosed by the co-occurrence of three primary characteristics: growth deficiency, a typical pattern of abnormalities primarily observable in the face, and

some manifestation of Central Nervous System (CNS) dysfunction. Figure 2 presents a diagram of the significant facial features in Fetal Alcohol Syndrome in the young child. The definition of CNS criteria used here is in keeping with that originally used by Jones and Smith (1973, 1975) and Clarren and Smith (1978) and is *not* wholly consistent with the modification suggested by the recent IOM report (1996). Fetal Alcohol Effects (FAE) and PFAE (possible or probable FAE) are terms that have been used clinically to apply to individuals who manifest some, but not all of the characteristics of FAS, but were exposed prenatally to significant alcohol. The terms FAE and PFAE, as they have been used by Seattle dysmorphologists since 1974, *are* consistent with the new diagnostic category of ARND (Alcohol Related Neurodevelopmental Disabilities) suggested by the IOM (1996). For this report, the FAE and PFAE categories are combined.

## The Face of Fetal Alcohol Syndrome




## In the Young Child

Patients with FAS had (1) a clear history of prenatal alcohol exposure; (2) a characteristic pattern of dysmorphic features including short palpebral fissures, midface hypoplasia, smooth and/or long philtrum, and thin upper lip; (3) growth retardation of prenatal onset for height and/or weight; and (4) central nervous system (CNS) dysfunction, as manifested by microcephaly, developmental delay, hyperactivity, attention and/or memory deficits, learning difficulties, intellectual deficits, motor problems, neurologic signs, and/or seizures. Patients with FAE or PFAE had a clear history of prenatal alcohol exposure and CNS dysfunction, but did not manifest all of the physical features of FAS.

The 415 patients in the Secondary Disabilities Study were those who were 6 years or older at the time of the study, and for whom a caretaker, or other person familiar with them, was available for a Life

History Interview (LHI) usually administered by phone, which took on average 70 minutes. Although the two samples are comparable with respect to the referral source, the diagnosing physician, and date of diagnosis.

The patients in the secondary disabilities study were 60 percent white, 25 percent Native American, 7 percent black, 6 percent Hispanic, and 2 percent Asian and other. 57 percent were male. 37 percent were diagnosed FAS, the rest were FAE or PFAE. 39 percent of the subjects were between 6 and 11 years old; 39 percent were 12 to 20 years old; and 22 percent were 21 to 51 years old. Their median age was 14.2 years. Informants for the 415 LHI's were varied: 33 percent were adoptive mothers, 17 percent biological mothers, and 12 percent foster mothers. The rest were other relatives, legal guardians, spouses, and others.

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

A set of 21 possible risk and protective factors were extracted from the LHI and these were examined through an analysis of odds ratio plots across the first six secondary disabilities. When risk and protective factors involved continuous scores (as in 1, 4, 5, and 8 below), the cut point for risk versus protective factors was defined as the sample median.

The 473 patients in the Primary Disabilities Study were those who had previously been examined at our Fetal Alcohol and Drug Unit on age-appropriate Wechsler IQ tests (WPPSI; WISC-R; WAIS-R) the Wide Range Achievement Test (WRAT-R). and the Vineland Adaptive Behavior Scale (VABS). Patients ranged in age from 3 to 51 years.

**FINDINGS: STUDY 2**

The findings from the 473 patients in the Primary Disabilities Study are as follows: Those with FAS (n = 178) had an average IQ of 79, average reading, spelling, and arithmetic standard scores of 78, 75, and 70, and an average Adaptive Behavior standard score of 61. Those with FAE (n = 295) had an average IQ of 90, average reading, spelling, and arithmetic standard scores of 84, 81, and 76, respectively, and an average Adaptive Behavior score of 67. (For IQ scores, Achievement Scores, and Adaptive Behavior, a score of 100 is normal and the standard derivation is 15.)

The findings from the 415 patients in the Secondary Disabilities Study are as follows:

- *Mental Health Problems*, defined as ever having gone to a psychotherapist or counselor or been an inpatient for a mental health problem or having any one of a long list of mental health problems, was by far the most prevalent secondary disability, experienced by over 90 percent of the full sample (6 years and over, and 12 years and over).
- *Disrupted School Experience,* defined as having been suspended or expelled from school or having dropped out of school, was experienced by 60 percent of patients (12 years and over).
- *Trouble With the Law,* defined as ever having been in trouble with authorities, charged, or convicted of a crime, was experienced by 60 percent of the patients (12 years and over).
- *Confinement,* including inpatient treatment for mental health problems or alcohol/drug problems, or ever having been incarcerated for a crime, was experienced by about 50 percent of the patients (12 years and over).
- *Inappropriate Sexual Behavior*, including having been reported to have repeated problems with one or more of 10 inappropriate sexual behaviors or ever having been sentenced to a sexual offenders' treatment program, was noted for about 50 percent of the patients (12 years and over).
- *Alcohol/Drug Problems*, defined as having been in treatment for an alcohol or drug problem or as having alcohol and/or drug abuse problems, was noted for about 30 percent of the patients (12 years and over).

In an effort to determine how many patients became self-sufficient as adults, two additional "secondary disabilities" (defined by a complex set of criteria, Streissguth et al., 1996) were evaluated for the 90 patients who were at least 21 years old (median age 26 years). Only seven of the 90 adults in this sample were reported to be living independently *and* without employment problems. Overall:

- *Dependent Living,* characterized about 80 percent of the sample (21 and over).
- *Problems With Employment*, characterized about 80 percent of the sample (21 and over)

The findings from the Risk/Protective Factors analyses are as follows: Eight universal protective factors were significantly related to secondary disabilities among patients 12 years old and older. These universal protective factors reduced the odds of an adolescent or an adult with FAS or FAE having any of the six secondary disabilities under investigation. In order of their strength, these protective factors are:

1. Living in a stable and nurturant home for over 72 percent of life;
2. Being diagnosed with FAS or FAE before the age of 6 years;
3. Never having experienced violence against oneself;

4. Staying in each living situation for an average of more than 2.8 years;
5. Experiencing a good quality home (10 or more of 12 "good" qualities) from age 8 to 12 years;
6. Being found eligible for DDD (Division of Developmental Disabilities) services;
7. Having a diagnosis of FAS (rather than FAE);
8. Having basic needs met for at least 13 percent of life.

Odds of Mental Health Problems and odds of Disrupted School Experience are reduced primarily by the universal protective factors. The rate of Trouble with the Law is related to all the universal protective factors, most notably DDD eligibility for services. Confinement also is related to the universal protective factors, especially living in a stable and nurturant environment, and being diagnosed prior to age 6 years. Odds of Inappropriate Sexual Behavior are reduced by all universal protective factors. Alcohol and Drug Problems have one specific protective factor in addition to universal protective factors: having lived with an alcohol abuser *less* than the median for the group, which was 30 percent of life.

Some secondary disabilities also act as risk factors for others. For example, Disrupted School Experience is related to almost triple the rate of Trouble With the Law. Alcohol and Drug Problems is related to almost double the rate of Trouble With the Law. Thus, any actions to prevent Disrupted School Experience and Alcohol and Drug Problems may also reduce Trouble With the Law.

In evaluating the backgrounds of these patients with FAS/FAE through the LHI, some alarming statistics are noted. When these are examined in light of their importance as risk or protective factors, the needed interventions become clear.

- Early diagnosis of FAS/FAE: While an early diagnosis is a strong universal protective factor for all secondary disabilities, only 11 percent of these individuals with FAS/FAE were diagnosed by age 6. Every effort should be made to provide an early diagnosis for every child with FAS and FAE.
- Receiving DDD services: While receiving services from the state's Division of Developmental Disabilities (DDD) is also a strong universal protective factor against secondary disabilities, only 56 percent of those that applied were found eligible for services. Clinical experience suggests that the services provided by DDD (such as a case manager, and help with housing, job training and employment) are useful and necessary services for patients with FAS/FAE, including those who do not now qualify for DDD, and all those others who never even applied.
- Freedom from violence and sexual abuse: Violence against individuals with FAS/FAE occurred at an alarming rate: 72 percent had experienced physical or sexual abuse or domestic violence. Being a victim of violence is related to a fourfold increase in odds of

Inappropriate Sexual Behavior. Children and adults disabled by FAS/FAE must have better protection against violence and their families may need special training and guidance when inappropriate sexual behaviors occur.

- Help with parenting, family planning, and family support: Thirty females with FAS/FAE had given birth to a child. Of these, 57 percent no longer had the child in their care; 40 percent were drinking during pregnancy; 17 percent had children diagnosed with FAS or FAE; and an additional 13 percent had children who were suspected by the informants of having FAS/FAE. Special advocacy services for these high-risk mothers who themselves have FAS/FAE and special attention to their birth control needs and child care needs should be a top priority (Grant et al., 1999; Ernst et al., 1999; Grant et al., 1997).

**OVERVIEW**

Our NIAAA study shows that there is a pattern of neurobehavioral problems that has been linked to prenatal alcohol exposure in a dose-dependent fashion. These can be measured throughout the life of the child from day one through 14 years (and studies into adulthood are continuing). These include attentional, memory, fine and gross motor problems, language problems, and academic problems, especially in arithmetic, and problems with speed of information processing. Furthermore, these occur against a background of behavioral problems that include impulsivity, poor comprehension, poor frustration tolerance, a rigid problem solving approach that makes new situations difficult, and behavior unpredictable.

The longitudinal prospective studies, employing careful covariate control and adjustment for competing risks, buttressed with a vast experimental literature, indicate that prenatal alcohol causes neurobehavioral problems that cannot be explained by environmental factors. Alcohol-affected individuals both with and without the face of FAS experience the neurobehavioral consequences of prenatal alcohol exposure. The root cause of the atypical behavior is prenatal brain damage from alcohol (Ioffe and Chernick, 1990; Mattson et al., 1996; Riley et al., 1995) Even correcting the environment will not necessarily be enough of an intervention to facilitate appropriate behavior. In developing appropriate interventions for people with FAS/FAE, both environmental manipulations and individualized treatments will be necessary.

Our CDC study reveals the startling environmental situations in which many children with a diagnosis of FAS and FAE are born and raised. There is no doubt that physical and sexual abuse and frequently changing households represent poor environments for children. But not qualifying for service, not being detected as needing services, and not getting needed treatments and interventions for their birth defects is also a disadvantage. How to change these conditions is the difficult question as they often have variable causes. While some represent the direct consequences of the mother's alcoholism, others

arise from public policy regarding service delivery, which inadvertently screen out alcohol-affected children who fail to meet entry requirements to intervention programs they may need.

### Intervention Issues for Reasonable Standards of Community Care

Some of the big question communities must ask as they attempt to resolve these problems include the following:

Why do over half the people born with these birth defects of FAS/FAE end up prematurely out of the protective care of our schools? Why do over half of them manifest behaviors that get them into trouble with the law? Why do half of them have behavioral problems severe enough to warrant expensive "confinements," at least for a time, in mental hospitals, jails and prisons, and/or residential alcohol and drug treatment programs? And finally, what kind of help do they really get when they go for mental health treatment, as over 90 percent of them do?

These are not the community profiles characteristic of people born with other birth defects or those born with other mental disorders with lifelong implications. There are some special aspects of FAS/FAE that, when understood, may help set the stage for appropriate community responses to this serious problem.

Several particular aspects of FAS/ARND conspire to inhibit detection and thwart prevention and intervention efforts. FAS/ARND are birth defects that are primarily represented in organic damage to the brain, but whose symptoms may not be easily observed until the child is older. These are birth defects that appear to have broad and variable impacts on the brain, thus producing a wide array of symptoms not easily categorized by conventional tests for determining service eligibility for other conditions. Finally, these are birth defects caused by maternal alcohol abuse, which is itself associated with family dysfunction and break up, another obvious cause of childhood behavior problems.

When family breakup occurs (as it does for the 80 percent of our 415 patients in the CDC study who are not in the care of their biological mothers) knowledge of exposure to the teratogenic agent (alcohol abuse by the mother) may not follow the child to his/her rearing family, and thus may not be readily available to help explain dysfunctional behaviors resulting from organic damage, as they arise in the developing child. Furthermore, as many of the early presenting symptoms are behavioral disturbances, help is sought from the mental health field. Although our CDC study revealed that over 90 percent of the patients with FAS/FAE in each age group and their families had sought help from mental health professionals, FAS, FAE, ARND are not in the primary diagnostic manual of psychiatric disabilities (American Psychiatric Association, 1994), so mental health practitioners are often untrained in appropriate interventions for this population.

Prenatal alcohol exposure causes a wide range of primary neurobehavioral disabilities that are associated with the primary brain damage occurring in utero. These are measurable as early as the first

day of life and on into adulthood. They are lifespan problems—so interventions must be addressed across the lifespan. There is no indication yet that early intervention will preclude later interventions, but early intervention could improve general adaptation, promote mental health, and prevent secondary disabilities. Much further research is necessary.

The neurobehavioral effects and maladaptive behaviors associated with prenatal alcohol exposure are not restricted to those individuals with the classic face of FAS—nor to those who meet pre-existing criteria for service delivery, such as "mental retardation," "learning disabilities," "childhood autism," "seizure disorders," "cerebral palsy," or even "low birth weight." Because the risk of secondary disabilities is so high among individuals with FAS/FAE, special interventions will be necessary for schools, mental health, alcohol and drug treatment, and juvenile and adult corrections. More research is needed focusing not only on the special needs of children and adults with FAS/FAE, but also on the selection criteria for service delivery. Neurobehavioral criteria (like those in the Fetal Alcohol Behavior Scale (Streissguth et al., 1998) may ultimately be more useful than reliance on face or growth dimensions, but further research is needed.

Key to developing effective treatment strategies is understanding the organic brain damage that is the central core of FAS and other fetal alcohol disorders. People with FAS show many of the same secondary disabilities as other people—truancy, school dropout, inappropriate sexual behaviors, trouble with the law, unemployability. But because the FAS disability has a narrow organic cause, one that is not necessarily suspected in the ordinary course of social work, many of the usual social responses to these problems (e.g., incarceration or expecting the person to outgrow the behavior) simply make the problems worse. Intervention on secondary disabilities in FAS must be based on a practical understanding of how the interventions work, on people with FAS not in general. Treatments and interventions that just respond to the secondary disabilities may fail to be responsive to the primary disabilities of the individual when the secondary disabilities are ameliorated. People with FAS/FAE have adaptive living problems even when they are no longer abusing alcohol or engaging in criminal behavior. Part of every successful intervention will be identifying that the person has FAS or other fetal alcohol effects and then activating or setting up an appropriate support system.

In conclusion, implementation of successful interventions and reasonable standards of community care for people with FAS/FAE will involve understanding the centrality of the prenatal brain damage from alcohol, and how that fact separates people with FAS/FAE from others in the community who may have the same problems, but from different causes. Although much more research remains to be done, families and communities can be effective advocates for this underserved population by increased public and professional awareness and by modifying public policy not only for appropriate intervention with people of all ages with FAS/FAE, but also to ensure that future children are not born with this preventable birth defect.

## ABBREVIATED SUMMARY OF PRESENTATION

The Social, Cognitive, and Mental Health Impact of Prenatal Alcohol Exposure

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Dr. Streissguth reviewed two research studies in which she was involved. An NIAAA-funded longitudinal prospective study followed a cohort of children selected from a group of mothers with a broad range of drinking histories. The second study, funded by CDC, supported the scientific examination of primary and secondary disabilities in a large group of children and adults with FAS/ARND.

The longitudinal prospective study began in 1974 and involved about 500 subjects. The children in the study were born in 1975 and 1976 and were examined at specific intervals. The study preceded the era of warning mothers not to drink during pregnancy and came on the heels of the initial description of FAS. To select the study cohort, 1,529 mothers, who were in prenatal care by the fifth month of pregnancy, were interviewed in their homes. From this group, approximately 500 offspring were selected-250 from the heaviest drinking and smoking mothers and 250 from abstaining or infrequently drinking mothers. The offspring were examined on the day after birth, day 2, 8 months, 18 months, 4 years, 7 years, 14 years, and 21 years. Additionally, teacher reports were collected at 8 years and 11 years. The study goal was to examine the long-term outcomes associated with prenatal alcohol exposure across the full spectrum of youth. The study results revealed that the effects of prenatal alcohol exposure were measurable from birth to 14 years (data from 21-year olds were recently collected, but not yet analyzed). Decreased mental development as measured by IQ was observed at 8 months, 4 years, and 7 years. Fine and gross motor development was diminished at 8 months and 4 years. The decrease was not observed at 2 years, perhaps due to insensitive testing. Decreased perceptual motor development and memory were noted at 7 and 14 years. Decreased attention and speed of information processing were observed on day 1, and at 4 years, 7 years, and 14 years. Standardized school tests, obtained at 11 years, revealed deficiencies in arithmetic and spelling, but not in reading. Maternal reports noted increased academic problems at 7 and 14 years. Psychometrists, using standardized rating scales, rated the children at 4 years, 7 years, and 14 years, as more distractible, uncooperative, reassurance seeking, and disorganized in their problem-solving approach. Teacher reports at 7 and 11 years noted similar observations. Among the children prenatally exposed to alcohol, teachers encountered increased problems with cooperation, impulsivity, comprehension, memory, and attention. Attention deficit, decreased speed of information processing and arithmetic deficits were observed longitudinally, consistent across the developmental life span of the subjects. The neurobehavioral deficits were not substantially attenuated by covariate adjustment, occurred in the absence of effects on the child's size, and were not mediated by birth weight. The mother's alcohol consumption per occasion was the most

salient aspect of prenatal exposure for behavioral outcomes. A dose-response effect was observed, without a clear threshold effect.

Two recent papers[1,2] supplement the longitudinal study findings. Carmichael Olson et al. examined the association of moderate levels of prenatal alcohol exposure with learning and behavior in early adolescence. Analyses revealed a statistically significant, subtle relationship between greater prenatal alcohol exposure and increased behavior and learning difficulties during adolescence. This relationship persisted after accounting for other developmental influences. Fetal alcohol exposure, even at "social drinking" levels, is associated with a profile of adolescent antisocial behavior, academic problems, and self-perceived learning difficulties. Adolescents showed continued impulsivity, poor organization, and increased delinquent behavior as well as increased use of cigarettes, alcohol, and drugs. Clinicians should be alerted to the potential role that prenatal exposure plays in behavioral and cognitive problems. Baer et al. examined the relative importance of prenatal exposure and family history of alcoholism for the prediction of adolescent alcohol problems. The investigators found that prenatal alcohol exposure was more predictive of adolescent alcohol use and its negative consequences than was family history of alcohol problems, even after adjustment for other prenatal and environmental covariates. Studies of alcoholism etiology and family history need to include consideration of even modest levels of fetal alcohol exposure.

The CDC-sponsored study, conducted in the early 1990s, examined primary and secondary disabilities in more than 400 patients diagnosed with FAS and fetal alcohol effects (FAE) or ARND. The patients ranged from age 3 to 51. Primary disability was defined as brain damage caused by prenatal alcohol exposure. Secondary disabilities were defined as those that are not present at birth. Presumably, these disabilities can be ameliorated with better understanding and appropriate interventions.

The primary disabilities study found that age-appropriate IQ scores ranged from 20 to 117 for FAS children and 30 to 120 for those with FAE. The mean score was 79 for FAS and 90 for FAE. Generally, an IQ of 70 is used as the threshold for providing interventions. Using that cutoff, only 27 percent of FAS and 9 percent of FAE children qualify for intervention. Obviously, many children above that cutoff need help, but are falling through the cracks.

The primary disabilities study, which also examined reading, spelling, and arithmetic skills, found that performance was decreased in relation to IQ score. The Vineland Adaptive Behavior (VAB) Scales measures communication, daily living, socialization skills, and overall adaptive behavior. Significant levels of maladaptive behavior were displayed by 81 percent of the subjects. The following problems were observed in the study cohort: 84 percent had poor concentration and attention; 82 percent displayed impulsivity, 68 percent were stubborn and sullen, 59 percent exhibited social withdrawal, and 59 percent

lied, cheated, or stole. The subjects do not function adaptively in their communities, and their behavioral problems lead them into trouble.

The secondary disabilities study divided the cohort into three-age groups—6 to 11 years (children), 12 to 20 years (adolescents), and 21 to 51 years (adults). The data showed that more than 90 percent of the cohort (across all age groups) experienced mental health problems. Approximately 60 percent of adolescents and 12 percent of children exhibited disruptive school behavior that resulted in suspension or expulsion and/or dropout from school. Confinement in prisons, mental hospitals, or inpatient treatment centers occurred with 50 percent to 60 percent of adults and adolescents. Approximately 40 percent of children and 50 percent to 60 percent of adults and adolescents displayed inappropriate sexual behavior. Approximately 30 percent of adolescents and 45 percent of adults had alcohol and drug problems. Among the adult cohort, 80 percent lived dependently and had problems with employment.

Mental health problems were observed across all age groups. Among children, 20 percent experienced depression and panic disorder and over 60 percent had attention deficit problems. Adolescents show the same rate of attention deficit problems as young children but an increased prevalence of depression (about 40 percent) and panic disorder. Suicide threats were made by 20 percent of children and 40 percent of adolescents and adults. Suicide attempts were made by 18 percent of adolescents and more than 20 percent of adults. Psychotic behavior (hearing voices or seeing visions) was exhibited by 18 percent of children, increasing to 30 percent in adults.

Protective and risk factors for secondary disabilities were also examined. Universal protective factors include (1) a stable and nurturing home environment for at least 72 percent of the subject's life, (2) FAS or FAE diagnosis before age 6, (3) no physical or sexual abuse, (4) infrequent moves (3 or more years per household). (5) good quality home from age 8 to 12, (6) intervention from the Division of Developmental Disabilities (DDD) services. Intervention strategies must go beyond improving learning skills and encompass policies that support stable home environments, infrequent moves (particularly in foster care settings). and DDD services.

FAS are a unique birth defect that results in two types of disability—primary and secondary. FAS is produced by a teratogen that is an accepted part of our culture and in high quantities produces dysfunctional families. Approximately 80 percent of FAS children are not raised by their biological family. Typically, the biological family is unaware of the consequences of prenatal alcohol exposure, and the rearing family is unaware of the etiology of the child's problems. This combination often results in multiple placements that increase the risk of secondary disabilities. The 20 percent of children who remain with their biological family often live in a dysfunctional environment that also increases the risk of secondary disability.

The most prevalent FAS symptoms are treated by professionals who know little about the syndrome. While 90 percent of FAS individuals have mental health problems, FAS is not included in the

Diagnostic and Statistical Manual (DSM-IV). Not surprisingly, most FAS individuals are treatment failures in many different settings, such as mental health, special education, vocational programs, alcohol and drug treatment, juvenile and criminal justice. Interventions must address the unique nature of FAS and the broad range of individual differences.

Future intervention research should examine treatments for primary and secondary disabilities, prevention strategies for secondary disabilities, policy issues to prevent secondary disabilities, and methods to detect FAE. Research areas for primary disabilities should focus on solving problems with attention, memory, psycholinguistics, speed of information processing, and arithmetic. Secondary disability research should target mental health, disruptive school behavior, delinquency problems, inappropriate sexual behavior, and alcohol and drug problems. Prevention strategies for secondary disabilities should support the family, health professionals, institutions, and the community. The ultimate goal is for individuals with FAS and FAE to live in a stable and appropriately supportive setting and to become participating members of society in terms of work, leisure, and fellowship.

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## FIGURE CAPTIONS

Figure 1. Schematic diagrams for the two studies. Study 1 is the Seattle Longitudinal Study on Alcohol and Pregnancy. Study 2 is on Primary and Secondary Disabilities in Patients with Fetal Alcohol Syndrome and Fetal Alcohol Effects.

Figure 2. The Face of Fetal Alcohol Syndrome in the Young Child [from Streissguth and Little (1992), a slide teaching unit on Alcohol and Pregnancy].

# DEFINING DESIRED OUTCOMES FOR CHILDREN WITH FAS AND ARND: A STANDARD OF CARE FOR TODDLERS, CHILDREN, ADOLESCENTS, AND ADULTS

## GATHERED FROM THE COLLECTIVE FAMILY EXPERIENCE BY THE FAS FAMILY RESOURCE INSTITUTE

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## A Crisis in America

### Introduction

The epidemic of kids killing kids in the schoolyards and classrooms of America may be more understandable than most people think. According to Michael Dorris, a featured author on ABC's 20/20 program a few years ago, fetal alcohol syndrome (FAS) leaves many individuals without remorse, without a conscience and unable to distinguish right from wrong. For thousands of years, many of these babies died soon after birth because they often have failure to thrive and/or they are premature ("For 50 years," 1998). However, with the discovery of penicillin and the invention of incubators and various other dramatic lifesaving techniques, babies now born with fetal alcohol syndrome or effects (FAS/E) usually survive.

According to the National Association for Families and Addiction Research and Education, over 750,000 alcohol or other drug exposed babies are now born every year in the USA (Bartley, 1996). While this is not to say that all of these children have FAS/E, it is obvious that the addictions of their mothers were so out of control that when they went to deliver their babies, they tested positive for alcohol and/or other drugs. It is quite possible that for many of these children, remorse, conscience and the ability to distinguish right from wrong has been diminished. Of course many complex factors converge when a child turns violent and many of these factors may have nothing to do with fetal alcohol exposure. But research has shown that individuals with FAS/E are very naive, vulnerable, volatile and easily drawn into anti-social behavior (Streissguth, Barr, Kogan & Bookstein, 1996). Truly, we have a crisis in America.

### Protecting People With Disabilities From An Overload Of Stress

One of the most basic and fundamental issues of human rights should be caring for people in our culture that cannot take care of themselves: babies, people who are physically or developmentally disabled and those with serious mental disorders. In some situations we, as a society, have developed interventions that really are effective but in other areas, such as FAS/E, serious work is still needed.

The good news is that interventions for individuals with FAS/E have been known for many years by parents struggling to care for these children. The problem was that there had been no systematic effort to gather up this collective family experience until November 19-21, 1997 at Rainbow Lodge in Washington State. Dr. Tim Brown and Mr. Kenneth Stark (Directors of the Divisions of Developmental Disabilities and Alcohol and Substance Abuse in the Department of Social and Health Services) funded a FAS Intervention Retreat for families. It is important to realize that families in crisis initiated this event and these men responded to those needs.

### The Difference Between Strategy and Intervention

Most professionals still testify to the fact that no one knows which strategies will develop into interventions that work for individuals with FAS/E. But a strategy is a theory. Interventions are actions

which alter the course of otherwise inevitable events. According to Dr. Ann Streissguth's Secondary Disability Study at the University of Washington, School of Medicine (1996), the natural course of the disability of FAS/E is catastrophic to the individual, family, and society. Consequently, as a community we are forced to provide interventions—either out of compassion for a developmental disability or out of fear through the criminal justice system. Unless we make a conscious, compassionate choice and learn how to protect individuals disabled by FAS/E from stress, they do not understand and are unable to cope with, we will end up serving them out of fear, as is currently being experienced across America.

Accepting the necessity for serving these individuals and understanding the unique wisdom and experience of the families we've had the privilege to meet over the past 9 years, The FAS Family Resource Institute (FAS*FRI) decided to hold a family FAS Intervention Retreat. We sent out invitations to all the parents in Washington State on our mailing list. The one requirement for attendance was that they have a medical diagnosis of FAS/E on a child they are raising or have raised.

We brought as many families together as we could (28 total) from all over the state who represented children in all four of the developmental stages, toddlers/preschoolers, children, adolescents, and adults. We spent three days brainstorming about all the positive, successful interventions we've devised for our children. This was not a strategy session nor was it a time to whine. It was a work session to share and collect interventions that have already altered the negative course of FAS/E. We families were focused and determined.

Our emotions were real, so we were able to acknowledge the grief that will always be a part of our lives. The grief is strong not only because FAS/E is a life-long disability but also because it is totally preventable. Our children could have been saved from this birth defect if society had been educated and committed to the best intervention—prevention. Until we as a society appropriately intervene in the lives of individuals with FAS/E, we will not be able to prevent the perpetuation of FAS in one of the highest risk populations. (See related article: Baer, Barr, Bookstein, Sampson & Streissguth, 1998.)

Because of the intervention data generated at this event and others over the years, FAS*FRI has the necessary information to develop an FAS/E "Standard of Care" from the collective family experience. We now understand the following:

- The developmental deficits of toddlers, children, adolescents and adults with FAS/E (Developmental Overview, FAS Times, Fall 94/Winter 95).
- The adolescent and adult behavioral profile that presents itself even when the IQ is normal ("We Love Children," 1992). This behavioral profile is reflective of the developmental deficits and the resulting symptoms should not be treated separately or apart from a basic understanding of FAS/E.

- There is a recognizable pattern of conduct that can be catastrophic to families (See "Battling the Beast of Burnout" sections within each age group, revised from "Battling," 1994/95).
- The proven interventions initiated by families, which were identified at the Intervention Retreat and through the crisis and referral phone line in operation since 1990.

One of the primary goals of our organization is to share this information with professionals and families that are struggling to raise children with FAS/E. Another primary goal of FAS*FRI is to foster communication between families, scientists, and organizations/agencies that allocate research funding. The public knowledge base on FAS/E includes many sound scientific research studies, but very little scientific inquiry on which interventions will produce healthy outcomes for individuals with FAS/E.

A good strategy has two components according to Webster's Dictionary, "science and art." The reason we share the collective family experience is to provide professional service providers and scientists the missing component of intervention research—the "art" of interventions that have been developed by creative families.

This paper will focus on these artful interventions gathered from parents who are successfully raising children with FAS/E. We are confident that this combination of science and art will produce exciting research projects for standardizing FAS/E interventions and subsequently generate sufficient funding to implement them.

We have identified the developmental characteristics families have seen in their children with FAS/E and sources of burnout for the parents. This information is foundational for understanding the interventions families have successfully employed. Within each age group, these characteristics and issues are listed, followed by age-appropriate interventions, which are categorized by the most prominent areas of challenge.

## TODDLERS/PRESCHOOLERS

In the summer of 1994, a collaboration between the FAS Family Resource Institute, the Division of Alcohol and Substance Abuse,[1] and the Department of Health brought together a group of parents that produced a comprehensive FAS Needs Assessment. Data to create a Developmental Overview of FAS/E were generated at this retreat. Identifying the major needs of individuals disabled by prenatal alcohol exposure is the first step toward developing strategies and interventions. The following characteristics compose the Toddler portion of this Developmental Overview. **Parents report that their toddlers with FAS/E (ages 2-5) have the following characteristics:**

[1] in the Department of Social and Health Services

- usually "high maintenance," keeping parents alert and on duty 24 hours a day
- often exhausted and irritable from uneven sleep patterns
- highly manipulative
- a danger to self and others because they do not grasp the universal laws of cause and effect
- deficient in the normal sequential learning abilities in reasoning, judgment, and memory
- very difficult to manage out in public
- lacking in the normal abilities to distinguish between friend and enemy
- misunderstood by service providers if their IQ's appear to be developing normally
- sometimes medically fragile

**These characteristics may appear to be typical behavior in a normal toddler, but in individuals with FAS/E, these traits occur in grossly exaggerated form and do not respond to typical treatment or interventions.**

## BATTLING THE BEAST OF BURNOUT

It is also important to recognize the challenges and pressures on parents as they try to meet the needs of their disabled toddler. The stress and pain of raising a toddler with an unrecognized and misunderstood disability such as FAS/E takes its toll on family health and relationships. Thus we have also identified the sources of parental burnout. Parents who raise toddlers with FAS/E specifically struggle with the following:

- providing limits and protection for volatile toddlers who daily generate "life and death" safety problems in our households
- physical exhaustion from being alert and on duty 24 hours a day, year after year
- deteriorating health caused by stress from trying to care for "high-maintenance" children
- insufficient resources and services for all disabilities and very few or none specifically for FAS/E
- lack of disclosure of medical and mental health histories of foster and adoptive children
- condescending attitudes of professionals who do not understand that healthy families parent children with disabilities (The child's behavior, which is based in the disability, is typically assumed to be the result of a dysfunctional family.)

- the humiliation of being scrutinized by professionals from every service system imaginable and having to assertively defend our competence as parents, over and over again
- the criticism of well-meaning family, friends, and counselors who misunderstand our grief and misinterpret our feelings of grief as guilt (for being dysfunctional)
- grief that is so overwhelming that it's like living your life in a revolving door of sadness, desperately loving a vulnerable, misunderstood child
- the eternal battle of trying to educate people that the source of grief is not only from the permanence of the disability, but also because service professionals do not recognize or understand the disability nor respect our efforts to describe it
- the anger we feel toward people who give us misguided, totally absurd advice like, "You look terrible! Get some rest. Why don't you trade respite care with another family who has a child with FAS/E?"
- the excruciating pain of watching the stress and frustration eat away at the happiness and health of other family members (Suicidal thoughts and severe depression are not uncommon.)

## INTERVENTIONS FOR TODDLERS/PRESCHOOLERS

The goal of the FAS Intervention Retreat in 1997 was to gather up the unique discoveries from families that have been proven to successfully alter the natural negative course of FAS/E and prevent or minimize the secondary disabilities that can result. By living with toddlers disabled by FAS/E and recognizing the common developmental deficits, families identified the most challenging areas for primary interventions in this age group as: sleep disorders, failure to thrive, lack of friends, education and learning, potty training, and rage. The interventions for Toddlers/Preschoolers are categorized by each of these areas of challenge. We have divided them into Family Interventions, which can be done within the resources of families, and Systems Interventions, which families have initiated through service delivery systems.

## SLEEP DISTURBANCES

Parents of toddlers with FAS/E agreed that irregular sleep patterns was one of the most difficult problems they had to handle. The situation may also be compounded by post-traumatic stress or other co-existing conditions.

### FAMILY INTERVENTIONS

- Establish a regular evening routine and bedtime. Schedules are extremely important for a child who is deficient in the ability to predict and organize. Routines help maintain steady biological rhythms and generate good physical health.
- Keep nap times in place until 7 or 8 years old, if needed.
- Verbalize and structure rituals with consistent words, such as, "It's time to go night-night."
- Use music to calm and soothe.
- Massage a child's back or body to prompt relaxation and sleep. However, some children with FAS/E are over-stimulated by touch so be especially sensitive to their personal comfort zone.
- Lay down with the child at nighttime; use the opportunity to discuss the child's flashbacks or concerns.
- Sing or read to the child.
- Put a special alarm on the door, which makes a loud, shrill noise if the child tries to leave the room at night. (This doesn't help the child sleep but it does allow the parents to sleep, knowing that the child is at least safe in his/her room and not wandering around in the house or outside without parental supervision.)
- Allow young children to sleep with you temporarily if they have reoccurring nightmares. One family eventually transitioned their child back to his own bed by putting him on his own pallet on the floor next to their bed, gradually moving the pallet into the hallway and eventually into the child's own room. Another family used a red ribbon to tangibly connect the child's bed with mom and dad's bed (concrete learning style) until the child felt safe and comfortable in her own room.
- Quiet and comfort the child for sleep by audibly praying over the child.
- Wake up the child for comfort, if extremely restless, and offer a snack if hungry.

### SYSTEMS INTERVENTIONS

- See the family primary care physician for help with sleep disturbances. If this is not helpful, request a referral to a specialist. Medications may be needed.
- Seek help from professional social services. Some families have had to request a "special dispensation" court order to allow them to use hook and eye locks on the outside of their children's bedroom doors to keep them safe and in their room at night. (Alarms won't work if the child can dismantle them.)

## FAILURE TO THRIVE

One of the diagnostic criteria for fetal alcohol syndrome is height and weight growth deficiency. Many times doctors do not gather, or are unable to access, information on prenatal alcohol exposure. Consequently, growth deficiencies are often diagnosed only as failure to thrive because the reason behind the growth deficiency is unknown.

### FAMILY INTERVENTIONS

- Provide the three keys for overcoming failure to thrive: good medical care; loving parent(s) to provide comfort whenever the child wants or needs it; calm, consistent daily schedules.
- Allow the child to keep bottles, baby blankets, thumb sucking, or special toys. The child's emotional development is likely to be below age level so these comforts are still appropriate.

### SYSTEMS INTERVENTIONS

- Obtain good, consistent medical and mental health care, which is absolutely essential to overcome failure to thrive in a child with FAS/E.

## FRIENDS

- The lack of ability to make and keep friends on their own is noticeable even in the toddler years. This increases dependence on the caregiver(s). Parents said that toddlers with FAS/E require such close supervision that they can't communicate when adult company comes to the house. Parent social opportunities are rare.

### FAMILY INTERVENTIONS

- Compensate for the child's inability to make and keep friends by becoming his/her full-time social director.
- Arrange for respite care through family and friends so you can have your own social life.

### SYSTEMS INTERVENTIONS

- Request respite care from public programs or state agencies, such as Adoption Support or the Division of Developmental Disabilities (DDD).
- Request extra supervision in the form of a Medicaid "personal care provider" through DDD or Social Security Income (SSI—a Federal disability benefit).

## EDUCATION AND LEARNING

Education for toddlers usually comes in the form of regular day care, therapeutic day care and preschool. However, many families today choose home schooling for their children.

### FAMILY INTERVENTIONS

- Educate school staff about FAS/E in three steps: 1) help the school staff connect your child's obvious behavioral problems with the disability; 2) teach the educators what you have instinctively learned — how to do the "dance" with your child to get as much cooperation as possible; 3) ask for the school staff to set up a situation so you can observe and evaluate each potential classroom without the child present. Then you can intuitively choose the most appropriate setting for your child.
- Set up a classroom or playground observation opportunity if a teacher has a concern for your child that you do not identify with. In this way, you and the teacher can both learn to understand the way different environments affect him/her. This helps identify the extent that your child is affected by moral chameleon qualities and his/her inability to sequence and follow rules, in contrast to other toddlers. The value of this intervention is early documentation of potential disability issues. (Some parents of toddlers with FAS/E and a normal IQ, adjust and compensate so much to meet the child's needs, they do not relate to behavioral complaints from teachers who see the child surrounded by peers with age-appropriate behavior).
- Communicate regularly with the school by phone or through E-mail or by using a notebook that the child transports.
- Document and keep a record of behavior problems because school staff will usually not keep written records of negative behavior. If the truth is that the child is not doing well, there needs to be a record to verify it in order to access (justify) appropriate diagnostic testing.
- Request that the school/daycare staff document specific times of the day if emotional outbursts occur, and the level of intensity of each one. Color-coding is an effective way to document intensity. Red is very volatile behavior to the point that the child needs to be removed from the classroom; green is for disruptive behavior that can be handled inside the classroom by the teacher; and blue is for behavior that is disruptive but the child can calm him/her self.

- Learn to use the appropriate words to communicate with school staff. For example, volatile outbursts can be a direct manifestation of the disability of FAS/E and do not necessarily mean that the child has a "behavioral disorder" in addition to FAS. The most appropriate qualifying category for special education services for FAS/E is "health impaired."

#### SYSTEMS INTERVENTIONS

- Be assertive in advocacy when trying to access appropriate schooling even for toddlers. (Many parents report that even toddlers with FAS/E are expelled from day care or preschool).
- Educate school personnel about FAS/E. One essential educational piece for teachers of toddlers with FAS/E and a normal IQ, is the fact that good behavior does not likely indicate the child is ready for mainstreaming, as most school policy dictates.
  - Quit work to care for the child. (Many parents report that they are forced to forgo employment and career opportunities in order to provide the level of care that toddlers with FAS/E require.)
  - Access resources such as SSI, Developmental Disabilities and Special Education Services, which can help pay for extra supervision in school or daycare classrooms.
  - Seek therapeutic day care if needed for a toddler with FAS/E and co-existing conditions.

## POTTY TRAINING

Since toddlers with FAS/E have difficulty relating behavior and consequence and identifying sensory integration sensations, potty training is often a very long and unpleasant task.

### Family Interventions

- Set a specific timetable for the potty-chair routine, similar to a feeding schedule at 10, 2 and 6.
- Develop a policy that toddlers sit on the potty-chair for 5 minutes after each meal.
- Educate yourself through books, parenting classes, etc., to acquire the best knowledge for potty training theories and techniques.

#### SYSTEMS INTERVENTIONS

- Enlist the help of your primary care physician. If this does not produce successful results, ask for a referral to a specialist.
- Retain the services of a counselor or psychiatrist to evaluate the child's emotional and mental health needs. For example, if the child is in foster care or is adopted, a reactive

attachment disorder or previous domestic or sexual abuse may be interfering with the learning process.

- Seek counsel and treatment from a sensory integration specialist.
- Contact university professors and other FAS research centers and enlist their help. Since this is such a common problem for toddlers with FAS/E, if the researchers have not studied it, they need to.

## RAGE

Some people think that individuals with FAS/E are violent. The collective family experience shows that they are not necessarily violent, but volatile. Appropriate interventions for volatile outbursts are essential to keep the toddler and the family safe. Many peculiar factors can evoke rage in a toddler with FAS/E.

### FAMILY INTERVENTIONS

- Restrict toys to anything that cannot be broken.
- Monitor food intake to detect sensitivities or allergies.
- Prevent low blood sugar by feeding your child in the middle of the night.
- Limit physical restraints to a hug and reassurance. Honor personal space.
- Involve both parents (in a two-parent family) in a family rage reduction program so that the child doesn't play one parent against the other.
- Educate professionals about the disability of FAS/E and your specific child.

### SYSTEMS INTERVENTIONS

- Advocate for medical and mental health assessments through Birth to 3, Child Find and Early Periodic Screening and Diagnostic Testing (EPSDT) evaluations.
- Locate a therapeutic preschool for your child.
- Avoid intensive holding therapy for the child with FAS/E who is prone to being over-stimulated by touch.
- Refuse to settle for a diagnosis that doesn't feel right. (If the diagnosis "fits," you will know it.) Many parents reported that the first diagnosis their child received was Attention Deficit Hyperactivity Disorder (ADHD), but the diagnosis just didn't "feel right" so they kept searching. A neuro-psychological examination can be helpful.

- Pursue good medical care, that may be essential for rage reduction, i.e., sensory integration deficits hide medical problems such as the need for tubes in the child's ears, undiagnosed hernias, and other painful conditions. If these problems are left unidentified and untreated, they can lead to rage.

## CHILDREN

- In the summer of 1994, as previously noted, a group of parents produced a comprehensive FAS Needs Assessment. Generating data to create a Developmental Overview of individuals disabled by prenatal alcohol exposure is the first step to finding strategies and interventions for each age group. The following characteristics compose the Children's portion of this Developmental Overview. **Parents report that their children with FAS/E (ages 6-11) have the following characteristics:**

- impulsive; unpredictable and mischievous, creating ongoing safety hazards, e.g., setting fires and running away
- often exhausted from uneven sleep patterns
- innately skilled in manipulative tactics
- desperate for stimulation and excitement to keep them entertained and happy
- emotionally volatile and often exhibit wide mood swings throughout the day
- overlooked as permanently disabled if their IQ's are normal (which includes the large majority)
- often disconnected from their own feelings and are unable to identify or express logical reasons behind their volatile outbursts or misbehavior
- isolated and lonely because the desire to be included remains intact while the reasoning skill to figure out why they are excluded is lacking
- angry and resentful toward more structure and supervision than their peers need
- void of natural empathy for others

**These characteristics may appear to be typical behavior in a normal child, but in children with FAS/E, these traits occur in grossly exaggerated form and do not respond to typical treatment or interventions.**

## BATTLING THE BEAST OF BURNOUT

It is also important to recognize the challenges and pressures on parents as they try to meet the needs of their disabled children. The stress and pain of raising a child with an unrecognized and misunderstood disability such as FAS/E takes its toll on family health and relationships. Thus we have also identified the sources of parental burnout. Parents who raise children with FAS/E continue to struggle with the toddler issues and, in addition, struggle with the following:

- Shock from learning that normal parenting skills and discipline techniques are ineffective for their children.
- Grief from trying to understand and explain their children's behavior. which is so inconsistent with their other attributes. The majority of children with FAS/E are very talented, cunning, and intellectually bright, with sweet, innocent, joyous, and charismatic personalities. Often they are physically strong and healthy. Yet they cannot cooperate, share, distinguish right from wrong, or understand behavior and consequence.
- Pain of also raising frustrated siblings whose plans are constantly disrupted. Parents can't put the child with FAS/E "on hold" because he/she can generate serious safety hazards very quickly. Consequently, siblings usually come in a distant second as far as time and attention. Thus siblings will eventually erupt in rage at the parent or turn their anger inward in the form of depression.
- Anguish of always being caught in the emotional crossfire between their children — understanding that both rage and depression can be dangerous to the mental and emotional health of children with FAS/E and their siblings.
- Exhaustion from the lack of sleep, rest and recreational activities. By the time their toddlers reach childhood, extended family members and close friends are fed up and burned out. Or parents say they are just too embarrassed by the child's disruptive behavior to even ask for help anymore.
- Conflict with spouses, which is intensified because of the lack of time to nurture the marriage and the erratic behavior of the disabled child that evokes disagreements on how to handle discipline. Some spouses refuse to share care-giving responsibilities. Divorce is a common and permanent form of respite and peace for one parent.
- Frustration that most professionals and society in general believe that counseling or behavior modification can cure the unacceptable behavior caused by the permanent brain damage in FAS/E.

- Isolation that results from being continually blamed for the child's behavior. By the time children reach 9 or 10 years old, (if they have normal IQ's) they are expected to be socialized into the local culture. Parents describe children with limited ability to follow any set of rules.
- Outrage from being unable to access critical information regarding their adopted children's social, medical and mental health history.
- Loss of money that is wasted on inappropriate counseling and treatment from professionals who hide or "gloss over" the fact that they really do not understand FAS/E.
- Panic over knowing that their children are growing older and have serious behavior problems. Cold fear grips their hearts because they know they are in desperate need of appropriate treatment and intervention, while at the same time no one seems to be listening. Professionals jump to the conclusion that the child's chaotic behavior is caused by the parents' dysfunction. Very few people, if any, in the community recognize that a child with a normal IQ can have serious organic brain damage directly attributable to prenatal alcohol exposure.

## INTERVENTIONS FOR CHILDREN

As previously stated, the goal of the FAS Intervention Retreat in 1997 was to gather up the unique discoveries of families that have been proven to be successful to alter the natural, negative course of FAS/E and prevent or minimize the Secondary Disabilities that can result. By living with children disabled by FAS/E and recognizing the common developmental deficits, families identified the most challenging areas for primary interventions in this age group as: conflict with siblings, concentration difficulties, sleep disturbances, mental health issues, sensory integration and education. The interventions for children are categorized by each of these areas of challenge.

## CONFLICT WITH SIBLINGS

When a child with FAS/E is born into or adopted into a family with normal children, a lot of anger and jealousy can erupt. The non-disabled siblings can be resentful of the constant time and attention demanded by the disabled child. Conversely, the disabled child can be jealous of the freedom given to the other children while he/she requires a much higher level of supervision and structure. When there are two or more children with FAS/E in the same family, conflict and chaos can become the norm.

### FAMILY INTERVENTIONS

- Work together as parents to minimize the disabled child's manipulation of the other siblings.
- Set separate schedules in the morning, e.g., one child eats breakfast while the other gets dressed.

- Don't leave even older children alone and without adult supervision.
- Educate non-disabled siblings about FAS/E.
- Make one-on-one time for non-disabled children.

#### SYSTEMS INTERVENTIONS

- Find a counselor trained in FAS/E for all of your children.
- Utilize suitable out of home placement if necessary to keep all family members safe and mentally healthy.

### CONCENTRATION

Many times professionals misunderstand the behavior that parents are describing. Consequently, children with FAS/E are often given a diagnosis of ADHD. Careful collaboration between parent and physician (or psychiatrist) needs to happen in order to understand the cause of the child's concentration problems. Unless the child has an accurate diagnosis, finding successful interventions will be very frustrating, like trying to paint with a scatter-gun, never understanding when or what will be successful. At the FAS Intervention Retreat, parents discussed interventions that were appropriate for improving concentration.

#### FAMILY INTERVENTIONS

- Provide constant adult supervision and structure.
- Arrange an environment (at least in part of the house) that has subtle lighting and low noise level to compensate for the child's inability to screen out stimulation.
- Honor individual needs. Some temperaments need boisterous fun-filled activity to be happy, others need peaceful, quiet recreation.
- Allow the child to choose how to spend his/her energy from a short list of possibilities.

#### SYSTEMS INTERVENTIONS

- Enlist a doctor to closely monitor children with attention/concentration problems. A child can have FAS/E plus other mental health conditions, such as ADHD and/or bipolar disorder. According to the collective family experience medication does not erase the illogical, troublesome thinking pattern unique to FAS/E, but it is often helpful with aggression, ADHD, bipolar and other mental health disorders.

- Find a professional who will treat your child with EEG biofeedback, which may help increase concentration. Local practitioners may be located on the Internet at www.eegspectrum.com.

## SLEEP DISORDERS

Children with FAS/E usually have the same sleeping problems that they had in the toddler years. Consequently many of the same interventions are still appropriate. Sleep disturbances start to interfere, not only in family life, but also in the broader community during the childhood years. This is very obvious at school where children are expected to fit in and adapt to schedules suitable for other students, while the child with sleep disorders is unavoidably exhausted and irritable.

### FAMILY INTERVENTIONS

- See interventions that were successful during the toddler years.

### SYSTEMS INTERVENTIONS

- Access special services for your child by providing data to prove that there is a medical disability or mental disorder that is interfering with the child's sleep and consequently, their physical health. This can be accomplished through either a medical doctor or psychologist. If the family cannot afford these evaluations, the school district, SSI Federal benefits, state Developmental Disability benefits, Adoption Support or other state child care systems (such as Early Periodic Screening & Diagnostic Testing (EPSDT) should be available to the child.
- Advocate with the school staff in the form of the child's Individual Education Plan (IEP) to allow the child to:
    1. Arrive late and/or
    2. Leave early for a shorter day and/or
    3. Take a nap at school when needed.
    4. Try medication. Three medications have been helpful in different children: Risperdal, Clonidine and Depakote.

## MENTAL HEALTH

If the child with FAS/E has a normal IQ and parents are available to provide early interventions, the disability may go relatively unnoticed and undocumented until age 8 or 9. This is a very big issue for families because the disability of FAS/E at age 9 begins to present itself as exaggerated antisocial behavior and culpable civil disobedience AND discipline techniques and/or positive reinforcement do not alter antisocial behaviors on a long-term basis.

### FAMILY INTERVENTIONS

- Provide a variety of social activities. Interventions that have been successful to bolster self-esteem and self-respect include sports, church or community groups, and activities for people with disabilities such as Special Olympics. One child who has FAS/E and ADHD, joined the summer youth circus. He and his mother spend their summers traveling with the circus, living in a motor home.
- Ensure that all matches and cigarette lighters are locked away from children to discourage fire setting.
- Use alarms on doors and windows at night so those children with disabilities cannot secretly roam around unattended.
- Give clear instruction, firm admonition of values and steady supervision to minimize inappropriate sexual behavior.
- Monitor and restrict TV, radios, videos, music, and even visitors to avoid overstimulation and minimize exposure to conflict in values.
- Be sensitive to the possibility of emotional volatility, panic attacks, mood swings, and anxiety which may look more like aggressive antisocial behaviors.
- Continue to provide exceptional nurturing techniques. Some children have passive temperaments. These children are especially vulnerable to being overlooked and ignored in public settings.
- Monitor and document moral chameleon qualities, i.e., record incidents when the child behaves in a totally different manner when with the family as opposed to being with peers or at school. This will help when trying to explain the disability to mental health providers or legal authorities.

### SYSTEMS INTERVENTIONS

- Seek appropriate mental health counseling. Typical talk therapy is not effective for children with FAS/E. If a family can find a psychologist or psychiatrist who understands that FAS/E is a neurological disability with a common behavior pattern, he/she can help guide the child into the antisocial adolescence years and more safely into adulthood.
- Obtain help from your state social service and/or mental health systems if necessary to preserve the family unit. Even though few professionals understand the disability of FAS/E, with clear and persistent advocacy, some of these services have been successful for families.

- Find appropriate group care or residential treatment. Even though the decision to place a child out of the home is extremely difficult, sometimes it is necessary to preserve family relationships.
- Investigate medications to help manage conditions such as panic attacks, anxiety, and mood swings.

## SENSORY INTEGRATION PROBLEMS

It is common for children with FAS/E to have deficits in associating cause and effect, behavior and consequence. According to the collective family experience, this appears to be an unusual deficit for professionals to understand when it occurs in children with normal IQ's. Families have found the most effective way to translate this information to professionals is to use the term, sensory integration problem. While parents do not mean to diagnose, they use the term to communicate deficits in associating cause and effect and the problems that subsequently follow in the child's own body and in relationships with family, school, and court. At the Intervention Retreat, families felt this area of FAS/E deficit and disability needed much research. The interventions that families have identified include:

### FAMILY INTERVENTIONS

- Devote more time, greater sensitivity, and energetic creativity to help the child associate behavior with consequences than you would with a normal child. This takes an unusual amount of structure and repetition.
- Develop a deeper, richer level of nurture, much like the swaddling of newborns who have been exposed to alcohol and other drugs. The high level of nurture necessary to prevent secondary disabilities usually requires a full-time caregiver with a wide level of knowledge of FAS/E and discernment of the unique needs of the particular child.
- Identify the triggers that precede sensory overload and result in unacceptable behaviors. Some children with FAS/E avoid or solve the problem of sensory overload on their own to a certain extent. Observe the child carefully to reinforce their successful techniques. Professional help may be needed to accomplish this goal.

### SYSTEMS INTERVENTIONS

- Find public and community resources through programs such as Adoption Support, SSI, and the Division of Developmental Disabilities. This is necessary because of the high cost of the medical and psychiatric specialists and services needed by the child and the reality that one caregiver may have to give up or reduce employment to care for the child.
- Retain the services of a professional who specializes in sensory integration therapy. One form of therapy that is showing promise for some children with FAS/E is pony riding.

- Find a professional who will treat your child with EEG biofeedback, which may help increase sensory integration. Local practitioners may be located on the Internet at www.eegspectrum.com.

## EDUCATION

Many school districts, as in Seattle, Washington, have implemented a new policy that children will not be allowed to pass into 5th grade unless they have mastered basic skills in reading, spelling and math. While this is an admirable goal in general, time will testify to the fact that many of the students who struggle to master these skills have unidentified FAS/E and, consequently, are unable to achieve this goal. We can use this mandate to identify and appropriately educate children with FAS/E, or we can look foolish because we did not have the vision to predict and prevent the educational failure of these students. Our only compassionate choice is to identify these disabled students and develop educational plans specific to their disability and personal strengths and weaknesses.

### FAMILY INTERVENTIONS

- See educational interventions that were successful during the toddler years.
- Make sure that the child's Individual Education Plan (IEP) targets specific interventions, e.g.:
  1. a quiet room where Leggos, a Walkman, cartoons, etc., are available so the child can choose to retreat and unwind when needed
  2. occupational therapy
  3. sensory integration treatment
  4. speech therapy
  5. special education transportation
  6. special supervision during sports or recess
- Take an advocate to staffing or IEP meetings.
- Tell the school, "I am withdrawing my signature" from the IEP if they insist on interventions or changes that you know won't work, such as behavior modification or punishment.
- Teach the child sign language if he/she is struggling to find an effective way to communicate and understand communication. Children with FAS/E do well with sign language because they are typically very visual learners.
- Request testing by a school psychologist. Test results can identify and document some of the areas where the child is having difficulty.

- Educate all school staff: playground staff, teacher, principal, school counselor, bus driver, etc. with specific information about how this disability presents itself in your child. This probably needs to be repeated every school year due to confidentiality issues.

### SYSTEMS INTERVENTIONS

- Access special education services through the category of "health impaired." The child with FAS/E is unable, not unwilling to follow the rules because of the deficits in memory, reasoning, and judgment. The Federal government mandates that a child with disabilities must be in school. So children with FAS/E cannot be permanently expelled for behavior problems that are a direct manifestation of their disability.
- Add an extra classroom aide or put the child with FAS/E into a small self-contained classroom. (Typically, "full inclusion" or "total mainstreaming" **doesn't work** for children with FAS/E.) If the school district refuses, ask for the district's appropriation in actual dollars for your health-impaired student. Then ask how many dollars are actually being spent on your student, over and above what is spent on the normal students.
- Set up a situation at school where the child has as much control as possible in coping with his/her disability. For example, the child may be too stressed to go to recess, so allow the child to choose to go to a quiet supervised place like a resource room, library, or counselor's office.
- Advocate for a full day of FAS/E training for school personnel. Among other things, educators need to understand that success does not mean the child is ready to be mainstreamed. It is likely the structure and supports of special education are necessary on an ongoing basis for the child to succeed. If those supports are withdrawn, success collapses into failure.

## ADOLESCENTS

In the summer of 1994, as previously noted, a group of parents produced a comprehensive FAS Needs Assessment. Generating data to create a Developmental Overview of individuals disabled by prenatal alcohol exposure is the first step to finding strategies and interventions for each age group. The following characteristics compose the Adolescent portion of the Developmental Overview. Parents report that their teens with FAS/E have the following characteristics:

- still in need of limits and protection like a 3-year-old because of their deficits in reasoning, judgment, and memory at the same time they are demanding more and more freedom to be with their peers

- at high risk for being drawn into anti-social behavior, such as stealing, lying, and addiction to legal and illegal drugs. Thrill-seeking peers are a total fascination to teens with FAS/E.
- able to recognize and willing to submit to raw power, making them vulnerable to gangs. Gang membership provides clear power, with the "structure" of submission and, consequently, peer acceptance and loyalty. They are fascinated by the intense emotions and stimulation of gang activity and identify with the majority who have as much difficulty in school as they do.
- unable to easily distinguish between friends and enemies
- struggling with understanding and accepting their disability at the same time they are trying to prove their ability to be independent
- terrified of major change and transition, such as moving to another town or making the adjustment to middle school with more students, buildings, classes, teachers, and expectations
- often obsessed by primal impulses, such as sexual activity and fire setting
- escalating in conflict with their siblings. Since the necessity for applying rules differently becomes extreme, it intensifies the resentment on both sides and sometimes becomes so severe that out of home placement is imperative for everyone's safety.
- innately attracted to chaotic activity. However, this can be used to help them accept a group home environment when necessary, since there are often other "stimulating" kids there. Parents report that family bonds often improve during out-of-home care.
- able to recover emotionally from confrontations or crises VERY quickly. Parents report that the discrepancy between the emotional recovery times of teens with FAS/E and their parents is a significant factor in parent burnout.
- seriously impaired when it comes to making decisions by not having the judgment or reasoning skills to logically make good decisions
- continuing to be a safety menace to themselves and others. Parents report their focus on safety expands from keeping just the child and family safe to also keeping surrounding community safe.
- often exhausted and irritable from uneven sleep patterns. This can disrupt the sleep of the parents and also contribute to their exhaustion.
- unaware or negligent of normal hygiene responsibilities. This can be especially humiliating to the family of teen girls who are menstruating.
- extremely vulnerable to suggestions in movies, videos, TV, and advertisements

- at high risk for dropping out of school if they do not have proper intervention, not necessarily due to low academic performance, but to social and emotional difficulties
- moral chameleons. Despite consistent loving care, family values and even general rules of social behavior are not being internalized.
- unable, not unwilling, to take responsibility for their actions

**Some of these characteristics may appear to be typical behavior in a normal adolescent, but in teens with FAS/E, these traits occur in grossly exaggerated form and do not respond to typical treatment or interventions.**

## BATTLING THE BEAST OF BURNOUT

It is also important to recognize the challenges and pressures on parents as they try to meet the needs of their disabled adolescents. The stress and pain of raising an adolescent with an unrecognized and misunderstood disability such as FAS/E takes its toll on family health and relationships. Thus we have also identified the sources of parental burnout. As parents of teenagers with FAS/E, we still struggle with many toddler and children's issues plus:

- Confusion in how to separate normal teen issues from the issues of FAS/E (Many professionals also have this difficulty.)
- Worry that our teenager will be severely harmed from getting involved with the wrong crowd or not understanding general safety issues, such as those involved in fire setting and inappropriate sexual behavior
- Serious financial problems due to: legal liability for our teen's actions, the need to take unpaid leave from employment to appear in court or advocate for services and/or payment of psychiatric in-patient treatment
- Enormous emotional trauma in the home from sibling rivalry as the teen with FAS/E grows older, bigger, and harder to control but not more mature
- Agony of accusations from professionals who assume we are irresponsible and dysfunctional parents
- Overwhelming depression when professionals who clearly do not understand FAS/E will not listen or believe us when we try to explain the disability
- Humiliation and grief from having a teen who is totally unaware of normal standards of hygiene
- Feelings of helplessness when our severely disabled teens turn defiant and refuse our help

## INTERVENTIONS FOR ADOLESCENTS

As previously stated, the goal of the FAS Intervention Retreat in 1997 was to gather up the unique discoveries from families that have been proven to be successful to alter the natural, negative course of FAS/E and prevent or minimize the secondary disabilities that can result. By living with adolescents disabled by FAS/E and recognizing the common developmental deficits, families identified the most challenging areas for primary interventions in this age group as: bonding and attachment, dangerous behaviors, panic attacks, rage, self-respect and self esteem, concentration and self regulation, education, and accessing services. The interventions for adolescents are categorized by each of these areas of challenge.

## BONDING AND ATTACHMENT

According to the data gathered at the FAS Diagnostic Clinic at the University of Washington, most individuals with FAS/E are not living with their birth mothers (over 80 percent). Bonding and attachment disorders are emotional and mental health problems that occur in a child as a result of the trauma of not having the opportunity to bond to at least one caregiver or when there has been a major interruption to the bonding that was in progress. Consequently, breaks and/or disruption in bonding and attachment are major mental health issues for children and adolescents with FAS/E, especially those who have been through the foster care system. The behavioral traits of adolescents with attachment disorders and adolescents with FAS/E can appear similar, or can be co-existing. A dual diagnosis of FAS/E and Attachment Disorder is common. Attachment Disorders are very complicated but are treatable. They can also be very dangerous if left unidentified or ignored.

### FAMILY INTERVENTIONS

- Protect adolescents who have FAS/E and Attachment Disorders from Intensive Holding Therapy. Many individuals with FAS/E are overly sensitive to touch. Parents at the Intervention Retreat were adamant in their opinion that Intensive Holding Therapy could cause additional, catastrophic mental health problems.
- Understand that a long-term commitment to teens with FAS/E is essential, since bonding/attachment is one of their insatiable needs. Because of their disability, they need the **intense availability** of parents through the teen years and sometimes into young adulthood, to cement the bonding process.

### SYSTEMS INTERVENTIONS

- Seek treatment by trained mental health professionals who understand the core disability traits of FAS/E so they can appropriately address the bonding and attachment problems.

- Provide education to service providers about the distinctions between these two conditions—FAS/E and Attachment Disorder.
- Initiate the level of supervision and support needed. The Division of Developmental Disabilities in Washington State has agreed to take the lead in support services. But funding has not been allocated by the legislature to date.
- Provide a firm, structured environment for the individual with FAS/E based on the core disability traits. When the environment is appropriate for FAS/E, the symptoms of Attachment Disorder become very subtle.
- Be aware that an adolescent with FAS/E who has experienced early sexual abuse and bonding breaks may develop, or may appear to develop, predatory behaviors if these interventions are not implemented.

## DANGEROUS BEHAVIORS

One of the core disability issues of FAS/E is the difficulty keeping the person and the community safe from dangerous behavior. During the toddler and childhood years, safety issues are largely within the family, but as the child enters the teen years the impulsive and unpredictable behavior begins to endanger others in the community. Dangerous behaviors include everything from fire setting, to recklessly driving a car, to inappropriate sexual behavior, to the need for birth control and the prevention of hepatitis and sexually transmitted diseases. While these issues might seem like typical adolescent behaviors, with FAS/E they occur in grossly exaggerated form.

### FAMILY INTERVENTIONS

- Adolescents with FAS/E who ***do not have dual diagnoses*** (such as ADHD, Attachment or Bipolar disorders) are ***easier*** for families to keep safe than those who have FAS/E and other mental health disorders. In other words FAS/E alone, is a protective factor in preventing dangerous behavior. Education about this fact is a major intervention for families and professionals because it begins to separate the disability of FAS from other causes of antisocial behavior.
- Delay the obtainment of a driver's license, if needed, for two reasons: many teens have a lot of difficulty following rules and thus driving safely; they are also vulnerable to misusing the freedom a car can bring and getting into bad situations. A logical family policy can be that teens can use the family car only after saving a year's worth of car insurance before the parents' sign for a driver's license.
- Long-term birth control for adolescents with FAS/E is critical for both guys and girls. There may be a few side effects with the 5 year Norplant and Depo-Provera but an unexpected

pregnancy is a devastating "side effect" for a disabled teen and his/her family. In Washington State it is now legal for parents to be held financially responsible if their sons are under 18 and father a child. Age 12 or 13 may not be too young to consider birth control for adolescents with FAS/E. Do not rely on pills that the adolescent (with FAS/E memory deficits) has to remember to take daily or other methods, which need to be used before every sexual encounter, such as condoms.

- Make sure that everyone has space to store individual towels, soap, tooth brushes and other intimate personal items. When cleaning use a good disinfectant in the bathroom and kitchen.
- Match interventions to behaviors. For example, if fire setting is an issue, remove and keep all sources of fire under lock and key. If stealing from the local 7-11 store is an issue, restrict any "travel" in that direction.
- Keep teens with FAS/E out of the juvenile system as long as possible by limiting unsupervised time. Since typical juvenile interventions are based on the supposition that negative consequences will deter future antisocial behavior, they will not work for adolescents with FAS/E.
- Install window and door monitors or alarms if necessary to allow both the adolescent and parents to stay in their bedrooms to rest at night. If this type of intervention is necessary, start it early and as a natural consequence for wandering around or leaving the house and getting into trouble during sleep hours.
- Approach therapy for sexual abuse issues very carefully, whether the adolescent is the perpetrator or the victim. Typical treatment modes do not work with FAS/E and could make things worse, especially if the person is *forced* to re-experience blocked memories, according to Dr. Ann Streissguth at the University of Washington. She is strongly recommended for consultation on these issues. (However, one family found intensive sex-offender treatment very helpful for their son when memories of his early childhood abuse surfaced as a natural result of the treatment and without force.)
- Establish firm boundaries. If necessary, provide close 24-hour supervision or residential treatment.
- Seek a diversion program if the adolescent becomes involved with the law, such as investing hours in community service instead of spending time in a juvenile institution. However, if the teen with FAS/E is a serious danger to the community, then there may be no other viable choice outside residential treatment or incarceration.

### SYSTEMS INTERVENTIONS

- Include documentation of genetic medical and mental health conditions in all medical records. (Special care should be given to ensure this information, as well as any history of prenatal alcohol exposure, is recorded in the medical files of all minors and released to every foster and adoptive caregiver.)
- Search for a psychologist or psychiatrist who understands the core disability traits of FAS/E. Some individuals with FAS/E who have angry or volatile outbursts respond very well to medication; this can be invaluable to the teens and their families by preventing behaviors that would endanger themselves and/or others.
- Check with local school districts to get their truancy regulations. Truancy laws in Washington State have been updated and adapted to help parents keep unruly adolescents in school. This intervention creates a team between parents, school officials, and judges to determine how to help teens who are at risk for school disruption and to provide appropriate community resources for these youths.
- Apply for eligibility for services through the Division of Developmental Disability in DSHS (The Department of Social and Health Services). This "public recognition" of disability helps if the adolescent becomes involved in the commission of a crime. Legal authorities are more likely to consider FAS/E as a mitigating factor if the disability has already been established, than if FAS/E is brought up after the fact and used as an excuse for criminal behavior.
- Investigate the possibility of using a visiting nurse (through medical insurance) or a public health nurse who can monitor the adolescent's progress. If she understands FAS/E, she will be able to support the family, identify and document the medical and mental health issues involved, and make referrals to appropriate resources.

## PANIC ATTACKS

Panic attacks that are not recognized as such are very dangerous and can prompt an adolescent with FAS/E into a suicide attempt. Adolescents with FAS/E "operate" by trying to read faces which very often can be misunderstood. For example, mom may be frowning, but it may be due to the sunlight in her eyes and not in response to what her son just said.

### FAMILY INTERVENTIONS

- Be extremely sensitive to the mood swings of your adolescent and keep them talking to you. Try to rephrase what they say to you so they can determine whether or not you have understood what they are trying to say. It is very hard for most of them to identify and express what they are feeling and thinking.

- Be available to them at all times, either in person or by phone.
- Realize they may need 24-hour supervision if they become self-destructive.
- Talk to other parents of adolescents with FAS/E and share frustrations and ideas. Support groups or other parent networks are often helpful.

### Systems Interventions

- Find a mental health counselor or psychiatrist who can have a long-term relationship with the adolescent, assuming of course they are very experienced and knowledgeable about the core disability traits of FAS/E.
- Place the adolescent in a residential or in-patient mental health treatment facility if they appear to need 24-hour intensive supervision. Agencies or programs such as public schools, Adoption Support, the Division of Developmental Disabilities, SSI, or private insurance may help pay for this type of treatment.

## Rage

Some people think that people with FAS/E are violent. The collective family experience shows that the core disability trait is not violence but volatility. However, violence can occur if they are not given proper support and a harmless outlet for venting their strong emotions, especially rage. Appropriate interventions for volatile outbursts are essential to keep the adolescent with FAS/E and the community safe.

### Family Interventions

- See toddler intervention list under rage. Many of the interventions for toddlers with FAS/E are still appropriate for adolescents.
- Use consequences for misbehavior that reflect the knowledge that the most appropriate interventions will be similar to those given a 3-year-old. Many adolescents with FAS/E are at the same developmental level as much younger children. In other words, adolescents with FAS/E are unable, not unwilling, to accept responsibility for aggression and rage. Because they are developmentally disabled in this area if push comes to shove, and someone tries to force them into being reponsible, rage will often multiply and can result in unexpected violence.
- Repeat instructions calmly until the meaning slowly sinks into their consciousness through their rage and they calm themselves.
- Designate a mutually agreed upon friend or relative who will provide a "safe house" if the teen panics and decides to run away.

### SYSTEMS INTERVENTIONS

- Locate a psychiatrist who is very knowledgeable about FAS/E and can provide supervision for medication therapy. Medications are often successful interventions for rage. However, special sensitivity is required when medication is needed for an adolescent girl with FAS/E, since there must be coordination with her gynecological needs and birth control prescriptions. Appropriate documentation of therapy is also needed in case residential treatment is necessary to keep the adolescent and the community safe.
- Vitamins and nutritional supplements have been successful for some individuals with FAS/E. The Division of Developmental Disabilities has authorized payment for this therapy in the cases of documented medical need.

## SELF-RESPECT AND SELF-ESTEEM

By the time children reach the adolescent years it is very important that they have a strong sense of personal identity and a deep awareness of their unique skills and special talents. Because most people with FAS/E are **exceptionally** vulnerable to peer pressure (i.e., have a moral chameleon quality), a deep sense of self is absolutely critical, according to the collective family experience.

### FAMILY INTERVENTIONS

- See the interventions for toddlers and children. Many of the interventions that were used during the toddler and childhood years to build self-esteem and self-respect are still appropriate interventions for the adolescent years.
- Involve individuals with FAS/E in the care of animals. Activities such as those through 4-H, that teach animal care skills, are very good interventions to build self-respect and self esteem. Some families moved to a farm; others made sure farm animals were part of the out-of-home placement experience.
- Provide clean, boisterous fun without alcohol or other drugs. A lack of social skills can be a deep source of depression for adolescents with FAS/E. Many families reported that participation in youth church choirs or youth groups with strong, healthy leaders and lots of adult companionship (supervision) have been very positive interventions. They not only teach social skills but encourage other teens to be friends with people who have disabilities while providing respite for weary parents.
- Involve the adolescent in sports activities, such as BMX races, skateboards, roller blades, or even Special Olympics.

- Role-play with the adolescents to help them understand what other people are thinking and doing in different social situations.
- Protect the teens from sexual victimization, which crushes self-esteem, by limiting phone access and closely supervising online computer use.

#### SYSTEMS INTERVENTIONS

- Find or help create a peer support group for adolescents with FAS/E, whether they have official meeting times or casual meetings. These relationships have been a very positive intervention for building self-esteem and self-respect because the teens identify with each other and communicate on a very clear, concrete level.

### CONCENTRATION AND SELF REGULATION

Adolescents with FAS/E continue to have problems staying on task and keeping goals and priorities in mind. Some of these issues are the result of FAS/E (e.g., reasoning, judgment and memory deficits), while others can be the result of an additional disorder, such as ADHD. Concentration problems are a major problem during the adolescent years for all youth. But it is a grossly exaggerated problem for teens with FAS/E, especially those who also have ADHD.

#### FAMILY INTERVENTIONS

- See interventions for children. Many of the same interventions that were appropriate for children with FAS/E, will still be effective interventions for adolescents.
- Understand that the sexual chemistry of the adolescent years multiplies their problems with concentration and attentional deficits.
- Continue daily routine and structure, with support and gentle reminders for ongoing responsibilities, such as cleaning the bedroom or doing the laundry.
- Supply immediate daily rewards, such as money for doing household tasks, instead of a weekly allowance.
- Insist on time for adolescents with FAS/E to be alone so they can disengage from the influence of their peers and think about their goals, priorities, and values. Many parents found that the inability of their adolescents to concentrate and self regulate became so severe that residential treatment or incarceration was required.

- Supply a Walkman with ear phones and their favorite music to help pass the time during long car or bus rides where they have problems concentrating and consequently, entertaining themselves. These issues are a direct manifestation of their disability and not an issue they can overcome by will power alone.

#### SYSTEMS INTERVENTIONS

- Arrange for a peer aide or tutor at school to help the student with FAS/E to transition into middle school with multiple classes, buildings, and teachers.
- Investigate EEG biofeedback that can help in this area. Local practitioners can be located on the Internet at http://www.eegspectrum.com.
- See also Systems Interventions under Dangerous Behaviors, Panic Attacks, Rage and Education, which are all interrelated with this area.

### EDUCATION

The most critical issue during the adolescent years is to help the person with FAS/E continue his/her education while preventing the teen from getting involved with people who will lead him/her into trouble. This intervention is very difficult because most normal adolescents soon grow weary with peers who have FAS/E. The only people that are typically available for companions are the social outcasts, gang members or drug abusers. Primary intervention includes close supervision or in some cases 24-hour supervision.

#### FAMILY INTERVENTIONS

- See Toddler and Childhood Interventions. Many of the interventions that are outlined under the toddler and childhood years are still effective for adolescents.
- Set up daily or weekly progress reports from some or all teachers to help keep the teen with FAS/E on track.
- Include the student with FAS/E in all meetings where decisions are being made about his/her future.

#### SYSTEMS INTERVENTIONS

- Focus on the "School to Work" transition program (or vocational training). Most adolescents with FAS/E have already peaked out as far as their academic progress is concerned.
- Insist on either a self-contained classroom or some type of special educational assistance, to the degree appropriate for the individual student.

- Let the student finish high school in residential treatment, through home schooling or by taking the GED, if they are not able to finish in a formal public or private school.

## ACCESSING SERVICES

A few people qualify for services because they have mental retardation and a few receive interventions for dangerous behavior. However, in the Division of Developmental Disabilities in Washington State, individuals with FAS/E are considered to be an unserved population. Mental Health therapy is meant to help the client gain insight and learn skills to overcome or cope with their weaknesses or to supply medication that will return equilibrium to the troubled soul. In Substance Abuse Treatment Programs, clients are expected to *work the program* or *follow the 12 Steps.* Individuals with FAS/E cannot do either, without long-term support and structure, so these standard approaches don't work. Currently there are no FAS/E-specific services in Washington State.

### FAMILY INTERVENTIONS

- Seek help from disability advocacy groups that offer help to people who have family members with disabilities: FAS*FRI,[2] The ARC, Washington P.A.V.E. (Parents Are Vital in Education), The March of Dimes, etc. Aside from FAS*FRI, these organizations are not specifically geared for people with FAS/E but their advocates understand common disability issues and have knowledge of the public service systems, so they can point families in the right direction for intervention.

### SYSTEMS INTERVENTIONS

- Attend training to learn how to advocate for people with disabilities. The FAS Family Resource Institute also provides private mentoring to families who need help from service delivery systems. Gaining knowledge of advocacy skills is often a critical intervention to preserve family relationships.

- Appeal all denials for appropriate services. Persistence pays off according to the collective family experience.

## ADULTS

In the summer of 1994, as previously noted, a group of parents produced a comprehensive FAS Needs Assessment. Generating data to create a Developmental Overview of individuals disabled by prenatal alcohol exposure is the first step to finding strategies and interventions for each age group. The

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[2] See attached, FAS*FRI: Who We Are and What We Do

following characteristics compose the Adult portion of the Developmental Overview. Parents report that their adult children with FAS/E have the following characteristics:

- moral chameleons
- often exhausted and irritable from uneven sleep patterns
- extremely vulnerable to anti-social behavior and at great risk for finding the structure and supervision they need in the criminal justice system
- unlikely to follow safety rules concerning fire hazards, safe meal preparation, vehicle operation, infectious diseases, basic life needs, etc.
- notably lacking in the ability to manage money
- volatile if pushed too far to do something they see as unreasonable, e.g., requesting money for rent or groceries.
- quite vulnerable to co-dependent relationships, which all too often turn violent
- incapable of taking daily medication or birth control pills on a regular and effective basis
- vulnerable to panic attacks, depression, suicide ideation, mental and emotional overload, and sometimes psychotic breaks
- very impaired as to entertaining themselves and keeping out of mischief when left alone
- not nearly as capable as they appear to be
- in desperate need of appropriate sheltered employment opportunities

**Some of these characteristics may appear to be typical behavior in a normal adult, but in teens with FAS/E, these traits occur in grossly exaggerated form and do not respond to typical treatment or interventions.**

## BATTLING THE BEAST OF BURNOUT

It is also important to recognize the challenges and pressures on parents as they try to meet the needs of their disabled adult children. The stress and pain of having an adult child with an unrecognized and misunderstood disability such as FAS/E takes its toll on family health and relationships. Thus we have also identified the sources of parental burnout. As parents of adult children with FAS/E, we still struggle with many toddler, children's, and teen issues plus:

- Fear of dangers to our adult child's personal safety, including possibilities of HIV infection and other STD's, unplanned pregnancies, etc. especially since they have full legal rights as adults.

- Our adult children's extreme vulnerability to substance abuse problems. One of the devastating results is that our daughters are at high risk for producing another generation of children with FAS/E.
- Full-time efforts required to access services for our disabled children in several systems, each with their own language and eligibility criteria and their own set of rules to follow to continue eligibility. This hits at the heart of their disability since they cannot follow rules on a continuing basis and endangers their eligibility for services.

## INTERVENTIONS FOR ADULTS

The goal of the FAS Intervention Retreat in 1997 was to gather up the unique discoveries from families that have been proven to be successful to alter the natural, negative course of FAS/E and prevent or minimize the secondary disabilities that can result. By living with adult children disabled by FAS/E and recognizing the common developmental deficits, families identified the most challenging areas for primary interventions in this age group as: alcohol and other drug addictions, transportation needs, diagnosis, and services, developing work opportunities, keeping appointments, depression, and following rules. The interventions for adults are categorized by each of these areas of challenge.

## FINDING STABLE LIFE COMPANIONS

One of the most critical needs that an adult with FAS/E has, is to develop and maintain healthy relationships. Of course this is true for everyone but, as is common with FAS/E, the need is grossly exaggerated. If interventions are unavailable, the results are often disastrous. Young men with FAS/E often get caught up with peers who revolve in and out of the criminal justice system due to robbery, vandalism, alcohol abuse, petty drug trafficking, etc. Young women with FAS/E fare no better, getting involved with people who shoplift and write bad checks. They are also vulnerable to sexual relationships with unstable partners who often lead them into chemical dependency and sometimes prostitution.

### FAMILY INTERVENTIONS

- Concentrate on providing the natural support of immediate and extended family. People with FAS/E are delightful additions to family life, but the extended family does need to know there is a disability; they need education about the core disability issues of FAS/E and how it has specifically disabled their family member.
- Encourage the adult with FAS/E to continue childhood and teenage friendships that involve clean and sober activities.
- Model stable marriage relationships that provide the greatest source of long-term intervention for individuals with FAS/E after age 18, according to the collective family experience. If the

person with FAS/E has seen secure and happy love relationships modeled by friends and family, they seem to seek out peers that recreate that good feeling of stability for themselves.

- Provide boisterous fun without alcohol or other drugs. People with the disability of FAS/E don't necessarily seek out wild parties and crummy friends but have an innate characteristic of an unquenchable thirst for a lot of active fun.
- Be available at all times to provide them with a listening ear and a "reality check" whenever they feel the need to talk. Meaningful communication skills do not come naturally to people with FAS/E.

#### SYSTEMS INTERVENTIONS

- Find organizations that have good community fun for people with disabilities and mental disorders, such as the ARC and The March of Dimes. (However, most of these activities are currently geared toward people who are mentally retarded or deeply mentally disturbed and don't appeal to adults with FAS/E who have normal IQ levels. More advocacy is needed in this area.)
- Support participation in church-affiliated or community activities for all young adults.

### ALCOHOL AND OTHER DRUG ADDICTIONS (CHEMICAL DEPENDENCY)

Stopping FAS/E from occurring in generation after generation of the same family hinges on providing interventions to men, and especially to women, who themselves have FAS/E. It is essential that this be done before their life habits are set and they become addicted to alcohol and/or other drugs. The collective family experience tells us that once a person with FAS/E is addicted, it is almost impossible to provide enough stability in their adult lives to help them return to sobriety. As a result of chemical dependency in people with FAS/E, most of their offspring "fall" into our foster care and adoption systems. Because of denial and the natural consequences of the disease of alcoholism in individuals with FAS/E, these children do not come into public systems at an early age. Consequently, they not only end up being another generation with FAS/E, but they have serious attachment disorders and are unable to trust and bond with other people. In some families, there are generations of individuals with FAS/E cycling in and out of the foster care system, a heart breaking and devastating tradition for their personal lives and for our society in general.

#### FAMILY INTERVENTIONS

- Implement the previous interventions proposed in this document to appropriately meet the needs of individuals with FAS/E. If their needs, especially for mental health and positive

social activities, are appropriately filled, they will be less likely to fall into chemical dependency. Excessive and/or illegal use of drugs can be easy ways to self-medicate, when appropriate, interventions are unavailable.

- Recognize that the onset of alcoholism can develop very rapidly if children begin bingeing with alcohol at 11 or 12 years old. Most parents at the Intervention Retreat reported that the birth mothers of their children were under 18 when the child with FAS/E was born.

#### SYSTEMS INTERVENTIONS

- Advocate for all chemical dependency (CD) treatment facilities to have screening methods to identify clients that have FAS/E.
- Request a referral from the CD treatment facility to an advocate who can help the newly identified person with FAS/E to access both State and Federal developmental disability benefits and other types of long-term support. Otherwise they will not be able to maintain their sobriety.
- Request court-ordered CD treatment through a criminal justice diversion program. Currently this type of intervention provides the most effective method for getting individuals with FAS/E into CD treatment. Whether they can maintain a clean and sober lifestyle remains largely a matter of on-going support services.

### TRANSPORTATION NEEDS

People with FAS/E who have normal IQ levels usually have more transportation problems than those who are mentally retarded. If the person has a lower IQ, the bus is often a satisfactory option. However, individuals with a normal IQ are keenly aware that their friends have a driver's license and cars to drive and they want that privilege, too. The problem is, without appropriate support, the disability leaves them without the financial means to acquire car insurance and keep up with car repairs. Frequently, they have problems with road rage, end up with lots of traffic infractions, lose their driver's license, and/or are unable to pay for traffic tickets and end up in jail.

#### FAMILY INTERVENTIONS

- Begin early to address this issue in conversations between the individual with FAS/E and his/her family. Children and adolescents with FAS/E need tight structure and supervision. However, once the person is over 18 they are free to abandon both structure and supervision. Families must learn how to guide and mentor the disabled child from the tight structure of the childhood years into the freedom of the adult years so they will accept and use the advice they get surrounding transportation and other issues.

### SYSTEMS INTERVENTIONS

- Let the criminal justice system intervene without interference if the individual with FAS/E is driving and has chemical dependency issues accompanied by other mental health disorders. Sometimes incarceration or diversion plans can instill caution into the memory bank; but it is a very painful way to learn for the individual, and it is an expensive, sometimes dangerous, time to intervene for the community.

## DIAGNOSIS AND SERVICES

Sometimes people conclude that seeking a diagnosis of FAS/E doesn't matter after the person reaches adulthood but according to the collective family experience, that is not the case. Individuals with FAS/E are not dumb, and they usually want and need to know why their lives have been so difficult and different from the norm. A genuine medical diagnosis of FAS or determination of FAE supplies the reason they act and feel the way they do. [3] The most typical response is, "Now I don't feel stupid because I know it's not my fault."

### FAMILY INTERVENTIONS

- Seek a diagnosis from the family physician or from the treating psychiatrist who knows the individual and family history.
- Trust your parental instincts as to the appropriateness of the diagnosis. If it "doesn't fit," continue to pursue an accurate diagnosis that does fit. Many individuals are misdiagnosed or under-diagnosed only with ADHD, Conduct Disorder, Bipolar Disorder, etc. According to the collective family experience, when the person finally gets a diagnosis of FAS/E, everyone feels relieved because it fits perfectly.

### SYSTEMS INTERVENTIONS

- Find a specialist or specialized clinic where doctors will give an FAS diagnosis if the family doctor does not feel comfortable diagnosing FAS/E. In Washington State, the legislature has funded a series of FAS/E diagnostic clinics originating from research at the University of Washington, to identify and diagnose **all disabilities** resulting from prenatal alcohol exposure, regardless of facial features.

Obtain eligibility for services or income to provide the necessities of life. Food can be obtained with Food Stamps or from food banks; the Housing and Urban Development (HUD) can provide assistance with shelter; medical care and some cash assistance are available through the Federal SSI program (Social Security Disability Income). Separate applications must be submitted for all these

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[3] SEE RELATED, ATTACHED DOCUMENT, FAS/E RESEARCH

programs. An FAS/E diagnosis does not automatically qualify a person for any of these programs, including SSI. Documentation must also be submitted with the SSI application to show **how** the applicant's ability to work full-time has been impaired. There are three identified approaches to this process of obtaining eligibility. Some families have the time and energy on their own to find the pathway through this procedure and paperwork maze; others hire an attorney who specializes in SSI applications; there are also non-profit organizations like Washington P.A.V.E., The ARC, and FAS*FRI, who help families through this complicated process.

## DEVELOPING WORK OPPORTUNITIES

Most individuals with FAS/E have not finished high school by the time they reach age 18. Those that have managed to get a diploma are frequently not skilled at anything that can produce a living wage. Since many of these individuals have IQ's in the normal range and have a desire to live in the mainstream of society, it is critical to identify roadblocks and provide interventions that help them accomplish this goal.

### FAMILY INTERVENTIONS

- Continue to educate all system personnel as to the core disability issues of FAS/E. Provide documentation as to how FAS/E has impacted their specific clients.
- Provide home schooling if feasible. Students then don't have as many opportunities to get entangled with troubled peers. (However, they still need boisterous fun built into any program.)
- Educate potential employers about FAS/E so if the individual has an emotional melt-down, they will be allowed to go home early or take a break rather than lose their job.
- Have all previous employers write a letter explaining the reason why the individual with FAS was fired or laid off. This is essential documentation for SSI eligibility, if needed.

### SYSTEMS INTERVENTIONS

- Individuals with FAS/E need an advocate-interpreter, especially in any legal arena or even filling out job applications, etc.
- Continue the School-to-Work transition program through the local school district. If the person with FAS/E has not graduated from high school, he/she will still be eligible for this program until age 21.
- Job skill training is often available through local junior colleges. Colleges and universities are also required by law to provide assistance to help people with disabilities get an education.
- Apply for services through Vocational Rehabilitation, which gives various types of support to people with disabilities so they can prepare for and obtain employment.

## Keeping Appointments

The ability to make and keep appointments is a crucial component of success in our society. However, individuals with FAS/E have great difficulty with this task and, indeed, it seems to be a direct manifestation of the disability itself. Even when their lives and freedom depend upon it, as a condition of their parole from prison, it is almost impossible for them to remember the day and time of scheduled appointments.

### Family Interventions

- Teach the individual with FAS/E to take use of personal notebooks, daytimers, wall calenders and magnetic notes on the refrigerator. Recognize that this type of intervention will not be 100 percent successful.

### Systems Interventions

- Require professionals to call and confirm appointments. Consistent times and days are sometimes easier to remember.
- Remind support professionals that this trait is a direct manifestation of the disability of FAS/E.

## Depression

Individuals with FAS/E seem to have an innate need for chaos and boisterous fun and without it gloom and depression can overtake their personalities. In times of social disappointment, especially, their depression and fear of isolation causes them to panic and can result in suicide ideation.

### Family Interventions

- Promote participation in music and/or singing, a very effective intervention to calm the fear and panic which precedes the depression.
- Encourage the development of a sense of humor, the ability to laugh at one's self, a critical intervention to overcome depression. To survive we must be able to learn to see the funny side of life.
- Be available immediately when the individual with FAS/E hits bottom. This is a very good intervention time to get them to listen and take a little advice.
- Provide music lessons and/or art lessons which are very helpful mood elevators. The best time to start is before age 5, but can still be effective in adulthood.
- Involve them in role-playing that helps them remember what values they have been taught and helps them form their own opinions and life goals.

- Help them find church study groups and (audible) prayer groups where they are comfortable with the other members and their beliefs. These are very effective interventions for individuals with depression, according to the collective family experience.
- Seek treatment methods such as EEG biofeedback to interrupt the depression cycle.

#### SYSTEMS INTERVENTIONS

- Explore medication for depression; it has been an excellent intervention and may prevent self-medication through alcohol, tobacco, and other drugs.
- Find professional counseling that is geared as a reality check, not just traditional talk therapy.
- Locate or create a support group with peers who have FAS/E.

### FOLLOWING RULES

Some people think that the most troublesome behavior of individuals with FAS/E is their inappropriate social interactions with other people. However, the collective family experience identifies the inability to sequence or follow rules as the area that is the most difficult in which to intervene and overcome. Most of us do not think about the fact that everywhere we go and everything we do has an incorporated standard of behavior. It is true that problems occur in social activities at the swimming pool, local shopping mall, or the high school dance, but this issue is a lot broader than one's social life. It also includes following the rules at the library, or using the toaster or VCR, directions on homework, following parole and diversion mandates, being able to remember the time and place of job opportunities and rules to make sure birth control is used effectively.

#### FAMILY INTERVENTIONS

- Educate the community on the core disability issues of FAS/E, other diagnoses that often coexist with FAS/E and time-tested interventions that support individuals with FAS/E and their families.
- Facilitate relationships, which will provide "reality checks" between someone who respects and understands the need for rules in a civilized society and the individual with FAS/E. This relationship can be between the adult child with FAS/E and a parent or counselor, or it can be in the context of an FAS/E support group.
- Set up activities to monopolize and supervise time even for adults with FAS/E, if needed.

#### SYSTEMS INTERVENTIONS

Adults who are unable to follow rules often wind up under the jurisdiction of the criminal justice system. The following interventions have had positive results:

- Offer to provide education on the core disability issues of FAS/E for attorneys, judges, jail and prison personnel, police and Department of Corrections officials.
- Seek eligibility for services, including 24-hour supervision for sexual offenders when necessary, through the Division of Developmental Disabilities.
- Request diversion or parole options that include random drug testing, community service, and regular attendance at Alcoholics Anonymous (AA) meetings or other supervised support groups. Some diversion and parole officers require documentation of attendance from the individual with FAS/E.
- Provide an interpretive advocate (which can be a parent) for all legal proceedings.

## CONCLUSION

We are convinced that information from the collective family experience is vital to professionals for building a sound foundation on which to base scientific inquiry into service demonstration projects for toddlers, children, adolescents, and adults with FAS/E. The positive outcomes of these projects will provide justification for the allocation of dedicated funding for standard, ongoing support for individuals with FAS/E and their families.

## The FAS Family Resource Institute
Who We Are and What We Do

I. Three Catalysts for Change

The FAS Family Resource Institute (FAS*FRI) origins:

A. Identification and diagnosis of FAS in an adolescent with a normal IQ revealed the total nonexistence of services which might have prevented out-of-home placement.

B. Careful search of the community led to the discovery that service providers could not recognize these disabled individuals on their caseloads, even though they had read the scientific research.

C. Dr. Sterling Clarren recognized that the researcher's role does not include translating research data into experience-based, practical knowledge to identify, understand, and care for individuals disabled by prenatal alcohol exposure.

II. Tactical Plan for Change: FAS*FRI Mission Statement

The FAS Family Resource Institute (FAS*FRI) is a grass-roots, private, nonprofit organization of parents working together with professionals who are dedicated to the identification, understanding, and care of individuals disabled by prenatal alcohol exposure and their families, and to prevent future generations from having to live with this disability.

III. Methods for Change: FAS*FRI Activities

A. Advocacy evolved out of the desperation of isolation and recognition of a common experience.

1. A letter was sent to other parents through Adoption Support.
2. A survey of educational, developmental, and family experiences was conducted with the families who responded to the letter. These responses helped to create the Adolescent Behavioral Symptoms described in the original FAS*FRI brochure (*We Love Children*), which was developed as a personal advocacy tool for parents. An updated, condensed version of this survey is mailed in information packets sent out

by FAS*FRI. Many parents return this survey, thus perpetually verifying the original data.

3. The first parent-initiated conference was held (1991) to validate the common experience of parenting a child disabled by prenatal alcohol exposure. Out of the conference grew the recognition of the need for advocacy on multi-dimensional levels that was facilitated for the parents by the Washington State Developmental Disabilities Planning Council.
4. A 1994 Needs Assessment Retreat (sponsored by the Department of Health and Division of Alcohol and Substance Abuse [DASA] in the Department of Social and Health Services) gave parents a chance to collectively identify the needs of individuals disabled by FAS/E and their families.
5. A developmental profile survey was developed from the data gathered at the retreat and mailed to the retreat participants for confirmation. Further substantiation of the developmental profile was achieved by consulting families on our newsletter mailing list. Responses from both parent groups overwhelmingly validated the survey data.
6. An FAS Intervention Retreat was held (1997) to collect from families the successful interventions they have implemented for their children with FAS/E.

B. Current Avenues of Advocacy mirror the definition of advocacy. Parent advocates are:

1. **Insisting** on being an integral partner in identifying, planning, and accessing services for their own child,
2. **Training** service providers who deliver services to their child,
3. **Interceding** on behalf of those families who have children in crisis or who have little experience in advocacy,
4. **Mentoring** other parents and adults with FAS/E to teach them how to access services,
5. **Educating** service systems personnel in general,
6. **Sharing** personal stories to educate the public through the media,

7. **Educating** public officials in the three branches of government in close collaboration with other parent advocacy groups,
8. **Working** at administrative levels of agencies and systems to develop appropriate public policy and procedure,
9. **Promoting** legislative action in identification, prevention, and intervention of FAS/E,
10. **Demanding** that state personnel be held accountable to follow state law, policies, and procedures in delivering services to families.

IV. Vehicles for Change: FAS*FRI Products

The tangible results of our relationships and advocacy for families and with service providers, evolved over the last 5 years into the following:

A. Provision of an FAS crisis and information phone line which:
   1. supplies a forum for networking and support of families raising children with FAS/E,
   2. assists callers by listening, validating, teaching, referring, and mentoring them.

B. Development and implementation of the FAS*FRI demographic tool. This tool is a perpetual data gathering and tracking process that documents the following:
   1. the successes and challenges of individuals with FAS/E and their families,
   2. the variety of professionals involved in developing and delivering appropriate care,
   3. the availability and/or difficulty of receiving a diagnosis, regardless of the presence of facial features,
   4. the FAS interest pulse of the media,
   5. the strengths and weaknesses in the educational system to address the needs of our children,
   6. the variety of types of families the children live in,
   7. the number of callers who have a child with a valid diagnosis of FAS and those with suspected or confirmed FAE, and
   8. an international base for networking with other parents and professionals.

C. Publication and distribution of our quarterly newsletter, *FAS Times*, which provides:

1. feedback on addresses that serve as a tracking system for individuals with FAS/E and their families,
2. a forum to validate the collective family experience,
3. education for families and the professionals who serve them,
4. information and strategies to help families access appropriate services, and
5. a conduit to link information and activities with other mental health and developmental disability advocacy groups.

D. Creation and presentation of the Intervention Touchpoint Seminars which:

1. translate and integrate research data with experience-based knowledge and interventions to identify, understand, and care for individuals disabled by prenatal alcohol exposure and their families, and
2. tailor each conference to the local culture, community and service providers in the audience.

After attending the Intervention Touchpoint Seminars, Kenneth A. Stark, the Director of DASA, stated, "The FAS Family Resource Institute volunteers are among the most passionate, enthusiastic, and tenacious people I have ever worked with. The services they provide to the community need to be sustained and expanded."

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.... Compiled by Jocie DeVries, Vicky McKinney, Ann Waller, Delinda McCann, and Linda LaFever on 4/25/96; revised /4/98.

## FAS/E Research Questions

Posed by the FAS Family Resource Institute
Jocie DeVries & Ann Waller

According to the collective family experience, there is a strong FAS/E common disability pattern. Descriptions from affected individuals and their families indicate **the aberrant cognitive processes of FAS/FAE include decreased ability to**:

- interpret sensory input and information;
- express feelings and ideas;
- think logically;
- integrate and appropriately respond to the current situation in context of: the past, the future, personal consequences, moral values, and societal rules;
- remember and/or acknowledge misconduct and negative personal experiences.

These deficits are the ones most disabling to individuals and disruptive to their families, communities and society, according to the collective family experience. These aberrations are common to both FAS and FAE. In fact, individuals with FAE actually have more problems than those with FAS.* Since FAE is not currently recognized as a medical diagnosis, there is an urgent need to determine clear anatomical, biochemical, and/or physiological criteria for establishing a medical diagnosis for individuals with FAS and FAE. **Therefore, the research goal of utmost importance is to identify one or more diagnostic tests that will enable practitioners to diagnose all individuals disabled by prenatal alcohol exposure (FAS and FAE).** In order to accomplish this goal, common anatomical and pathophysiological abnormalities, which could result in diagnostic criteria, need to be identified, using MRI, PET scans, and other modern techniques. Thus the PRIMARY research question is:

1) **What consistent anatomical, biochemical, and/or physiological damage can be used to develop diagnostic tests to establish a medical diagnosis for FAS and FAE?**

A particular place to begin on the path to this goal is strongly suggested by the convergence of two findings. First, common physical characteristics have surfaced in FAS/FAE research—individuals with

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* According to a 1996 FAS secondary disabilities study at the University of Washington

FAS and FAE have been shown to have anomalies in the corpus callosum, the basal ganglia and cerebellum. One study suggests that a possible consequence of the corpus callosum anomalies might be that certain cognitive processes are compromised, i.e., those requiring communication between the brain hemispheres. ** More study in this area was recommended.

Second, when the common FAS disability pattern emerged from the data gathered by the FAS Family Resource Institute, we searched to find similarities in the behaviors of patients with other brain disorders or conditions. The patients studied in split-brain research (where connections between the brain hemispheres, including the corpus callosum, have been severed) caught our attention. *** The knowledge and expertise of the collective family experience testify to the fact that there is enough similarity between the behavior in these two groups (where damage to the corpus callosum is a common factor) to warrant investigation.

Consequently, it is only logical that the corpus callosum, the basal ganalia and the cerebellum be the areas of the brain to investigate first. **Therefore, it is crucial that we also pursue the following research questions:**

2) **Do all individuals disabled by FAS/FAE have damage to the corpus callosum, basal ganglia, and cerebellum?**

3) **If so, is this damage directly correlated to the aberrant cognitive processes common to this population?**

4) **Are variations seen in the size and shape of the corpus callosum, basal ganglia, and cerebellum directly caused by the teratogenic effects of alcohol or secondary to some other phenomenon (e.g., anomalies in other parts of the brain), or both?**

5) **Can diagnostic tests be developed from these findings?**

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** Riley, Edward P., *Abnormalities of the Corpus Callosum in Children Prenatally Exposed to Alcohol,* (1995).
*** Sperry, Roger, 1981 Nobel Prize in Physiology and Medicine for split-brain research.

## ABBREVIATED SUMMARY OF PRESENTATION

Defining Desired Outcomes for Children with FAS and ARND
The Family Perspective

JOCIE DEVRIES,
FAMILY RESOURCES INSTITUTE

Ms. DeVries, as an experienced advocate and adoptive parent, shared the family perspective in raising children with FAS. She noted that the first challenge is dealing with the shock of the FAS diagnosis, a diagnosis of permanent disability. The larger challenge is finding support services. In her case, she visited 24 specialist service providers and found no help. To prevent similar frustrating experiences for other families raising children with FAS/E, she began the FAS Family Resources Institute (FAS*FRI) in 1990. While the FAS diagnosis is shocking, Ms. DeVries emphasized that it is the starting point for stability in the life of the individual with FAS/E.

Ms. DeVries briefly reviewed available FAS*FRI packets of information, particularly "FAS/E: A Standard of Care for Toddler, Children, Adolescents, and Adults." The paper is based on the collective family experience and outlines family and systems interventions across the life span of the individual with FAS. It is important to recognize the different types of families with FAS/E children—the birth family with an ongoing history of drug or alcohol abuse, the recovering birth family struggling toward sobriety, a family adopting a child diagnosed with FAS/E soon after birth, and a family adopting a child with FAS/E after multiple placements. Interventions must consider the different needs of these various families.

A four-track development profile can be used to gather the history of the individual with FAS. The profile addresses four domains-physical, social, educational, and moral. The physical domain explores birth defects, physical problems (e.g., hearing loss), and type of family (e.g., biological or adoptive). The social domain examines family and peer relationships and emotional equilibrium (e.g., ability to laugh, play, and enjoy the company of others). The educational domain targets the cognitive experience. It examines the child's history of learning abilities and disabilities and the ability (or disability) to reason, acquire, and maintain knowledge of facts. The moral domain includes feelings of empathy and remorse, understanding the need for social cooperation and rules of conduct, and the ability to follow rules. The individual with FAS/E experiences disruption in all four domains.

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# Defining Desired Outcomes for Children with FAS and ARND The Education Perspective

Dr. Gail Houle,
U.S. Department of Education

Dr. Debra Cohen,
New Jersey Department of Human Services

## ABBREVIATED SUMMARY OF PRESENTATION

Defining Desired Outcomes for Children with FAS and ARND
The Education Perspective

DR. GAIL HOULE,
U.S. Department of Education

DR. DEBRA COHEN,
New Jersey Department of Human Services

Dr. Houle explained that one law governs Federal special education services, the Individuals with Disabilities Education Act (IDEA). A child must exhibit a disability related to their educational functioning to qualify for special education services. The law describes who will receive special education services and the nature of the services individuals will receive through age 21. Another component of the law provides for research development and validation of successful practices and pilot programs.

As special education categories differ from medical diagnostic categories, some confusion may result concerning how, when, and what services children can receive. Categories of service for children are not based on the etiology of the disability, but the functional manifestations of the disability. For example, the etiology of mental retardation does not determine which special services a child receives. Instead, services are based on the types of learning disabilities and cognitive impairment the child exhibits. Following diagnostic testing, functional assessment and intervention planning is used to plan a child's individualized education plan (IEP). The child is evaluated each year and services are based on the progress for the particular year. IDEA states that children are entitled to the least restrictive educational environment. A child is not immediately placed in a segregated special education class, but given the opportunity to participate in the regular curriculum and classroom setting.

The Department of Education funded a 5-year descriptive research project to study children prenatally exposed to drugs and alcohol. The study cohort consisted of preschoolers up to age 5, who were in special education settings. Very few children were diagnosed with FAS or FAE, but a large percentage of the children had been exposed to alcohol prenatally. The study cohort did not appear significantly different from children in the special education setting with cognitive impairment due to an etiology other than prenatal drug or alcohol exposure. A longitudinal study with the same cohort is planned to track the children through the elementary grades.

Dr. Cohen remarked that the developmental overview compiled by the FAS Family Resource Institute would be extremely useful for educators. The overview describes behavioral characteristics of toddlers with FAS (age 1 to 5), children (age 6 to 11), adolescents (age 12 to 17), and adults with FAS (age 18 and older). Teachers need to understand the behavioral deficiencies that impede learning.

Vocational options should be considered when FAS students reach adolescence. The individual's strength should be matched to vocations such as graphic arts, culinary arts, or electrical work. FAS individuals perform best when jobs or tasks can be broken down to a series of structured steps.

Educators should be informed of the FAS student's medications. The teacher can provide valuable feedback to determine if the student is overmedicated, undermedicated, or on the wrong medication.

Most students with FAS remain in regular classrooms and are not segregated in self-contained special education programs. For this reason, the classroom teacher should be provided with training or resources to understand the unique differences of FAS. Educating a child with FAS requires a team approach with many players—the student, the parents, classroom teacher, resource room teacher, special education teacher, guidance counselor, mental health professional, and physician.

# DEFINING DESIRED OUTCOMES FOR FAS FROM A CLINICAL RESEARCH PERSPECTIVE

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**What are the steps, which should be taken by the research/clinical community to increase the rate of successful outcomes for persons with fetal alcohol syndrome?**

- **Establish a solid working relationship with families and individuals** with FAS/FAE/ARND to develop a true understanding of the impact of these disorders and to **outline priorities** for future research.
    1. families need help now, and will be willing partners to address important research and clinical questions if approached
    2. good, on-target research will never be conducted unless families are actively involved
    3. family involvement can help keep research focused and targeted to real problems
    4. a recent IOM report (summer 1998) directs the NIH to more family involvement in developing research priorities because the quality of research which results is better and more relevant
- **Develop a prioritized list of questions or issues that deserve the most urgent attention.** Allocate a certain percentage of effort and funding to address those questions through both pre-clinical and clinical research programs, or to activities that will allow such research to take place.
    1. draw up a list (with family involvement) of those behaviors (both positive and negative) which have the greatest impact on day to day functioning, stratified by ages (a list for infancy, preschool, early grade school, pre-adolescent, adolescent, adult, and aging)
    2. encourage population-based studies
    3. identify which problems are seen in other developmental disabilities, and encourage cross-collaboration with researchers in those fields
    4. focus not only on those families who are experiencing difficulties, but also look at families who are not experiencing problems
- **Encourage other activities which will facilitate achieving research goals.**
    1. plan family/researcher and cross-disciplinary conferences
    2. establish a research registry and eventually a brain bank
    3. provide input to medical school curriculum development/CME training
    4. encourage collaborative research/clinical programs
    5. examine the impact of current service delivery (i.e., the educational system)

6. seek to understand the current barriers to care, including policy, attitudes and how policies are carried out around FAS
7. bring related organizations up-to-speed about FAS, including the judiciary, foster care and adoption, developmental disabilities, mental retardation, and education
8. recognize that the primary setting for serving individuals with FAS will be the educational setting and focus efforts there

**What might be on the list of priorities?**

- **Diagnosis**—consistent, routine diagnosis is the fastest path to intervention—we need to institutionalize it, to make it a part of school screening, foster care and adoption placement, etc. Research should be directed to identify a brief screening protocol, which could be used in hospital, at well-baby visits or at any other early point of entry into the health or educational system. A standardized, comprehensive assessment method should be the next step.
- **Early barriers to learning**—We must understand what facilitates and hampers early learning so that appropriate interventions can be developed to prevent many of the poor outcomes we are now hearing about.
- **Early determinants of inappropriate sexual behavior and how to identify and treat them**—This issue is of the highest priority to families.
- **How is FAS like other CNS disorders?**—Work in this area has already begun, but the possibilities for useful data are so rich that efforts should be greatly increased here.
- **Determinants of success**—Understanding the factors, which allow some individuals with FAS to be successful, are critical in planning intervention studies.

**What are some critical adjunct activities, which should be supported?**

- acceptance and use to the FAS diagnosis as meaningful and reliable
- training of physicians, etc.
- enlarging the field, broadening the range of specialties who work in and understand FAS, and have fresh approaches to the problem

## ABBREVIATED SUMMARY OF PRESENTATION AND PARTICIPANT DISCUSSION

The Research Perspective

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Dr. Morse emphasized that research projects should be designed for quick and efficient translation to the clinical setting. Researchers need to think about outcomes and how added information will help the FAS individual and family.

Research is needed to help identify an FAS individual's strengths in behavior and brain structure. Most likely, alcohol does not affect all developing brain structures equally. Some structures are less susceptible to the teratogenic effect of alcohol. The less susceptible areas and their underlying functions need to be identified. Additionally, a fine-tuned psychometric battery of tests should be developed to pinpoint behavioral strengths. Then, interventions could target the behavioral and neuroanatomical strengths of the individual.

An effort should be made to locate FAS success stories and identify the components of success. Many possible factors may shape success, such as level of alcohol exposure, timing of exposure, age of diagnosis, home environment, types of intervention, timing of intervention, and medication. A methodical approach is needed to sort through these factors and identify those that make a critical difference between success and failure.

An important step forward would be the establishment of a nationwide working relationship with FAS/FAE families and individuals. It would serve as a mechanism to bring together the research community and family groups to learn from each other. Families should provide input in setting research priorities. Families are willing partners, anxious to help.

The establishment of a research registry and centralized database would promote collaboration. Many models exist, serving other disorders. Additionally, a brain tissue bank should be established. The bank may answer questions concerning the variability of FAS. How does the brain of a severely affected FAS individual differ from an individual mildly affected?

Other areas of research include cross-disciplinary approaches to examine whether interventions for other behavioral disorders (e.g., ADHD, autism, William's syndrome) may work with FAS individuals. Medical school curricula, continuing medical education, and teaching training must be improved regarding FAS issues. Consistent and routine FAS diagnostic techniques are needed. FAS screening should become part of initial school physicals or inoculation schedules. Ideally, research will lead to reliable screening of newborns. Clearly, more children have FAS than are being diagnosed. All avenues leading to improved identification of FAS individuals must be explored.

**Discussion**

Ms. Dehoney asked Dr. Houle to clarify the difference between a functional deficit and a diagnosis of disability. A child may present with a constellation of functional deficits but have no medical diagnosis. Dr. Houle explained that functional assessment can be used to determine whether the child has a disability. If a child's functioning were significantly different from normal functioning, it would indicate a disability, and the child would be eligible for remedial services. The child may not be diagnosed as FAS or FAE, but would be identified as learning disabled or speech and language disabled to qualify for services.

Dr. Floyd inquired if the Department of Education was receptive to adopting a less standard battery of tests that would improve the detection of FAS/FAE children. Dr. Houle replied that the ongoing practice is to incorporate the latest input from the research community. She added that on the local and State levels assessment practices might vary. Dr. Riley noted that in California children are more likely to receive services with a medical diagnosis of disability.

Dr. O'Malley questioned if it were possible to incorporate models of multiple intelligence within assessment practices, particularly to identify strengths. Dr. Houle remarked that incorporation is already ongoing in some areas. The IEP process is supposed to identify strengths and weaknesses, but implementation varies depending on the teacher.

Ms. Vicky McKinney commented that FAS children with normal IQ may qualify for services under the category of "health impaired."

# INTERVENING WITH CHILDREN WITH FAS AND ARND: WHERE DO WE START?

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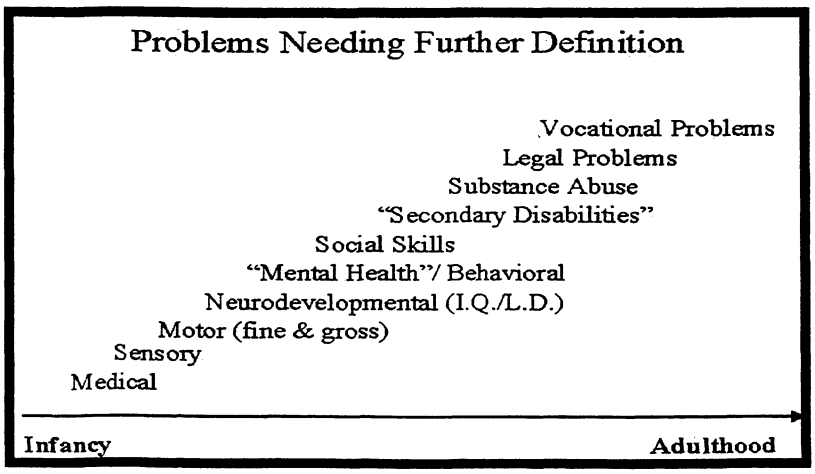
**ABSTRACT**

There has been limited attention to intervention with and treatment of individuals affected by prenatal alcohol exposure despite the cognitive, social, and emotional problems common in this group. At the present time, there are no empirically validated treatment methods that have been demonstrated to be effective in helping to treat the primary effects of prenatal exposure or the secondary conditions that appear to be associated with this diagnosis. Surveying caregivers of affected individuals indicated that children's unmet needs were particularly important in the areas of mental health, education, and remedial services. Agencies report providing alcohol-affected individuals with customary services if they meet qualifying criteria but no services are targeted to this group. Professionals report needing further training in diagnosis and treatment/intervention. Recommendations for beginning to work effectively with this group include: further research on the deficits associated with FAS and alcohol-related disabilities, further research on specific neurocognitive and functional deficits, improved early identification, involvement of families in treatment, improved professional training, and development of well-evaluated treatment resources and facilities.

Since the recognition of FAS almost thirty years ago (Jones & Smith, 1973). a primary public health goal has been prevention of alcohol-affected births. There has been relatively less attention paid to intervention with affected individuals and to prevention of associated or secondary conditions that may develop in such persons. Unfortunately, the problem of drinking in pregnancy has persisted despite the information that now is available about its negative consequences. As a consequence, there are many individuals who have been affected by prenatal exposure and who need intervention and treatment to improve their quality of life. As the Institute of Medicine (IOM) report noted (Stratton, et al., 1996), meeting the multiple needs of such individuals will require a multidisciplinary approach and a spectrum of programs and services. These needs arise not only from the range and complexity of the consequences of prenatal exposure but also from the life-long disabilities associated with FAS.

People affected by alcohol can be any age, from birth through adulthood, and may have a variety of associated problems. Medical problems are more common during infancy, but these often resolve as



the person grows older. Intellectual (cognitive) deficits, which often become apparent at preschool and school age, are evident in many affected children with the majority of those with FAS having IQs in the mildly delayed range (i.e., IQ=50 to 69) and the majority of those with fetal alcohol effects (FAE) or partial FAS, having scores in the "borderline" range (IQ=70 to 85) (Streissguth et al. 1996). However, scores of affected individuals appear to have a normal distribution so that some individuals score in the average range for the population as a whole (IQ=85 to 115). Many individuals with FAS, particularly those who are identified in clinical samples, have behavioral or mental health diagnoses, but this is not always the case, and there may be risk and protective factors associated with such outcomes (see Streissguth, this volume). Attentional disorders (e.g., Attention Deficit, Hyperactivity Disorder [ADHD]) have often been diagnosed in alcohol-affected individuals (Astley, 1994; Nanson & Hiscock, 1990) but the universality of this association has been challenged recently (Coles, et al, 1997). Specific learning deficits are beginning to be identified in school-aged, alcohol-affected individuals. However, not all exposed individuals show such patterns and there is some variability in reported outcomes. Finally, among older individuals with prenatal exposure, there may be a higher than usual vulnerability to alcohol and drugs. The possibility of such vulnerability has been discussed for some time; recently, Streissguth and colleagues have demonstrated that it may be related to the effects of prenatal exposure (Baer, et al., 1998) as well as to previously recognized familial factors (e.g., genetics, social learning) (Smith, et al, 1995).

Whatever the behavioral manifestations of prenatal alcohol exposure, it is certainly true that such individuals are at higher risk in terms of their care-giving experiences. Many affected children remain with dysfunctional parents for years while others experience multiple home placement. Others are adopted early in life and experience stable care-giving environments (see, Stratton, et al., 1996, pp. 171-173). Such patterns many interact with the cognitive and other deficits inherent in prenatal exposure to produce a variety of disorders and needs for intervention services.

In practice, identifying or developing appropriate interventions to deal with these problems may be difficult. In a given individual, prenatal exposure may be associated with a variety of outcomes so that it can be difficult to predict what kinds of interventions and treatments will be necessary. In addition, because there has been little or no research on intervention, there is no information to guide programmatic interventions or social and educational policies.

## THE CHALLENGE

Alcohol affected individuals have a significant need for services and yet there is a lack of information to guide recommendations for policy at any level. This dilemma presents a formidable challenge. In practical terms, the challenge for the interventionist might be stated as follows:

| To improve outcomes for alcohol-affected individuals (and their caregivers/families) through effective interventions that can be implemented within existing systems. |
|---|

This statement includes several assumptions. First, that while the evident goal is to improve outcomes for affected individuals, it is also important that their caregivers and families be included in this goal and included in the process of planning. Another assumption is that, at least in the initial stages, the approach should be through existing service systems. Such an approach would be most cost effective and could be implemented most quickly. Only if it is demonstrated that existing systems cannot be effective for alcohol-affected individuals and their families should other alternatives be examined.

An additional provision should be that any interventions or treatment methods must be required to demonstrate effectiveness. This suggestion may seem self-evident; however, in many other situations, services are provided without research or program evaluation to support effectiveness. For instance, in many cases, adult medications are prescribed to children without clinical trials to demonstrate their appropriateness or effectiveness in such situations.

Given these assumptions, it is important to understand the availability and effectiveness of existing resources. Accordingly, several studies were undertaken to explore in a preliminary way, the needs of families, the utilization of resources, and the status of knowledge about intervention/treatment for alcohol-affected individuals (Falek, Drews & Coles, 1998)

### TREATMENT AND INTERVENTION: ARE THERE EXISTING RESOURCES?

**Identifying services needs of affected individuals/families.** Clinical and experimental studies of individuals, which were cited above, suggest that families must have many needs for services from a variety of providers. To identify needs that might be specific to families of children with FAS, 17 caregivers, both biological and adoptive/foster parents, of children, ages 2 to 17 years, were interviewed and their response compared to those of caregivers of non-affected children who were matched for ethnicity and social-class status (Coles, 1998). Caregivers of FAS children were more likely to be poor, less educated, unmarried, and un(der)employed than were other caregivers. They also experienced more medical and mental health problems and were more likely to have been in drug/alcohol abuse treatment than those in the other group. Alcohol-affected children were more likely to have been placed in foster homes than matched controls and had less contact with biological parents.

In this sample, the alcohol-affected children had been diagnosed early in life and noted to have developmental delays. They experienced significant academic and social problems in school and were maintained on a number of medications (e.g., Tegretol, Lithium, Ritalin, and Dexedrine).

Adoptive and foster parents reported that intervention resources for academic and social problems were not adequate and that treatment for behavioral and emotional issues was not available or limited by insurance restrictions. Perceived limits in the adequacy of educational systems were noted by all parents. Few children had received Early Intervention services although FAS and prenatal exposure are qualifying categories in Georgia. Due to restrictions in qualifying criteria from those older than 3

years, special education services were not available to all of the affected children. Biological parents, often significantly impaired by alcoholism (e.g., liver failure; alcoholism-induced seizure disorders). did not report the same degree of dissatisfaction as did the adoptive/foster parents although they were aware that children were negatively affected by prenatal alcohol exposure.

In this low income, predominantly minority population, those with FAS were more likely to have adequate medical insurance than were those in the contrast group who reported that, due to the nature of their employment, they often did not have adequate insurance but also did not qualify for Medicaid. Caregivers of alcohol-affected children also were more likely than controls to have received Aid for Dependent Children (AFDC) and WIC services. Despite such access, early diagnosis and treatment and, in particular, mental health services were mentioned as unmet needs

In this small sample, caregivers of children with FAS, both biological and foster/adoptive, identified a number of service needs for themselves as well as children. Basic medical needs appeared to have been met when caregivers qualified for medical insurance; however, educational and mental health services were lacking.

**Review published treatment/intervention practices.** In view of the needs of this group of individuals, published information was reviewed to identify effective methods for treatment/intervention for alcohol effects which met the following criteria: 1) Information on treatment was presented in a way that would allow the treatment to be replicated; 2) The treatment methods used were evaluated appropriately. That is using control or contrast groups, random assignment of subjects to treatments, and statistical analysis of results. Despite a comprehensive review, conducted between 1993 and 1996, no published information regarding intervention was identified that met these criteria.

This review of published material revealed a significant gap in knowledge base necessary to design appropriate response to this problem.

### SERVICE RESOURCES/PATTERNS IN ATLANTA METROPOLITAN AREA, 1993

In designing interventions directed at the needs of alcohol-affected individuals, it is important to identify those systems that currently provide services to such individuals as well as evaluate existing treatment methods, if these can be identified. Currently, alcohol-affected individuals come to the attention of a number of public and private systems including those shown in Table 1.

Table 1

Systems Involved With Alcohol-Affected Individuals

Medical
Early Intervention (EI)
Foster Care/Protective Services
Mental Health
Developmental Disabilities (DD)
Education/Special Education
Legal/Justice
Substance Abuse

To identify the extent to which appropriate services were available to alcohol-affected individuals and to women using alcohol and drugs during pregnancy, a survey was conducted in the Atlanta Metropolitan area (Coles, et al., 1998). Based on previous research and clinical experience, several service areas were targeted as being important for these groups. These were: Alcohol/Drug Treatment/Prevention Programs, Educational Resources, including Early Intervention Programs as well as Preschools and School Systems, Social Service Agencies, Medical and Therapeutic Services, Mental Health Services, and miscellaneous other services. Information was requested about the kind and number of clients served, specific services provided and agency characteristics (e.g., geographic area served, funding type, agency mandates).

Three hundred and five agencies in the Atlanta Metropolitan area were sent surveys and 214 responded. Of these 105 reported working with women who abused substances or with alcohol-affected children. Among those agencies responding were most serving special-needs children. The response rate and number of clients reported served by these agencies suggested that the survey had adequately sampled the available resources. Eighty-seven agencies reported sometimes working with individuals with FAS or who were otherwise affected by alcohol but no specialized programs or services were reported. The majority provided clients with "usual and customary" services (medical, educational, or therapeutic) but did not tailor services to the particular needs of those who were prenatally exposed. A problem in interpreting these data was that few programs were able to provide specific information about the number of alcohol-affected clients served. Most agencies did not keep records adequate for the identification of the number of individuals actually served or the type of services provided to them. Examination of agency responses also suggested that those focusing on drug treatment may not be attuned to the impact of alcohol on offspring. In addition, there appeared to be a lack of coordination among different kinds of service providers.

### OPINIONS OF CLINICAL SERVICE PROVIDERS AND SPECIAL EDUCATORS.

Because service agencies did not provide specialized services to alcohol-affected individuals, educators and other professionals were asked about their knowledge and clinical practice in order to provide a better understanding of how the needs of this group were being met. Professionals included special educators, speech/language pathologists, physical and occupational therapists. In general, clinicians and special educators reported that they were aware of FAS and fetal alcohol effects as diagnostic entities and had some opinions about clinical characteristics and treatment. After being presented with a review of the published research on FAS and related disabilities, most clinicians felt that that the knowledge base in this area was limited and what did exist had not been translated into clinical applications.

In a separate study, special educators in county school systems (n=78) reported that they had received no special training in working with children with this diagnosis. Eighty-two percent felt a need for such training and 88 percent wanted resources and practical teaching materials.

### SUMMARY OF RESULTS

Based on the results of these surveys, the following statements can be made about Intervention/Treatment Services for alcohol-affected individuals:

- Biological and foster /adoptive families have high service needs and limited resources. This is particularly true for mental health and educational needs.
- There are no empirically validated methods for Treatment/Intervention.
- Service providers/agencies do not keep specific data on individuals with FAS/alcohol-related disabilities and provide "general" rather than "targeted" services.
- Clinical providers are cognizant of FAS but do not feel well equipped to diagnose and treat.
- Special educators report having little training in treatment/education with alcohol-affected children.

### DESIGNING INTERVENTIONS

It is clear that there is a need for better and more focused interventions with alcohol-affected individuals. However, based on our current knowledge, it is impossible to state what these should be. There are a number of steps to be taken in the process of identifying specific needs and designing appropriate interventions for any problem. Briefly, these steps include:

- Identify specific problem(s)
- Find or develop appropriate interventions

- Evaluate effectiveness of interventions
- Introduce methods into existing systems
- Evaluate the effectiveness of the intervention
- Change methods or systems, as necessary based on this feedback
- Re-evaluate outcomes
- Go on to next problem
- Repeat (as necessary)

In approaching the actual planning of interventions, it is important to note that there is evidence that existing systems have not been totally effective in meeting the needs of affected individuals and their families. These reports suggest that a first step will be to define factors that influence the effectiveness of interventions, existing and planned. Following that step, we will need to develop strategies suited to specific problems where these are known. When the specific processes affected are not clear, further research will be required to clarify such issues.

Given our present level of knowledge it appears important to examine the effectiveness of approaches that are generally useful for individuals with developmental or behavioral disorders to see if these can be applied directly to alcohol-affected individuals or whether existing methods can be adapted to fit these slightly different situations. Since there have been no clinical studies or program evaluations of this kind done, it is too soon to abandon the idea that such methods may be helpful.

For some situations, different solutions may have to be found involving new methods or approaches designed for the specific needs of this group of individuals. The investigation of such individual needs and the appropriate methods for treatment and intervention may be an area of particular interest in the future.

#### QUESTIONS IN EVALUATING OUTCOMES

In clinical practice, whether medical, psychological, or educational, many treatments and interventions are applied, based on professional judgement, experience and for other reasons. Often, it is not clear whether a given intervention has the desired outcome because there is no opportunity either for the assessment of individual change or for more systematic group evaluation. It is important in approaching intervention and treatment of alcohol-affected interventions to ensure that those methods that are implemented be appropriately evaluated for effectiveness. This is important not only because effective interventions will provide for the best use of scarce resources but also because individuals and families need to know that treatments are scientifically validated.

In the IOM report (Stratton et al., 1996), it was suggested that there were several questions that should be addressed in evaluating outcomes systematically. These included:

- **IS THE METHOD USED IN THE INTERVENTION EFFECTIVE?** That is, is the target behavior or problem changed as a result of the intervention? Further, is it changed for alcohol-affected individuals more or less than, or equally as much as, it is for other individuals?
- **WHAT ARE THE EFFECTIVE ELEMENTS OF THE INTERVENTION/TREATMENT?** It will be important to examine whether the intervention is most effective at a particular age (e.g., infancy versus school age). for a particular problem (e.g., for behavior but not learning) and under what circumstances it is effective (e.g., center versus home-based).
- **WHAT ASPECTS OF THE PROGRAM ARE IMPORTANT?** It is often the case that some aspects of a program of treatment are salient while others are not necessary. Only through thoughtful evaluation can programs be refined.
- **ARE THE EFFECTS PERSISTENT?** Many interventions have immediate effects but often these do not persist if the treatment is stopped. This is certainly the case for most medications that are given for behavior problems. The situation is less clear for educational and behavioral interventions that may or may not persist. It is important to be aware of the "dose" necessary to produce long-term effects.
- **CAN EFFECTS BE GENERALIZED?** Another issue that is often addressed is the extent to which treatment effects are generalized outside the learning situations itself. The most meaningful interventions are those which can be generalized and it is often possible to design interventions to include attention to this issue.

### WHERE DO WE START IN DEVELOPING METHODS FOR INTERVENTION AND TREATMENT?

This review of the status of intervention and treatment resources for alcohol-affected individuals indicates that, at the present time, knowledge is very limited despite significant need. In planning our approach to these issues, it may be helpful to consider the following:

A first step will be to increase the breadth and depth of knowledge about the needs of alcohol-affected individuals. In doing so, it will be important to identify those elements that are held in common with other groups like developmentally disabled individuals, addicted individuals and those with neurological damage. In addition, it will be important to identify unique characteristics of alcohol-affected persons and their families.

Research on specific neurocognitive and functional deficits resulting from prenatal exposure will provide the basis for more effective and efficient diagnosis and interventions, both medical and educational. And, although information about neurocognitive functioning is vital, it is equally important to *focus on mental health (behavioral) and educational needs* in addition since these have been identified as both highly significant and poorly served (e.g., Stratton, et al., 1996; Streissguth et al., 1996).

Because development early in life is so important, it is necessary *to improve methods for early identification and intervention of affected infants and to include biological as well as foster, and adoptive families in intervention processes.*

Research with providers and professionals suggests that improved professional training is both needed and desired. By *providing more targeted and specific information to providers and agencies,* existing services could focus and improve services using existing resources. This could be accomplished by *developing more effective methods of professional training and improving the distribution of existing curriculums.*

Efforts must also be directed at *developing (and evaluating) treatment program and facilities* that can provide services to alcohol-affected individuals. This may *involve expanding service categories to include problems associated with alcohol effects, establishing a FAS registry to improve record keeping or creating regional "Centers" to coordinate efforts.*

Most importantly, it is necessary to actually "start" the process of helping alcohol-affected individuals. For many years, little has been done to treat their medical, emotional, and educational deficits and, as a result, they and their caregivers continue to suffer and struggle without adequate understanding or access to treatment. It may now be possible to change this situation for the better.

## ABBREVIATED SUMMARY OF PRESENTATION

Where Does One Start Intervening with Children with FAS and ARND?

DR. CLAIRE COLES,
EMORY UNIVERSITY

Designing effective interventions for FAS individuals is challenged by the wide spectrum of FAS characteristics. FAS individuals can be any age, with or without a history of mental health problems, with or without behavioral or attention problems, with severely limited intelligence or within the normal IQ range, from a variety of care-giving experiences, with or without a history of sexual, physical, or substance abuse.

An important intervention issue concerns the use of general versus specific techniques. For example, do general interventions for the mentally retarded work effectively with mentally retarded FAS individuals? One approach is to compare the outcomes of FAS individuals with IQ-matched individuals with a different disability. Determining whether FAS-specific strategies are required for successful intervention is critical. Creating specific strategies versus adapting general ones impacts many arenas, including financial resources, and training education health professionals.

The effectiveness of all interventions must be systematically evaluated. Interventions may be age-specific and ineffective at a younger or older age. The duration of the intervention might be critical. For example, autism research found that intervention 40 hours a week yields positive outcomes, but 10 hours a week is ineffective. The persistence of positive outcomes is another important factor. Interventions should be evaluated for long-term effects that translate to settings outside the home or classroom.

Dr. Coles reached several conclusions concerning resources and treatment or intervention for FAS individuals in the Atlanta area. She remarked that Atlanta's limitations are not unique but probably reflect most communities across the nation. Remarkably, no empirically validated methods for treatment or intervention exist. Biological, foster, and adoptive families have high service needs and limited resources, particularly for mental health and educational needs. Service providers and agencies do not keep specific data on FAS individuals and provide general rather than targeted services. Clinical providers recognize the unique problems of FAS but do not feel well equipped to diagnose and treat the syndrome. Special educators report little FAS training and do not know how to work with FAS children.

Dr. Coles offered the following recommendations concerning FAS interventions: (1) increase the breadth and depth of knowledge about the needs of alcohol-affected individuals among health professionals, educators, and legislators; (2) research specific neurocognitive and functional deficits for better design of interventions; (3) focus on mental health, behavioral, and educational needs; (4) provide targeted and specific information to providers and agencies; (5) improve methods for early FAS

identification and intervention; (6) establish an FAS registry and improve record keeping; (7) expand service categories to include problems associated with alcohol effects; (8) include biological, foster, and adoptive families in intervention processes; (9) develop more effective methods of professional training; (10) develop and evaluate treatment methods; (11) create regional centers to support collaborative efforts.

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# NEURONAL PLASTICITY: IMPROVING COGNITIVE FUNCTIONING IN CHILDREN AFFECTED BY IN UTERO ALCOHOL EXPOSURE

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## ABBREVIATED SUMMARY OF PRESENTATION AND PARTICIPANT DISCUSSION

### MOTOR SKILLS LEARNING AS REHABILITATION FOR ALCOHOL-RELATED BRAIN DAMAGE

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Cerebellar structural deficits in FAS individuals have been recognized through autopsy and neuroimaging studies. Developmental alcohol exposure in animal models damages the cerebellum by gross measures and fine structure, such as cell loss and altered cell morphology. Postnatal rat studies that model the human third trimester demonstrate the loss of granule and Purkinje cells, diminished dendritic trees, and decreased density of synapses. Purkinje cells appear more sensitive to alcohol at the time of differentiation, relatively late in brain development, than when they are produced.

An acrobat-training paradigm was used to distinguish rehabilitation or brain plasticity specifically associated with learning versus brain plasticity associated with physical exercise. Female rats were divided into four groups—voluntary exercisers that could use activity wheels at will, "forced" exercisers that jogged on a treadmill for two 30-minute periods a day, and "acrobats" that traversed obstacles on an elevated obstacle course. There was also an inactive group that did not exercise at all (but otherwise were handled in the same manner as the other animals).

Several parameters were measured in the paramedian lobule of the cerebellar cortex—the density of Purkinje cells per unit volume of molecular layer, density of capillaries, and density of synaptic connections. Increased capillary density resulted from exercise, while the acrobat or learning group showed an increase in synaptic number per neuron. This study, along with several others, demonstrates that motor skill acquisition can affect behavior and cerebellar organization (e.g., synaptic number). The capacity for plasticity remains unanswered.

In a rat study modeling the human third trimester, postnatal alcohol exposure caused decreased density of Purkinje cells and glial tissue hyperplasia. Additionally, a reduced overall volume of the paramedian lobule was found in alcohol-exposed rats. Rats exposed to alcohol and then acrobat trained showed rehabilitation in the number of synapses per Purkinje cell. Motor therapy had a biologically detectable rehabilitative effect on the cerebellar cortex. In addition, complex motor skills training significantly improved motor performance in alcohol-exposed rats. The alcohol-exposed cerebellum retains the capacity for behavioral and anatomical plasticity.

## Discussion

Dr. Hagerman commented that the cerebellum is important for cognition, in addition to motor paths. She asked if Dr. Greenough also tested for cognitive or attention abilities. Dr. Greenough explained that the next study phase would include some cognitive tests.

Dr. Anderson asked about similar studies examining the basal ganglia or corpus callosum. Dr. Greenough stated that there are no immediate plans to study these areas, but perhaps the caudate nucleus will be studied in the future.

Dr. Floyd inquired about a critical window for plasticity. Dr. Greenough stated that the region remained plastic through adulthood, but younger animals might exhibit greater plasticity. Age-related degrees of plasticity are currently under investigation

# THE ROLE OF LANGUAGE IN THE COGNITIVE REHABILITATION OF CHILDREN AFFECTED BY PRENATAL ALCOHOL EXPOSURE

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## INTRODUCTION

A discussion of language intervention for children prenatally exposed to alcohol must first address the nature of the language problem that characterizes this population. The conclusions reached by this review will naturally provide direction for intervention, including what to treat and how to treat. The discussion that follows will attempt to examine language and language impairments associated with alcohol exposure. The literature addressing the syntactic, semantic, phonologic, and pragmatic deficits will be reviewed, and conclusions drawn. This will be followed by a discussion of intervention approaches that are being reported in the literature and being examined in our laboratory.

## NATURE OF THE LANGUAGE PROBLEM

The research indicates that children affected by prenatal exposure to alcohol have speech and language problems (Becker, Warr-Leeper, & Leeper, 1990; Carney, & Chermak, 1991; Church, Eldis, Blakley, & Bawle, 1997; Greene, Ernhart, Martier, Sokol, & Ager, 1990; Hamilton, 1981; Janzen, Nanson, & Block, 1995). It is hard to find a description about these children without some reference to delayed speech and language. However, close examination of this research reveals discrepant results. This is due to the variations in the methodologies across the studies, including age of subjects and experimental control. For the most part the studies have examined the speech and language problems of preschool and school-aged children relative to standardized norms, or chronological age-matched controls. From this standpoint, the children appear to be demonstrating problems in syntax, semantics, and phonology (Carney, & Chermak, 1991; Greene et al., 1990; Janzen, et al., 1995; Church, Eldis, et al., 1997). But what accounts for these problems? As Church and Kaltenbach (1997) have pointed out, many of the children with fetal alcohol syndrome have problems with hearing, either sensorineural hearing loss, conductive hearing loss, or central auditory deficits, often associated with craniofacial anomalies. These problems could certainly account for the speech and language problems associated with fetal alcohol syndrome. In addition, cognitive deficits confound the question of whether speech and language problems are particularly unique to children affected by exposure to alcohol. Few studies have compared the children to cognitive-matched and /or language-matched controls. Where these have been controlled (Becker, 1990; Hamilton, 1981), the results still have been somewhat mixed. Becker's results revealed that the children with fetal alcohol syndrome (FAS) had poorer performance on measures of syntax (morphology and sentence complexity), phonology (sound production), and semantics (single word vocabulary) than mental age-matched controls (Becker, 1990). However, this study included only six children with FAS and the controls were mixed in native language and bilingual ability. In Hamilton's (1981) study, the 10 children with FAS performed similar to their language-matched controls on grammatical comprehension measures, and more poorly at forming grammatically complete sentences; phonology was not measured. Interestingly the children with FAS produced more wh-questions than their language-matched peers. Hamilton (1981) compared her FAS sample to 10 cognitive-matched children

diagnosed with Prader Willi Syndrome. The children with FAS out-performed those with Prader Willi on all language measures. Finally, Hamilton's comparison revealed that the children with FAS and their language-matched controls performed similarly in their initiating and responding, but she found that the children with FAS had fewer communicatively adequate and more inadequate responses. This is an important finding to which we will return.

The results of these studies, at best, suggest discrepant language performance among children prenatally exposed to alcohol. Some children show differences from cognitive-matched and language-matched controls, others do not. The speech and language problems that are reported may reflect hearing or cognitive complications, rather than specific language deficits. These results are different than other populations. For example, children with Down Syndrome and specific language impairment repeatedly demonstrate quantitative differences from their language- and cognitive-matched (as well as chronological age-matched) peers. This is not the case with children affected by prenatal alcohol exposure. What does appear to be true is that these children have uneven speech and language profiles, and that they seem qualitatively different than their peers (Abkarian, 1992). These results are consistent with anecdotal data suggesting children affected by alcohol often use language quite well. They are frequently described as loquacious and friendly. While they appear verbal, they may also be viewed as ineffective in their communication. Hamilton's (1981) data support these observations. Children exposed to alcohol seem to have difficulty formulating communicatively adequate utterances.

Communication or subtle pragmatic deficits appear to be a theme that relates to other areas of research as well. Children with FAS are known to have difficulties in social behaviors. Streissguth and others (Streissguth, Barr, Kogan, & Bookstein, 1996; Spohr, Willms, & Steinhausen, 1993; 1994; Thomas, Kelly, Mattson, & Riley, 1998) have reported adaptive function problems, including difficulties with interpersonal relationships, in children exposed to alcohol. Socialization difficulties repeatedly show up in the research and are consistently identified by parents and teachers as a major obstacle. Recently, the research from Kodituwakku and his colleague in New Mexico (Kodituwakku et al., 1995) and Coggins (1997) have suggested that the behavioral problems associated with fetal alcohol effects may reflect underlying difficulties with executive control functioning (planning and response inhibition) and theory of mind (attributing states of beliefs, intentions, and thoughts to oneself and others). Further, Coggins and colleagues (1998) have shown that these children have difficulty planning and executing oral narratives. They appear to be unaware of the listener needs as they retell a story. Their narratives lack cohesion and coherence. The children "fail to organize their stories around the onset, unfolding and resolution of key story events and, also fail to clearly express the essential elements of the story to the listener" (Coggins, 1997). These children appear unable to provide sufficient information to their communication partners because they lack an understanding of the partners' intentions and interpretations. This type of deficit would seriously alter a child's ability to socially adapt. This appears to be the case in children exposed to alcohol.

As the data are examined, the interesting story that seems to be revealing itself is a deficit at the intersection of the cognitive, social, and language domains. Drawing from psycholinguistics and speech/language pathology this area is called metapragmatics. As children enter school they must move beyond simply initiating and responding, acknowledging and answering, and begin understanding their own beliefs, desires, and intention, and also be able to attribute these states to others. The former might be construed as simple pragmatics; the latter, metapragmatics. Astington (1994) defines metapragmatics as the ability to judge the appropriateness of speech acts a step beyond producing them. Metapragmatic abilities allow children to solve social problems: to appraise a situation, generate options regarding how to behave, and to evaluate the consequences of one's actions. For example, metapragmatic understanding allows a child to know when and why a person is lying, and how to analyze and manipulate another person's beliefs. Metapragmatics describes that part of language that is a tool for social interaction and negotiation. This definition of language is extremely useful for discussing the language characteristics of children with alcohol-related disabilities. From anecdotal data and the research described above, these children appear to have difficulty using language in subtle ways required for negotiating complex social situations in everyday interactions with caregivers and peers. They appear to lack the understanding that is necessary for complex social communication, and, by extension, for social success and adequate adaptive function. This deficit shows up when they are required to appropriately enter groups, work cooperatively, deal with peer pressure or rejection, monitor their own behavior, or ask for help. These problems make the socialization of these children very difficult. They reveal the real life challenges that they and their families face daily. It appears that the uneven profile of syntactic, semantic and phonologic skills for children affected by prenatal exposure to alcohol is complicated by cognitive and sensory impairments, and that the deficit that is characteristic of this population may be in the area of metapragmatics. The evidence for this particular perspective is becoming increasingly convincing, but additional empirical support is clearly needed.

### LANGUAGE INTERVENTION: FOCUS ON METAPRAGMATICS

WHAT TO TREAT? The logical intervention for this deficit is one that focuses on a complex set of skills at the intersection of the social, cognitive, and language domains. This focus would have the most impact on functional change, affecting life-long performance (i.e., secondary disabilities). The goal of intervention would be to improve the children's ability to perform successfully in solving social problems. The question that must be answered next is how to treat? What would such an intervention look like? Simply, the treatment should promote/enhance the children's capabilities and enhance their quality of life. But how is this accomplished?

HOW TO TREAT? As we look to intervention designed for other populations of children with disabilities, two major approaches emerge. Recognizing the distinction between these approaches is extremely important for appreciating how children affected by alcohol might best be treated.

One set of approaches is designed to teach children the skills they are missing; that is, changing inherent capabilities. These approaches are oriented towards the individual's deficits. They focus on the nature of the disorder by attempting to change the children's abilities. For the most part these approaches utilize behavioral teaching strategies, but they may also include pharmacological therapies. Given the deficits we've been discussing, these approaches would attempt to actually improve metapragmatic competence by improving underlying cognitive abilities, increasing social knowledge, and teaching the language of complex social interaction; that is, teaching specific skills in the cognitive, social, and language domains. Treatment would directly target social problem solving, teaching children how to appraise social situations, determine the beliefs, desires, intentions of others; develop options for how to behave; and evaluate the consequences of their actions.

A second set of approaches focuses on the environment and attempts to enhance the quality of the child's life by constructing a supportive context for performance. These approaches are oriented towards the individual in context. Treatment adjusts the environment to create surroundings that support maximum achievement, or treatment changes expectations of those people who interact with the child. The result is a point of convergence on strengths rather than weaknesses, and the creation of an environment that optimizes performance. These latter approaches "allow the child to have his/her deficits;" treatment acknowledges deficits and alters the environment. Such approaches shape the context and provide a host of visual prompts and cues to enable children to successfully perform and fit in.

It is important to appreciate that although these approaches have been described as mutually exclusive, they can and often do overlap. However, considering the relative contribution of each to an intervention package is critical for deciding specific treatment targets and strategies, and allocation of resources. These approaches have been used repeatedly in speech/language pathology and special education. Treatment approaches focusing on deficits have taught children grammatical and phonological rules, simple pragmatics, colors, reading, etc. They have increased the capabilities of children with Down Syndrome, specific language impairment, attention deficit disorders, and autism. Approaches focusing on the environment and the individual in context have enabled children with traumatic brain injury to follow schedules and complete complex routines. They have assisted children with Down Syndrome and autism to function in a classroom.

In the area of social problem solving, the intervention research has yielded mixed results. The primary approach has been to teach children new social behaviors and skills. No particular set of treatment strategies have resulted in robust change. Unfortunately, this research has often been characterized by large group studies that have included children with a variety of problems. Failure to change may reflect a complex interaction between child characteristics and the treatment approaches. Recently Ozonoff and Miller (1995) attempted to directly teach children with autism to take other people's perspective and comprehend inferences. Direct instruction including role playing, behavioral techniques,

and some multiple modality prompts/cues were used to solve false belief tasks (i.e., knowing what other people think and know). Although children demonstrated improved skill at taking other people's perspectives and comprehending inferences in the teaching tasks, they did not generalize these skills to everyday conversations demanding "on line" perspective taking (Ozonoff & Miller, 1995). The literature demonstrates that changing social performance in children with disabilities is difficult. In part, this difficulty arises from the interaction between child characteristics and the complex set of social, cognitive, and language abilities that must be learned.

INTERVENTION FOR CHILDREN AFFECTED BY ALCOHOL. Literature regarding the success of intervention with children affected by prenatal alcohol exposure is primarily anecdotal. Parents and teachers report that children can learn and do learn. Different treatment strategies have been used, many with positive effects. However, the literature repeatedly reveals the importance of an environment that provides substantial structure and consistency to insure optimum performance (Dyer, Alberts, & Nieman, 1997; Kleinfeld & Wescott, 1993; Streissguth, 1997). Children with alcohol-related disabilities appear to be most successful when they are involved in routines, when they can predict what will happen next, and when they know what is expected of them. Although the anecdotal information appears clear, and extremely useful, it has not attempted to systematically examine the benefits of intervention, nor explore the relative merits of a deficit versus environmental approach to treatment. Nor has intervention particularly been targeted to improve the social reasoning of this population. Where do we stand now? Research needs to determine the extent to which children affected by alcohol can change. What degree of social problem solving can be learned? And what degree of contextual support is needed to maximize performance?

UNIVERSITY OF WASHINGTON PILOT PROJECT. During the past year a pilot intervention study has been conducted at the University of Washington in the Department of Speech and Hearing Sciences. This study was funded by the Washington State Association for Retarded Citizens to examine an intervention package that has attempted to teach three children diagnosed with FAS to solve social problems. The intervention primarily focused on a deficit approach, where we attempted to teach the children new skills. We have been teaching them how to appraise a social situation, generate options regarding how to behave, and evaluate the consequences of their actions. The intervention has also utilized environmental support to ensure maximum performance. We have incorporated highly structured predictable social scenarios to teach social reasoning and problem solving through role-playing. Further, to assist the children solve the complex social problems, we have introduced a checklist—a visual prompt—to systematically take them through the steps of social reasoning. The children have participated in individual and group treatment several times a week throughout the summer. During treatment we have been examining their performance as they role-played different social problems that required them to appraise the situation, develop options for behaving, and evaluate the consequences of their behavior. In addition, every third week we evaluated their ability to solve social problems that were

presented in a story format accompanied by object manipulation. Preliminary results are suggesting that the three children benefited differently from the treatment. All of the children performed very well in the group role-playing activities. One of the children seemed to generalize the social reasoning skills to the stories; the others did not. We are currently evaluating the data and exploring different child characteristics related to the outcomes.

## SUMMARY AND CONCLUSIONS

The research has convinced us that the language profiles are uneven for children affected by alcohol. Deficits in syntax, semantics, and phonology are compromised by cognitive and sensory impairments. Although the children appear to be able to produce a variety of speech acts (i.e., initiate, respond, acknowledge, answer, protest, comment, etc.), they seem to have difficulty judging their appropriateness use. Children affected by alcohol appear to have difficulty understanding the beliefs, desires, and intentions of themselves and others, which makes them ill-equipped to solve social problems and get along in society. This area of deficit has been termed metapragmatics and may characterize the language deficits of this population. As metapragmatics has been described, it is a complex set of skills at the intersection of the social, cognitive, and language domains. This conclusion regarding the nature of the problem directly translates to an intervention that should include speech/language pathologists, and should target metapragmatic abilities. Given our current knowledge of this population, intervention should attempt to both alter the children's inherent capabilities, but must also determine how the environment can maximize and sustain the most sophisticated, socially appropriate performance possible. The relative contribution of these two approaches needs to be investigated in relationship to child characteristics, so that realistic goals can be targeted and intervention resources can be used most effectively.If we truly wish to help children affected by alcohol, we must teach them to get along in our world. This is their greatest challenge and ours. In order to teach them, we must begin conducting research that will show us the most efficacious intervention approaches. We must determine what children can learn and what they can't. And when they can't learn, we must understand the resources that will be necessary to support their optimum performance

## ABBREVIATED SUMMARY OF PRESENTATION

The Role of Language in the Cognitive Rehabilitation of Children

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Dr. Olswang began by outlining the types of language problems experienced by FAS children. Their language and speech are delayed compared to normative data and can be complicated by hearing problems and cognitive impairment. FAS children exhibit an uneven language profile in syntax, semantics, and phonology when compared to language-matched and cognitive-matched peers. While loquacious, their communication is inadequate, and they experience difficulty participating in conversations. They provide insufficient information to communicate as they lack an understanding of the listener's intention or interpretation. Adaptive function problems, including difficulty with interpersonal relationships, and impaired executive control (planning, response inhibition) are observed. FAS children poorly execute oral narratives, exhibiting difficulty in structure, cohesion, and determining what the listener needs to hear. Deficits in metapragmatics, the tools for social interaction and negotiation, are observed. The interplay between cognition, complex language, and social interaction is impaired, leaving FAS children unable to appraise how to behave and evaluate the consequences of their actions. Language interventions focus on metapragmatics, the skills that intersect the social, cognitive, and language domains. FAS children and families struggle with social interaction and predictability in social situations. Intervention can consist of an individual deficit approach or an individual in context approach. In the first approach, one tries to change the deficit by teaching new skills. An attempt is made to change behavior by altering abilities, such as cognitive ability, social skills, and language performance. The second approach involves restructuring the environment. It includes providing support to maximize performance, changing the expectations of people who interact with the FAS individual, and focusing on strengths, not weaknesses. Interventions should include both approaches, but it remains unclear what proportions maximize effectiveness.

To better understand the optimal balance between the two intervention approaches, the Department of Speech and Hearing at the University of Washington is conducting a small pilot project with three FAS children. It is funded by the Washington State Association for Retarded Citizens and will focus on the development, implementation, and evaluation of metapragmatics interventions. Techniques using the individual deficit approach include teaching children to (1) appraise social situations, (2) generate options regarding behavior, and (3) evaluate the consequences of their actions. The second approach, creating an environment that supports maximum performance, involves aids such as checklists and structured, organized activities. Project evaluation will examine whether children could execute this approach independently, or if they need external cues or prompts. Preliminary results show that the

children do well in a structured and familiar environment. However, if several variables are changed at the same time, the children perform poorly. They cannot generalize what they have learned.

Dr. Olswang concluded her presentation with the following observations: (1) The uneven language profile in syntax, semantics, and phonology, observed in FAS children, may reflect different levels of cognitive and sensory involvement; (2) FAS children have difficulty understanding the beliefs, desires, and intentions of themselves and others; (3) FAS children have deficits in metapragmatics and, as a result, have difficulty judging the appropriateness of speech acts and solving social problems; (4) Interventions should target metapragmatic skills, using a team approach that includes cognition, language, and social domains.

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# A MODEL FOR TREATING THE SOCIAL DISABILITIES OF COGNITIVELY IMPAIRED CHILDREN

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The connection between positive peer relationships and healthy personality development has been known for decades. Harry Stack Sullivan (1953) identified the vital importance of "chum" relationships in early adolescent development. He described how the reflected appraisals from peers help form the cornerstones of the adult sense of self. In a longitudinal study examining the development of psychiatric difficulties in adulthood, Cowan et al (1973 in Cartledge and Milburn 1995) found that peer ratings in the primary grades were the best predictor of later psychiatric difficulties. Similarly, Nowicki (1998) reports research that indicates a predictive link between social rejection in childhood and psychological maladjustment in adults. Recently, Judith Rich Harris (1998) in her controversial book *The Nurture Assumption* has concluded, based on a review of the literature, that peer relationships are of primary importance in the development of psychological well-being. Human beings grow and adapt through their relationships with others. As a result, the ability to develop and maintain relationships is critical to social and emotional growth and development. Deficits in the ability to interact with others are likely to contribute to the development of psychological problems.

Social skills and the concomitant nonverbal communication skills are important building blocks in the development of healthy relationships. There are multitudes of definitions of social skill in the literature but generally it is viewed as the knowledge of how to interact with others in acceptable ways and the ability to use that knowledge. One critical aspect of social skill is the ability to communicate nonverbally and the ability to understand nonverbal communication. Nonverbal communication skills include the ability to send and receive accurate information using channels like eye contact, personal space, touch, facial expression and tone of voice. Nonverbal skills are similar to verbal skills in the sense that both involve developed communication systems which are quite complex and are learned through the course of development (Nowicki, 1998). However, Nowicki (1998) outlines some critical differences between verbal and nonverbal communication. Unlike verbal communication, nonverbal communication is continuous, cannot be stopped at will and generally takes place out of awareness. When verbal messages and nonverbal messages are incongruent people are much more likely to believe the nonverbal message. In addition, there is no formal education process for nonverbal communication and conscious knowledge of its significance is generally considered to be minimal. As a result, people are often unaware of their own strengths and weaknesses with regard to nonverbal communication skills.

A number of researchers have demonstrated that nonverbal communication is an essential component of human interaction. It has been referred to as the language of human emotion (Ekman & Friesen, 1975) but, in fact, it also regulates social interaction (Nowicki & Duke, 1994). A verbal transcript of an exchange without the nonverbal content fails to indicate the message that was conveyed. For example, a statement like "Thanks a lot" can carry very different meaning depending on how it is said (for example, sincerely or sarcastically). Duke, Nowicki, and Martin (1996) identify channels of nonverbal communication. These include understanding and sending communication in the following domains: facial expressions, gestures, paralanguage (tone of voice, rate and volume of speech), posture and gestures, space and touch, rhythm and timing and objectics (factors such as interests, style of dress, or hygiene).

Nowicki and Duke (1992) coined the term "Dyssemia" to describe individuals who have difficulty understanding and/or displaying nonverbal cues accurately. Nonverbal skills not only are important to the communication of emotions, feelings and attitudes, they also are critical to the process of seeking and providing support within the context of relationships (Riggio, 1992). Nowicki and Duke (1994) reported that individual differences in nonverbal skills were related to interpersonal and teacher ratings of peer functioning. Consistent with these findings, Riggio (1992) reported research indicating that nonverbally skilled individuals have larger social networks. The converse was also true: children who had measurable nonverbal communication deficits tended to have poorer status among their peers (Nowicki and Duke, 1994).

A wide variety of factors can contribute to social and nonverbal communication skills deficits. Some children may simply not have learned appropriate social skills. Others have neurological problems or psychological problems that result in social skills difficulties, including deficits in nonverbal communication. Deficits in nonverbal communication skills have been documented in some groups of children who have a neurological component to their difficulties (For an example, see Philippot et. al., 1992). Antonello (1996) cites research demonstrating that children with developmental disabilities can be helped with social skills training. Riggio (1992) has demonstrated that nonverbal communication skills can be improved through training. In fact, he states that substantial gains can be made in relatively short periods of time.

Recently, a number of studies have examined the components of good social skills intervention. Erwin (1994) recommends multimodal training programs since different approaches to social skills were found to have different therapeutic benefits. Ogilvy (1994) cautions that while social skills training may be

a necessary component to assisting children with problems in the area of social competence, it may not always be sufficient. Cartledge and Milburn (1995) strongly advocate for opportunities for practice, generalization and transfer of behavior. Similarly, Walker (1994) indicates that for training to have long-term value there must be opportunities to integrate skills into students' repertoires and for students to use them in a natural setting. Specifically examining the development of nonverbal skills, Minskoff (1980a, 1980b) describes the necessity of a step-by-step teaching approach. Her sequence involves discrimination, understanding, meaningful usage, and finally, the integration of nonverbal communication skills with each other.

Goldstein and his colleagues have developed a curriculum to address a multitude of social skill difficulties in a systematic manner. Referred to as "Skillstreaming," its overall purpose is to teach prosocial skills in an age appropriate manner to children and adolescents who are demonstrating deficiencies. Examples of some of the skills addressed include Joining In, Listening and Dealing with Teasing. Skills are described in terms of the component steps. For example, the steps outlined in Joining In for adolescents are: 1. Decide if you want to join in. 2. Decide the best way to join in. 3. Choose the best time to join in. 4. Join the activity. (Goldstein & McGinnis, 1997). Training involves defining the skill, having the skill modeled, role-playing the skill and receiving feedback.

As outlined above, to promote the development of healthy relationships, it is important to remediate the communication and social skills problems that often underlie relationship problems. Toward this end, the first author developed *Beyond Words: Center for Social Skills Training in* the Fall of 1996 as an outgrowth of his child, adolescent, and family psychotherapy practice. While many children who were referred to him clearly could benefit from psychotherapy, a subset needed assistance developing their social skills and nonverbal communication skills. Some children clearly needed a combination of the two. In summary, a significant number of children referred to his practice had not learned some critical components of the communications skills people are naturally expected to pick up in the course of growing up. Some children seemed to have the skills but not know when to use them, while other children appear "oblivious" to "obvious" cues from their peers and/or adults. In particular, some children and adolescents diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Nonverbal Learning Disabilities (NVLD), and Pervasive Developmental Disorder (PDD) seemed to need some

specific skills training to assist them in developing and maintaining positive relationships with peers and adults.

Drawing from the work of Duke and Nowicki on dyssemia and Goldstein and others on teaching prosocial competencies, *Beyond Words* incorporates a combination of nonverbal communication skills training with more traditional social skills training. Children with dyssemia typically have difficulties with a variety of social skills, due to their problems with nonverbal communication. For example, knowing when and how to join a conversation are skills that are typically very difficult for people with dyssemia. It is the "when" and the "how" of a variety of social skills that dyssemic children have difficulty with. At *Beyond Words*, these types of skills are taught, while at the same time, teachers work toward increasing students' repertoire of verbal responses which often is necessary to complete the remediation process.

The addition of a nonverbal communication skills curriculum adds essential elements to the traditional, systematic approach to teaching prosocial skills. It allows social skills teachers to provide comprehensive and meaningful exercises that enhance the students' understanding of skill usage. For instance, applying the nonverbal curriculum to the "Joining In" skill, teachers add a subset of instruction beginning at Step 2; "Decide the best way to join in". Here, training focuses on expressive nonverbal communication skills such as pleasant facial expression, appropriate eye contact, proper voice tone and appropriate use of space. Then, Step 3; "Choose the best time to join in," alludes to the need for good timing skills, a largely receptive nonverbal tool, as well as other nonverbal skills. Students receive explicit instruction on how to accurately read a situation to determine its approachability. They are also coached on how to use their expressive skills in a manner that will make it most likely that their approach will be well received. While there are many programs described in the literature for remediation of social skills deficits, relatively little attention has been paid explicitly to the nonverbal communication skills component.

At *Beyond Words*, the program begins with a clinical interview and a detailed assessment of the child's strengths and weaknesses in the areas of social skills and nonverbal communication. While individual, group and family psychotherapy are available as options, recommendations often are made about remediating problem areas through direct training. Classes with other children, individual tutoring,

and parent training are among the potential recommendations. An extensive curriculum in nonverbal communication skills has been blended with a curriculum focused on basic social skills along the lines of the program developed by Goldstein (1988). The *Beyond Words* curriculum has many adaptations, and it is applied to each class of 4-6 students in a manner that reflects the students' needs. Skills are taught through discussions, demonstrations, exercises, role-plays, videotaping and ongoing feedback. Many children who have some degree of dyssemia have strengths in some areas of nonverbal communication. However, they do not always know how to use their strengths nor are they aware of times when they are not communicating what they intend. Practice and feedback from others are important components to the development of more effective nonverbal communication and other aspects of social competence.

Having worked explicitly with dyssemia for 2 years, several issues have become clear. Patterns of nonverbal strengths and weaknesses vary by diagnosis in children. In addition, not all children with the same diagnosis have identical patterns of deficits. As a result, social skills training and nonverbal communication remediation have to be adapted to the special needs of individual children. A wide range of problems can result in social skills deficits and require different foci for remediation. The most effective approach demands flexibility and occurs within the context of ongoing contact and a positive teacher-student relationship. Isolated work on individual skills is not recommended.

Neurological damage from prenatal alcohol exposure can result in severe cognitive, behavioral and attentional deficits. Fetal Alcohol Syndrome (FAS) children have also been described as having marked deficits in social learning and "the development of personal responsibility" (Houle & Cohen, 1998). Similarly, Don and Rourke (1995) describe FAS children as having trouble understanding social rules and expectations. A lack of social skills, combined with poor judgment and suggestibility makes FAS adolescents open to exploitation by "friends." It can be argued that these deficits can be explained as secondary to problems with short-term memory and executive functioning. Whatever the cause of these problems, if we accept the premises that: 1) Healthy personality development occurs in the context of positive relationships and 2) Basic social skills and nonverbal communication skills are essential for positive relationships, then it seems clear that social skills training in combination with developing nonverbal communication skills would be important components of remediation efforts. It is hypothesized

that effective social skills training is an important component for a remediation program for children with problems related to fetal alcohol exposure. Other important elements would include early intervention (see Coles, 1998) and activities to maximize cognitive development. Clearly, research is needed into remediation of social and behavioral deficits with FAS children. A social skills program for FAS children would need to take into account the well-documented strengths and weaknesses of this population. While many aspects of the approach used at *Beyond Words* are likely to be applicable, the special needs of this population would require interventions tailored to address their unique characteristics.

## ABBREVIATED SUMMARY OF PRESENTATION

A Model for Treating the Social Disabilities of Cognitively Impaired Children

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Dr. Jones' work at the Beyond Words Center for Social Skills Training incorporates the skills streaming curriculum of Goldstein and the nonverbal communication skills training of Marshall Duke and Steve Nowicki. The curriculum focuses on basic social skills such as listening, using nice talk, using brave talk, joining in, and dealing with teasing, recognizing feelings, making an invitation, and offering help. Each skill involves multiple steps and role-playing to practice the skills. The Center works with children who have impulse-control problems and problem-solving difficulties.

Social skills training dovetails with nonverbal communication. Nonverbal communication is indirect and involves tone and emphasis of speech, facial expression, posture and gestures, the space between speakers and listeners, and the rhythm and timing of speech. Nonverbal communication is multi-channeled and entails expressive and receptive skills. People may have strong receptive skills but poor expressive skills, or may be weak in both areas. Dyssemia is a dysfunction in nonverbal communication. Different types of dyssemia are observed in specific disorders. For example, depressed children may be capable of reading facial expression but do not do so, as they rarely make eye contact.

A 1973 study found that poor peer ratings are the best predictors of psychiatric difficulties. Duke and Nowicki showed that strong nonverbal communication skills correlated with positive peer ratings. Positive peer rating indicates a process of learning and growing socially. Dyssemia should be considered in evaluating individuals with poor social skills.

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# DEVELOPING CLINICAL PRACTICE GUIDELINES FOR PHARMACOLOGICAL INTERVENTIONS WITH ALCOHOL-AFFECTED CHILDREN:

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## HISTORICAL PERSPECTIVE

The use of medication in changing the natural course of a chronic illness affecting the brain has many remarkable examples from the 20th century.

- The neuroprotective effect of folic acid given to pregnant women to prevent neural tube defects.
- The use of penicillin to prevent the progression of primary syphilis to tertiary syphilis (or neurosyphilis).
- The recent development of "triple therapy" that has changed the rapid down-hill course of AIDS illness and dementia.

The natural history of children prenatally exposed to alcohol currently has 25 years of research, which describes a patient population where there has been no consistent proven pharmacological interventions. Thus, the parallels between neural tube defect before folic acid intervention, syphilis before penicillin, or AIDS before triple therapy seem appropriate.

## INTRODUCTION TO TREATMENT: THE MENTAL HEALTH CLINICAL ISSUES

The Secondary Disabilities Study at the University of Washington has highlighted the prevalence of mental health problem in patients with Fetal Alcohol Syndrome spectrum disorders: Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Fetal Alcohol Effects will be called Alcohol-Related Neuro-developmental Disorder (ARND) for the purposes of this paper (Stratton et al.,1996). This study showed a prevalence of 90 percent of mental health problems in this patient population through the lifespan. The cohorts studied were 6 to 11 years, 12 to 20 years, and 21 to 51 years (Streissguth et al., 1996). This is really quite remarkable when you compare the prevalence of mental health or psychiatric disorders in patients with developmental disabilities in general, e.g., Corbett 1985 (47 percent), Gilberg et al.1986 (57 percent), Reiss 1990 (40 percent), Einfeld and Tonge 1996 (40.7 percent).

All the previous work, beginning with Michael Rutter in 1970, present data showing that mental health/psychiatric problems increase as the I.Q. level of the patient decreases. The epidemiological data on FAS/ARND, however, show that the I.Q. alone is not a determinant of mental health problems. (Streissguth et al., 1996, Streissguth, 1997a; Streissguth, & Kanter, 1997b). The research data has, in fact, shown that a diagnosis of FAS, more commonly associated with a lower I.Q. than ARND diagnosis, is actually a protective factor for all the secondary disabilities including mental health problems.

The mental health problems that the University of Washington study identified were grouped into six categories:

- Attentional problems
- Depression

- Suicide threats
- Panic attacks
- Hearing voices and seeing visions
- Suicide attempts

The first sign of mental health problems by age of onset showed a different pattern through the lifespan. Thus, not unsurprisingly, attentional problems were the most common first signs for patients 6 to 11 years of age. Depression was a more common initial presentation in the 12 to 20, and 21 to 51 age group. Also, panic attacks became more common as the patients aged.

The severity of mental health problems was another important factor analyzed in this study. A distinction was made between those receiving out-patient therapy and those patients requiring hospitalization. So, it could be seen that approximately 25 percent of the FAS/ARND patients with attentional symptoms were receiving outpatient therapy. Whereas, 15-20 percent of patients with depression were receiving outpatient therapy.

Patients with FAS/ARND were most commonly hospitalized when they presented with depression or suicide threats, and information on hospital length of stay showed that 16 percent of hospitalized patients had been there 2.1 to 4 months and 15 percent of hospitalized patients had been there 4.1 to 12 months. Also, the study showed that 3 percent of the patients with FAS/ARND had been hospitalized for over a year. This information on hospitalization confirms that this patient population has a significant morbidity often requiring a longer than average stay in hospital.

The severity of mental health problems in patients with FAS/ARND can also be indirectly analyzed by looking at the use of medication in this population. The University of Washington study showed that over 30 different medications were used in varying combinations, and some with a certain medical risk (O'Malley, 1997a). This is obviously a patient population that requires more than just psychosocial treatment for management. However, medications are often used in a haphazard way because of the lack of efficacy studies in this population.

**Table 1: Families of Drugs Used in Patients With FAS/ARND**

| | n | % | | n | % |
|---|---|---|---|---|---|
| **Psychostimulants** | **157** | **38 %** | **Anticonvulsants** | **18** | **4%** |
| Methylphenidate | | | Tegretol | | |
| Dexedrine | | | Depakote | | |
| Pemoline | | | Dilantin | | |
| | | | Phenobarbital | | |
| **TCA'S** | **61** | **15 *** | **Antipsychotics** | **10** | **2%** |
| Imipramine | | | Risperidal | | |
| Desipramine | | | Chlorpromazine | | |
| Amitriptyline | | | Stelazine | | |
| Clomipramine | | | Clozapine | | |
| Other | | | Other | | |
| **SSRI's** | **33** | **8 %** | **Others** | **39** | **9%** |
| Prozac | | | Lithium Carbonate | | |
| Zoloft | | | Clonidine | | |
| Paxil | | | Antianxiety drugs | | |
| Other | | | Tenex | | |

Patients with FAS/ARND have a legacy of physical problems called Alcohol-Related Birth Defects (ARBD) (Stratton et al.,1996) that are important clinical considerations in management. This population is at risk for cardiac, renal, or liver problems, and so medications such as the tricyclic antidepressants which have a known cardiotoxicity; lithium carbonate which has renal, cardiac, and thyroid problems; and pemoline which has caused liver failure, should probably be avoided for medical safety reasons alone.

### COMPLEX MENTAL HEALTH PROBLEMS IN PATIENTS WITH FAS/ARND

The Secondary Disabilities Study (SDS) of the University of Washington opens the understanding of the importance of mental health issues in this population but their complexities require a closer scrutiny. These patients offer a mixture of environmental and neuropsychiatric problems that are invariably interlinked, e.g., 72 percent of the patients suffer abuse, 75 percent of the patients live outside the *birth* family (a recent study even put that figure at 90 percent, Egeland et al., 1998), and language, memory, and social judgment problems inhibit standard behavior management (Streissguth et al., 1996; Streissguth, 1997b; Carmichael et al., 1997; La Due et al., 1992; Coggins, 1998), Thus, clinical issues such as Post Traumatic Stress Disorder and Reactive Attachment Disorder, as well as Specific Learning Disorders often co-exist. The mental health issues are invariably a combination of syndromes.

Clinical experience, clinical studies (Coe et al., 1999; O'Malley,1998b) and the University of Washington Secondary Disabilities Study are beginning to unravel the complexity of comorbid issues in this patient population. They reflect not just the structural effect of prenatal alcohol on the brain (Streissguth,1997), but also the effects on developing neurotransmitter systems such as dopamine, serotonin, norepinephrine, and GABA (Hannigan et al 1996, Harris 1995a). These systems have already been implicated in psychiatric disorders such as schizophrenia (dopamine), ADHD (dopamine and

norepinephrine), major depressive disorder (serotonin), anxiety and panic disorder (norepinephrine), and seizure disorder (GABA) to mention a few (Harris 1995a, Cyr et al 1998).

**The infant and young child** (under 5 years) can show a temperament which is difficult to settle or slow to warm (Thomas & Chess 1987). They may also display a level of physical hyperactivity consistent with ADHD, as well as a level of mood irritability and instability that needs treatment. This clinical presentation reflects the primary disability of FAS/ARND and also the influence of the environment, e.g., abuse, multiple placements. Thus, a secondary disability of an anxiety nature needs to be considered, such as PTSD or Reactive Attachment Disorder of childhood.

**The 6- to 11-year old age groups of patients** may present with ADHD, hyperactive impulsive type initially, but this is frequently seen with comorbid mood disorder or anxiety disorder (including panic attacks). It is also important to assess for the presence of auditory or visual hallucinations. The comorbid mood or anxiety/panic disorders can often be missed because of the patients' inability to express themselves verbally. The experience of hearing voices and seeing visions may be linked to a Post Traumatic Stress Disorder, or may harbor a true psychotic disorder with an organic etiology. The patients may even be showing the toxic side effects of too aggressive a dosage of psychostimulant reflecting excessive dopaminergic effect.

**The 12- to 20-year old age group of patients** may present with affective disorder features of a major depressive disorder or bipolar disorder. These depressive features are not uncommonly seen with comorbid ADHD or anxiety features, The adolescent population of FAS/ARND patients also show visual and auditory hallucinations that may be a true psychotic feature. However, alcohol and drug problems might be contributing to the visual and auditory hallucinations, or may be linked to the patients' "self-medicating" and anxiety/panic disorder. The alcohol and drug problems might signify the risk that patients prenatally exposed to alcohol have been showing a greater alcohol preference that is a biological determinant rather than a psychosocial determinant. Finally, suicidal threats and attempts should always be taken seriously in this age group because they can become more of a risk when in association with the impulsivity of an ADHD disorder. (Bond at al., 1976; Reyes et al., 1985; Dominguez et al., 1993; Baer et al., 1998).

**Adults** with FAS/ARND present complex mental health disorders that have been briefly described by Famy et al. (1998). Clinical experience is also showing that the comorbid issues in adults include such diagnoses as major depressive disorder with mood incongruent psychotic features, anxiety and panic disorder that may be triggered by cognitive dissonance when faced with a complex decision. The comorbidity of ADHD and depressive disorder continues in this age group, as does the suicide risk. These patients offer another important clinical feature that increases their suicidality, namely the possible presence of a personality type such as borderline personality with its inherent impulsivity. As well as that,

the presence of auditory or visual hallucinations may indicate psychotic features or even neurological problems such as complex partial seizure disorder.

The complex mental health issues are a mixture of the primary and secondary disabilities of FAS/ARND. They reflect:

- the effect of prenatal alcohol on the developing brain;
- the influence of the environment through the lifespan on the patient, (e.g., home, school, work);
- the influence of familial history of psychiatric disorder.

These patients are rarely what they seem at first assessment. The implications for psychopharmacological management are muftifaceted.

### THE DIAGNOSTIC ISSUES INVOLVED WITH THE PSYCHOPHARMACOLOGY OF PATIENTS WITH FAS/ARND

The previous sections of this paper have dealt with the prevalence of mental health disorders in patients with FAS and ARND (or FAE), as well as the animal research and behavioral phenotype that has informed and complemented human studies.

The practical issues of prescribing psychotropic agents for this patient population involve the ability to accurately diagnose the problem being treated by the prescribed agent. Although target symptoms such as physical hyperactivity, impulsivity, sleep disorders, explosiveness and mood instability have been described, a more holistic diagnostic frame is needed.

The psychiatric nomenclature DSMIIIR used to be very helpful in describing patients with FAS or ARND and highlighted the origins of the patient's mental health or psychiatric disorder.

Terms include:

1. Organic Anxiety Syndrome
2. Organic Mood Syndrome
3. Organic Delusional Syndrome
4. Organic Hallucinosis
5. and Organic Personality Disorder (which included an explosive type).

These terms all spoke a language easily understood by other mental health professionals and served as a warning or explanation for atypical drug responses.

The current psychiatric nomenclature DSMIV is not so helpful. Patients with FAS or ARND are now placed in a category called Mental Disorders due to a General Medical Condition.

This category includes terms such as:

- Delirium due to a General Medical Condition
- Dementia due to a General Medical Condition
- Amnesic Disorder due to a General Medical Condition
- Psychotic Disorder due to a General Medical Condition
- Mood Disorder due to a General Medical Condition
- Anxiety Disorder due to a General Medical Condition
- Sexual Dysfunction due to a General Medical Condition
- Sleep Disorder due to a General Medical condition
- Personality Change due to a General Medical Condition (e.g., Labile, Disinhibited, Aggressive, Apathetic, Paranoid).

Such terms have not helped in the understanding and description of the complex mental health problems that these patients often present. This category also appears to be poorly understood by current mental health professionals and is rarely used.

The International Classification of Diseases (ICD 10) groups similar disorders under the general terms:

- Catatonic Disorder due to a General Medical Condition
- Personality Change due to a General Medical Condition
- e.g., Labile, Disinhibited, Aggressive, Apathetic, Paranoid or combined Mental Disorder NOS due to a General Medical Condition.

Already pilot studies for the 25-year follow-up of the Seattle 500 study are beginning to reveal complex psychiatric diagnoses such as Major Depressive Disorder With Mood Incongruent Psychotic Features, Bipolar Disorder, or Borderline Personality Disorder (Famy et al., 1998). The relationship between Psychotic Disorder and Temporal Lobe or Complex Partial Seizure Disorder may have clinical significance for this patient population (Stevens, 1991; Bredkjaer et al., 1998; O'Malley & Barr, 1998a).

There needs to be a diagnostic way to capture that at the root of these problems, there is an organic etiology. This is relevant, not just for Axis I diagnostic problems, but also for Axis II personality diagnosis. The latter category is quite in keeping with the recent literature, which has looked at the

neurobiological underpinnings to social interaction and personality disorder (Siever et al., 1991; Insel , 1997). Already there is a comprehensive literature on the use of pharmacological interventions in the treatment of Personality Disorders (Sanislow et al., 1998).

These patients are not just the children of alcoholics (COA) or the adult children of alcoholic parents (ACOA) (Hill et al., 1996; Weinberg, 1997). Careful attention to diagnosis will guide psychopharmacological treatment and open the way to clear recognition and understanding of the clinical legacy of prenatal alcohol exposure.

### GENERAL QUESTIONS FOR CONSIDERATION IN PSYCHOPHARMACOLOGICAL MANAGEMENT IN PATIENTS WITH FAS/ARND

There are some fundamental questions that should be considered when prescribing psychotropic agents for patients with FAS/ARND. These questions include information obtained from animal research (Hannigan et al., 1988; 1996). Also, the general principles of psychopharmacological management in children and adolescents has been recently reviewed by Campbell et al., (1995a; 1995b).

- **What Is the Interaction between the developing brain and the psychotropic drug?** (Vitiello, 1998; Farwell et al., 1990; Harris, 1995a; Wolraich, 1996; Rakic et al., 1998; Reiner et al., I 998; Rubenstein ,1998; Lombroso,1998)

  CLINICAL EXAMPLE: Chronic administration of phenobarbital to children at risk for recurrent febrile seizures resulted in lower I.Q. after 2 years of treatment and this impairment was still present 6 months after the drug was discontinued. (Farwell et al., 1990)

- **Is the interaction between the psychotropic drug and the brain made more complicated by the fact that the developing brain may already be damaged by prenatal alcohol exposure?** (Abel at el., 1981; Ulug & Riley, 1983; Means et al., 1984; Harris, 1995b; Wolraich, 1996; Vkiello, 1998)

  CLINICAL EXAMPLES: A I0-year old patient with prenatal alcohol exposure and clinical presentation of Attention Deficit Hyperactivity Disorder (ADHD) with comorbid mood disorder is managed on desipramine. The dosage is increased by 5 mg. and the patient becomes uncontrollably aggressive and punches three students at school.

  A patent with FAS is given thioriadizine for sedation and he becomes very agitated, lashing out at his parents.

- **Should all apparently inappropriate behavior seen in patients with FAS/ARND be classified as a mental health disorder? Or are some of these behaviors a natural, and even not unexpected, response to living in a chaotic or abusive family environment?** (Najman et al., 1997; Russell, 1997; Sprenger et al., 1998)

  CLINICAL EXAMPLES: A 10-year old patient with FAS crawls on the floor, making dog noises, and begs to be whipped and punished for being bad.

  A 13-year old patient with ARND who had been physically abused by his maternal aunt, constantly verbally abuses and is physically defiant with female teachers and his adopted mother.

- **Is the mental health disorder in patients with FAS/ARND merely a reflection of the patient's I.Q. or the severity of the learning disability?** (Russell, 1997; King et al., 1998; State et al., 1998; Lewis, 1993; Harris, 1995b; Wolraich, 1996).

  CLINICAL EXAMPLES: A 9-year old patient with ARND and average to below average I.Q. has chronic sleep disturbance in which he talks to his recently deceased maternal grandfather. This disappears when he performs a burial ritual.

  A 15-year patient with ARND with above average intelligence climbs a tree in the center of a residential area so he can think more clearly. The time in the tree relaxes him and helps him find a solution for the family management issue he could not solve.

  An 8-year old patient with ARND and below average intelligence becomes very aggressive in school, with hyperventilation, excess sweating, and agitation. This is in the context of being faced with an arithmetic test that the patient could not do, but he is unable to tell the teacher that the test is too complex.

- **Are the mental health problems of patients with FAS/ARND who have quantified brain dysfunction (static encephalopethy) more severe than those patients without quantified brain dysfunction?** (Astley & Clarren, 1996; 1997; Harris, 1995b; Russell, 1997; Rutter, 1983).

  CLINICAL EXAMPLES: A 9-year old patient with FAS also showing temporal lobe seizure activity (complex partial seizures) displays auditory and visual hallucinations.

  A 10-year old patient with FAS with no temporal lobe seizure activity, but with a history of early abuse displays auditory and visual hallucinations.

These five questions should be considered and inform decision making by the physician about the "role" of pharmacological intervention in the mental health disorder of a patient with FAS/ARND.

**PREVIOUS PHARMACOLOGICAL STUDIES IN PATIENTS WITH FAS/ARND:**

There has been only one controlled study published regarding psychopharmacological intervention in FAS spectrum disorders (Snyder et al.,1997). This study utilized stimulant medication and included only 11 children who were known responders to stimulants. Since controlled studies are limited and even anecdotal information is sparse (Coe et al., 1999; O'Malley, 1997a; O'Malley, 1997b), one must look to the animal literature regarding the neurochemistry and psychopharmacological responses of mice and rats prenatally exposed to alcohol to give us information. We can also be guided by the human studies involving psychopharmacological interventions in children and adults with cognitive deficits or mental retardation, although more specific information about FAS is lacking.

Animal studies with prenatal alcohol exposure not only demonstrate dysmorphic physical features typical of FAS in humans, but also demonstrate hyperactivity in rats and mice (Driscoll et al., 1990; Hannigan et al., 1991; Riley, 1990; Sulik et al., 1981). This hyperactivity improves with age and is worse in males compared to females, which parallels the situation in humans. However, the hyperactivity in FAS rats worsens when treated with methylphenidate, amphetamine, or clonidine (Hannigan et al., 1991; Riley, 1990; Weathersby et al., 1994) contrary to what is typically seen with humans with ADHD with or without FAS. Of great interest in the animal studies is the fact that cholinergic agents, such as neostigmine or physostigmine, which are acetylcholinesterase inhibitors that increase acetylcholine levels, generally decrease hyperactivity in these animal models (Bond, 1988; Riley et al., 1986). These studies suggest that cholinergic function mediates at least part of the hyperactivity problem in patients with FAS, but cholinergic agents have never been used to treat ADHD in humans with or without FAS (Coe et al., 1999).

Animal studies have allowed a detailed look at the neurotransmitter systems of prenatally exposed animals, and deficits have been found in most, including dopaminergic, noradrenergic, serotonergic, cholinergic, glutamatergic, GABAergic, and histaminergic systems (Druse, 1992; Manteuffel, 1996). The deficits in dopamine and norepinephrine systems likely relate to the ADHD problems, although structural changes in the size of the caudate, corpus callosum, and cerebellum are also associated with ADHD in humans (Mattson et al., 1995; Mattson et al., 1996; Riley in this volume). The rat research has shown that the $D_1$ receptors of the mesolimbic dopamine system are more impacted by alcohol exposure than the nigrostriatal or the tegmental dopamine system (Hannigan et al., 1996). This suggests that dextroamphetamine, which impacts the mesolimbic system to a greater extent than methylphenidate (Matochik et al., 1993; Harris, 1995c), might be a more optimal medication for children with FAS and ADHD. Deficits in dopamine may also have an effect on neuronal structure and branching generally, since dopamine plays a role in neuronal differentiation and neurite elongation (Ferrer et al., 1987; Manteuffel, 1996; Miller et al., 1990). Fetal serotonin levels also have a trophic effect that modulates neuronal outgrowths to target areas and promotes formation of collateral connections (Manteuffel, 1996). These findings suggest that enhancement of these neurotransmitter levels by

pharmacological means early on in development would be beneficial for later neuronal development. Animal studies also support this concept, in that treatment of pregnant alcohol exposed rats with buspirone (Buspar), a 5-$HT_{1A}$ agonist, prevented or reversed many of the serotonin abnormalities caused by alcohol exposure in the offspring (Gillespie et al., 1997; Kim et al., 1996).

Most importantly, the animal studies have demonstrated CNS structural and neurochemical changes, even when dysmorphic facial features are not present (Clarren et al., 1990; Driscoll et al., 1990; Streissguth, 1997). This finding has influenced the diagnostic criteria for FAS spectrum disorders and the diagnosis of ARND is not dependent on the presence of dysmorphic facial or other physical features (Stratton et al., 1996). This has allowed a diagnosis in more mildly affected individuals who are at greatest risk for secondary disabilities (Streissguth et al., 1996), so that aggressive treatment can be instituted early in childhood (Hagerman, 1999a).

Lastly, the animal studies have demonstrated the plasticity of the neuronal systems, because intensive motor therapy can ameliorate the motor deficits brought on by loss of Purkinje neurons in the cerebellum of rats exposed to alcohol. Therapeutic motor training, which includes training in motor inhibition, enhances the number of synapses per Purkinje neuron and normalizes the motor performance (Klintsova et al., 1997; Greenough in this volume). Motor training should be studied in children with FAS, and it is one component of a comprehensive treatment program that also includes psychopharmacological intervention. Clinically, we often see a synergistic effect with motor therapy and stimulant medication, which can also improve motor abilities (Barkley, 1990; Hagerman, 1999a).

We will survey several medication categories that are often used in individuals with FAS spectrum disorders. We will review previous studies carried out in individuals with cognitive deficits, in addition to the benefits, side effects, and experience regarding their use in individuals with prenatal alcohol exposure. Special attention will be given to possible medical complications that may occur in individuals with FAS related to CNS, cardiac, renal, hepatic or nutritional problems. In general, individuals with organic or structural changes in the CNS, including those with FAS or ARND, are often extra sensitive to the effects of medication, including the side effects (Hagerman, 1999b; Reiss et al., 1998). In addition, the response to medication, particularly the stimulants, may improve with age; that is, a negative response may occur in a child under 5 years, but a subsequent positive response may be seen when the child is 6 or 7 years of age (Coe et al., 1999; Hagerman, 1996).

Recent work by Sprenger et al., 1998 has suggested that the practice of pediatric psychopharmacotherapy should acknowledge and incorporate the family environment. This would suggest that any pharmacological studies of this patient population should also include a family assessment at the very onset. This would facilitate an immediate understanding and recognition of the critical environment/brain injury interaction. As Sprenger et al. point out, the family environment stability and support is critical to the patient's response to any psychotropic agent. The disability in patients with

FAS/ARND makes judgment and self-knowledge suspect, not just in childhood but throughout the lifespan. This patient population is often not the best arbiter of psychotropic agent success or failure, and a "critical observing other" is essential. As well, these patients may come from chaotic family environments that make the understanding of the effectiveness of medication all the more challenging.

**STIMULANTS**

Since the 1990's, stimulants have been commonly used in patients with mental retardation and ADHD with controlled efficacy studies documenting their benefit (Aman et al., 1993a; Aman et al.,, 1993b; Gadow et al., 1992; Handen et al., 1990; Handen et al., 1992; Mayes et al., 1994; reviewed by Arnold et al., 1998). Some diagnoses have a response rate of 60 percent or better, such as fragile X syndrome or spina bifida, (Hagerman et al., 1988; Mayes et al., 1994) whereas other diagnoses may have a response rate under 50 percent, such as autism (Mayes et al., 1994). The response to methylphenidate correlated positively to IQ in children with cognitive deficits; an IQ below 45 was associated with a poor response in studies by Aman et al. (1993a; 1991).

The most commonly used stimulants include methylphenidate (Ritalin), dextroamphetamine (Dexedrine), Adderall (a mixture of 4 dextro and levo-amphetamine salts), and pemoline (Cylert). The FDA reported in 1996 that pemoline was associated with 13 cases of liver failure yielding a low but definable risk of 1:70,000 to 1:300,000 for liver failure. Because of this severe complication, pemoline should not be used as a first line drug for treatment of ADHD particularly in patients with FAS, since their liver may be more vulnerable to damage, especially if they drink alcohol. Recent studies suggest that the acute hepatic failure related to pemoline's use is caused by an autoimmune process that can be treated with steroids (Hochman et al., 1998; Rosh et al., 1998).

Stimulants in general enhance dopamine and norepinephrine neurotransmission by blocking reuptake and enhancing release of the normal neurotransmitter at the synapse. Enhanced metabolism is seen in PET studies in the frontal regions, parietal regions, striatum, and even in the cerebellum in patients treated with stimulants (Lou et al., 1989; Matochik et al., 1993; Volkow et al., 1997). The side effects include appetite suppression and deficits in height and growth if weight loss occurs. Individuals with FAS often have difficulty in gaining weight during childhood, and shortness of stature is part of the diagnostic criteria for full FAS. Therefore, height and weight, and head circumference growth percentiles need to be followed closely in children treated with stimulants. If growth does not increase appropriately, then the stimulant dose must be decreased or the calories increased. Stimulants may also increase the heart rate and blood pressure, and patients with heart disease or renal disease require careful medical follow-up to make sure that these parameters stay in the normal range.

The one published controlled study of stimulants in patients with FAS/FAE included 11 patients, and there was improvement in hyperactivity by parental report, but no significant improvement in impulsivity or attention on a continuous performance task (Snyder et al., 1997). The majority of the

patients were treated with methylphenidate in doses ranging from 5 to 20 mg bid with no consistency in the mg per kilogram dose; two were treated with pemoline, and one was treated with dextroamphetamine. Clearly, more controlled studies are warranted, since ADHD symptoms are so common in FAS spectrum disorders.

Medication surveys of patients with FAS spectrum disorders are beginning to be published, and in a Denver survey, 63 percent of 27 trials of stimulants showed mild to marked improvement in ADHD symptoms (Coe et al., 1999). Patients with ARND had an 80 percent response rate, whereas patients with FAS had a 48 percent response rate. This fits with Aman's finding that patients with a higher IQ generally have a better response to stimulants. In the secondary disabilities study, 34 percent of 415 patients with FAS or FAE were given methylphenidate for ADHD, and in 53 percent it was discontinued by either the physician, parent, or the patient themselves (O'Malley, 1997a; Streissguth et al., 1996). This leaves a long-term response rate of 47 percent. O'Malley et al. (1998b) found a higher response rate to dextroamphetamine in 30 patients with FAS or FAE who were followed closely in Canada and USA. Only 22 percent of the 23 patients who were treated with methylphenidate had a positive response, whereas 79 percent of 19 patients who were treated with dextroamphetamine had a positive response. Eight patients who did not respond to methylphenidate had a subsequent positive response to dextroamphetamine. This data suggests that dextroamphetamine should be the first type of stimulant tried in treatment of ADHD associated with prenatal alcohol exposure. This finding is also consistent with the predictions of Hannigan & Randall (1996) regarding the use of a stimulant that impacts the $D_1$ receptors of the mesolimbic dopamine system (Harris, 1995c).

### TRICYLICS AND $a_2$ PRESYNAPTIC AGONISTS

Second line treatment of ADHD typically includes the use of tricyclics and $a_2$ presynaptic agonists, such as clonidine or guanfacine. Tricyclics have not been beneficial in anecdotal reports of patients with FAS, and they are associated with prolongation of cardiac conduction that can lead to arrhythymias and death in overdose (Coe et al., 1999; Sovner et al., 1998). For these reasons and because heart disease can be seen in over 30 percent of children with FAS, (Spohr et al., 1987), it is safest to avoid tricyclic medications in patients with FAS spectrum disorders. Clonidine, on the other hand, may be helpful for calming down hyperarousal and hyperactivity in patients with prenatal alcohol exposure and in seven patients treated with clonidine, four had a positive response (Coe et al., 1999). Side effects of clonidine include sedation and hypotension, so it should be used in low dose to avoid these complications, particularly in young children. A typical dose in a 5-year-old child is ¼ or ½ of a 0.1-mg tablet twice a day. Clonidine can also help to treat the sleep disturbance and the rage outbursts, common in children with FAS (DeVries et al., 1998). A rare arrhythmia may occur in patients treated with clonidine, and the clinician must be extra cautious when clonidine is combined with other medications, particularly stimulants (Hagerman et al., 1998). A baseline EKG is recommended before clonidine is started in patients with

FAS to rule out cardiac pathology that may not be detected by auscultation. If the examination is abnormal, consultation should be sought with a cardiologist to diagnose and treat cardiac disease and to evaluate the safety of clonidine in the presence of cardiac disease. In the Denver survey of patients with FAS spectrum disorders, guanfacine was tried in two patients, but it was not beneficial (Coe et al., 1999). Although guanfacine, a more specific $a_{2A}$ presynaptic agonist compared to clonidine, typically has less sedation and a longer half life than clonidine, it has not been shown to be helpful in patients with FAS yet.

Recent work in humans has postulated that ADHD is related to a dopamine dysregulation in the frontal neostriatal system, which manifests as widely varying states of arousal. This has obvious implications for the understanding of the neurochemical basis to some of the "hyperactive behavior" seen in animals and in humans with prenatal alcohol exposure (Cyr et al., 1998).

### MELATONIN

An alternative medication that can be used to treat the sleep disturbances in patients with FAS is melatonin (Hagerman, 1999a). This is a natural sleep hormone produced normally after the sun goes down, but melatonin's production is inhibited by light (Brzezinski, 1997). In developmentally disabled populations, melatonin is helpful in 80 percent (Jan et al., 1996). Melatonin is helpful anecdotally in patients with FAS in doses of 3 mg or less at bedtime in the authors' experience.

### SEROTONIN AGENTS

Serotonin agents, specifically selective serotonin reuptake inhibitors (SSRIs), raise serotonin levels by blocking reuptake channels at the synapse (Leonard et al., 1997). Treatment with SSRIs may improve depression, anxiety, panic attacks, obsessive compulsive behavior, suicidal ideation, and aggression, all of which are related to low serotonin levels and occur frequently in patients with FAS. (Hagerman, 1999a; Streissguth et al., 1996). These problems, in addition to disruptive behavior, are related to the high rates of secondary disabilities and should be treated aggressively with multimodality therapy that includes counseling and medication. The SSRIs are relatively safe medications that do not irritate the heart, liver, or kidneys and do not require monitoring of blood levels (Leonard et al., 1997). The side effects include gastrointestinal symptoms, such as nausea or loose stools, but in general they are usually well tolerated. SSRIs can cause an activation effect, particularly fluoxetine (Prozac), which is helpful in the treatment of depression or dysthymia, but the activation can exacerbate hyperactivity and insomnia. Sertraline (Zoloft) and fluvoxamine (Luvox) may have less activation than fluoxetine or paroxetine (Paxil). On occasion, the activation may be severe and hypomania or overt mania may occur, particularly with higher doses. The side effect of hypomania or mania is a reflection of mood instability that is more common in individuals with developmental disabilities, compared to those with a normal IQ (Hagerman, 1999b; Wozniak et al., 1997). Mania also occurs in those with bipolar disorder and points out the need of a mood stabilizer described below. In the Denver survey of FAS spectrum disorders, 80

percent of patients responded to an SSRI; however, mania was eventually seen in three of six patients treated with sertraline, and all of these patients had FAS instead of ARND (Coe et al., 1999). This side effect should be watched for carefully, particularly in those patients on the severe end of the FAS spectrum of disorders. SSRIs are frequently combined with other agents, such as stimulants or anticonvulsants. In the latter instance, an SSRI agent should be used that interferes the least with the cytochrome P450 system, since this is important in the metabolism of many anticonvulsants. Sertraline has been shown to interfere the least with the P450 system (Preskorn, 1996), although anticonvulsant serum levels should be checked within a month of starting any SSRI.

### ANTICONVULSANTS

Anticonvulsants are not only helpful for treating seizures that are common in FAS, but two in particular, valproic acid and carbamazepine, also have a beneficial psychotropic effect. These two agents act as mood stabilizers and are particularly helpful for rage episodes and aggression, in addition to severe mood lability or bipolar disorder. Coe et al. (1999) found that seven of eight trials (88 percent) of anticonvulsants or mood stabilizers were helpful in patients with FAS spectrum disorders. Both valproic acid and carbamazepine require careful and frequent monitoring of blood levels, liver function studies, CBC, and electrolytes. Side effects include hepatic dysfunction, neutropenia, thrombocytopenia, sedation, appetite changes, gastrointestinal irritation, pancreatitis, and hair thinning. In approximately 3 percent of patients treated with carbamazepine, a hypersensitivity reaction may be seen presenting with fever and rash (Bellman et al., 1995), and it requires immediate discontinuation of the medication. Recently, a high percentage of women treated with valproic acid have been found to have polycystic ovarian disease on follow-up, so this medication should be avoided whenever possible in women (Isojarvi et al., 1993, Irwin et al., 1998).

If the EEG demonstrates spike wave discharges even without clinical seizures, then carbamazepine or valproic acid should be considered for the treatment of outburst behavior or aggression if these are clinical problems. Even when the EEG is not abnormal, these agents are effective mood stabilizers in individuals with mental retardation (Alvarez et al., 1998) and in individuals with a normal IQ (Bowden et al., 1994,).

Recently, new anticonvulsants have been developed that can help to control refractory seizures, but which are also effective adjunctive agents for mood stabilization and anxiety. These agents include gabapentin (Neurontin) and lamotrigine (Lamictal). Gabapentin is a structural analogue of GABA, but it does not interact with GABA receptors. Gabapentin does not require serum level monitoring, and it is usually well tolerated, although the most common side effects are sedation, dizziness, ataxia, and fatigue. It is usually started at a low dose in children (100 to 300 mg/day) (McElroy et al., 1997). Lamotrigine is not recommended for use in children under 16 years, and in 10 percent a severe rash related to a

hypersensitivity reaction may occur. Valproic acid inhibits the metabolism of lamotrigine, and the combined use of these agents may predispose individuals to a rash and other side effects (Alvarez et al., 1998). The use of these agents in individuals with FAS has not been reported.

It is not known to what degree alcohol effects in one neurotransmitter system (e.g., dopamine) may be secondary to alterations in other interacting neurotransmitter systems, e.g., descending GABAergic inhibition of dopamine cells (Hannigan et al., 1996; Zhong et al., 1998; Soldo et al., 1998).

### LITHIUM

Lithium is an effective mood stabilizer, and it has also been used to treat aggression in individuals with cognitive deficits (Hagerman, 1996). However, lithium also causes significant renal side effects, including polyuria and electrolyte abnormalities. Since renal dysfunction is common in FAS, these patients need a detailed medical work-up of kidney dysfunction before lithium should be prescribed. Careful medical follow-up is also necessary for all patients treated with lithium. Children in general and children with FAS in particular, may be particularly vulnerable to the CNS side effects of lithium, including ataxia, tremors, confusion, or excessive drowsiness, even when lithium is in the therapeutic range (Hagino et al., 1995).

### ANTIPSYCHOTIC AGENTS

Antipsychotic agents are frequently used in individuals with FAS for treatment of psychotic symptoms, aggression and mood instability, as reflected in rage outbursts. Psychotic symptoms are common problems in individuals with FAS, as reported by (Famy et al., 1998). In the Denver survey, six trials of an antipsychotic resulted in a positive response in five cases (83 percent) (Coe et al., 1999). The use of atypical antipsychotic agents, such as risperidone (Risperdal) or olanzapine (Zyprexa), which block both dopamine $D_2$ receptors and serotonin 5-$HT_{2A}$ receptors and lead to a lower risk of extrapyramidal symptoms and tardive dyskinesias, are recommended because they are safer than the older antipsychotics (Kapur et al., 1996; Kumra et al., 1998). The atypical antipsychotics have been used in many groups with cognitive deficits, including autism, PDD, and mental retardation of unknown etiology (Khan, 1997; McDougle et al., 1995; Vanden Borre et al., 1993), and anecdotal experience has been positive in individuals with FAS (Hagerman, 1999a).

### OTHER MEDICATIONS

Many other medications not described in detail here may be beneficial in patients with FAS spectrum disorders. Anecdotal information suggests that Depo Provera IM injections every 3 months is helpful in males with sexually aggressive behavior (O'Malley, 1998; Meyer et al., 1992; Greenberg et al., 1998). Buproprion (Wellbutrin) is an antidepressant with a unique pharmacological profile, because it is helpful in the treatment of ADHD, but it does not have significant abuse potential even when administered

to subjects with a history of amphetamine abuse (Griffith et al., 1983). The most important side effect of buproprion is seizures; however, if the dose is maintained at less than or equal to 450 mg/day in adults, the seizure rate is 0.4 percent (Barrickman et al., 1995). Since buproprion is a weak dopamine agonist, individuals prone to psychosis may experience an increase in hallucinations, delusions, or confusion (Barrickman et al., 1995), so this should be followed closely in patients with FAS spectrum disorders.

### CASE EXAMPLES

The following individual case histories illustrate the problems in psychopharmacological management of this patient population:

- One of the most common clinical problems seen in treating patients with FAS/ARND is the prevalence of "iatrogenic encephalopathy." These patients are commonly treated with widely different combinations of psychotropic medications used for symptomatic treatment. For example, one patient was taking methylphenidate, clonidine, and nozinan (a first generation antipsychotic). The patient presented in a chronically confused state, markedly sedated, and with chronic sleep disturbance. The combination of methylphenidate and clonidine has been shown to have a certain cardiac risk that is further complicated in patients with FAS/ARND because of the prevalence of Alcohol Related Birth Defects (ARBD). (Cantwell et al., 1997) Also, the nozinan markedly oversedated the patient as well as increasing the patient's risk for liver problems, e.g., cholestatic jaundice.
- Another patient with ARND presents a clinical picture consistent with ADHD and Comorbid Mood Disorder and responds to a combination of dextro-amphetamine and fluoxetine. The fluoxetine is increased by 10 mg and the patient becomes uncontrollably giddy, with pressure of speech and hypomania, suggesting a Bipolar Disorder (Manic Depressive Disorder).
- A patient with ARND is on methylphenidate for ADHD symptoms but begins to hear voices and see visions. The methylphenidate is stopped and dextroamphetamine commenced, but the voices and vision still persists. A sleep-deprived EEG is done showing temporal lobe seizure activity and carbamazepine is added to the dextro-amphetamine. The patient ceases to hear voices and see visions that have been rooted in a complex partial seizure disorder. (Seizure problems have been associated with FAS, O'Malley et al., 1998a.)
- Sleep disturbances may be signs of different issues. One patient with ARND has a true fear of the dark and being alone, and so could not go to sleep and always went into the parents' bedroom. Three other patients with FAS were unable to have a consistent good quality sleep and were easily aroused. This sleep problem had been present from infancy and early childhood. A sleep study on one patient showed that his heart rate accelerated to 160 beats

per minute in the middle of the night, associated with increased REM sleep. This cardiac arrhythmia is of sufficient concern that a pediatric cardiologist has been consulted. (All three of the latter patients with sleep problems are being treated with melatonin. A positive clinical effect on rhythm synchronicity of sleep has been seen and all three sleep well on melatonin.)

## SUMMARY

This preliminary review of the literature and our personal experience has also led us to recommend the avoidance of some medication in the treatment of emotional and behavioral problems in individuals with FAS spectrum disorders. Phenobarbital causes an exacerbation of hyperactivity and therefore should be avoided. Tricyclics have significant cardiac side effects, and preliminary data suggests that they are not helpful behaviorally in patients with FAS, so they are not recommended for use. Regarding stimulants, preliminary results suggest that dextroamphetamine has a better response rate than methylphenidate and should be tried initially; however, pemoline should be avoided because of a risk of hepatic failure.

**TABLE II: PSYCHOTROPIC AGENTS TO USE WITH CAUTION**

**Tricyclic Antidepressant (TCA)** (amitriptyline, imipramine, desipramine, clomipramine)
Cardiac toxicity, lower seizure threshold, lethal in overdose

**Diazepam** (Valium)
Long half-life, cognitive blunting and behavioral excitation may be a problem the next day

**Chlorpromazine**
Lower seizure threshold, liver toxicity, excess sedation

**Haloperidal, Nozinan, Stelazine**
All cause excess sedation, increased risk of EPS and possible liver toxicity especially Nozinan

**Paroxetine (Paxil)**
Increased interaction with other drugs due to inhibition of Cytochrome P450 2D6 Isozyme, which is the metabolic pathway of Tricyclic Antidepressants and Antipsychotics. Also has greater molecular equivalency than other SSRI's (interaction with drugs is possible with all SSRI's).

**Pemoline (Cylert)**
Liver toxicity, several reported deaths.

**Lithium Carbonate**
Cardiac, renal, and thyroid problems.

**Drug Combinations**
Methylphenidate/clonidine higher risk for arrhythmia. Paroxetine/major tranquilizer—because of increased risk of major tranquilizer toxicity.

**GENERAL PRINCIPLES** that should be remembered in the psychopharmacological intervention of individuals with FAS include:

- Medication represents only one aspect of a treatment program for psychopathology. Counseling, family support, and case management are important components of a treatment program, and they should be utilized simultaneously (Hagerman, 1999a; Streissguth, 1997). Medications often work synergistically with other interventions, such as motor therapy, speech and language therapy, social skills and pragmatics training, and counseling (Hagerman, 1999a).
- A combination of medications may be needed for treatment of multiple psychopathologies. For instance, a stimulant for ADHD may need to be combined with an SSRI to treat depression or anxiety or combined with a mood stabilizer to treat rage outbursts. It is important, however, to change only one medication at a time (Wilens et al., 1995; Preda et al., 1998).
- Because of the organic brain damage in FAS spectrum disorders, individuals may be very sensitive to the doses used in treatment. Low doses should be used, at least initially, with a careful assessment of side effects. Do not use a second drug to treat the side effects of the first drug. If side effects are problematic, the dose should be lowered or the medication should be changed to something else.
- These children and adults need close medical and psychological follow-up so if a psychiatrist is prescribing the medications, a physician who can follow the medical complications in FAS must assess growth, cardiac function, renal function and other medical issues. Likewise, if a developmental and behavioral pediatrician is prescribing the psychotropic medications, consultation with a psychiatrist or a psychologist regarding the psychopathology of the patient is usually necessary, as is counseling. It is important for medical and mental health professionals to work closely for aggressive intervention, which will decrease the high rate of secondary disabilities in this disorder.

## ABBREVIATED SUMMARY OF PRESENTATION AND PARTICIPANT DISCUSSION

Developing Clinical Practice Guidelines
for Pharmacological Interventions with Alcohol-Affected Children

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Dr. O'Malley began by noting that mental health problems are a major issue within the FAS/ARND population. The 1996 study by Streissguth et al.* revealed that 90 percent of FAS patients have a history of mental health problems. The FAS/ARND population presents a different profile than the traditional developmental disability population because of the prevalence of psychiatric and mental health problems that are not necessarily associated with low IQ.

The mental health problems most commonly identified in the FAS population include attention deficit, depression, suicide threats, suicide attempts, panic attack, and hearing voices or seeing visions. Attention deficit is the most common mental health problem in 6 to 11 year olds. For individuals with FAS age 12 to 20, the most common mental health problem is depression. Incidence of panic attack increases throughout the lifespan.

An investigation of inpatient care for mental health problems provided an indirect means to assess severity of the problems. Approximately 18 percent were hospitalized longer than 2 months, 15 percent longer than 4 months, and 3 percent longer than 1 year. In an era of managed care and short hospital stays, the investigation revealed that a significant portion of the FAS population suffers from severe mental health problems.

Dr. O'Malley continued with a review of the general principles of pediatric psychopharmacological management of FAS/ARND patients. The interaction between the developing brain and psychotropic drugs has been studied in animal models and humans. A recent controlled study showed that IQ decreased in patients given phenobarbital for prophylactic febrile seizures and remained decreased 6 months after the medication was stopped. Many FAS patients have injured brain tissue and may respond differently to psychotropic drugs than individuals with undamaged tissue.

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*Streissguth, A.P., Baff, H.M., Kogan, J., Bookstein. F.L. 1996. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Final Report to the Centers for Disease Control and Prevention. University of Washington, Seattle.

Rats prenatally exposed to alcohol showed an altered response to psychotropic drugs in adulthood compared to controls. FAS patients may exhibit atypical reactions to small dose changes in medication.

FAS and ARND patients with quantified brain dysfunction (i.e., static encephalopathy) often display the same range of mental health problems as patients without quantified brain dysfunction. Quantified dysfunction is not an automatic entry to a more severe psychiatric morbidity. FAS patients can present with bizarre behavior that may reflect an abusive or chaotic family environment. Psychiatric morbidity is not linked to IQ or degree of learning disability

FAS populations exhibit layers of mental health problems. In an FAS secondary disability study, more than 100 patients from 6 to 11 years old, presented with ADHD as the primary complaint. Comorbid issues of depression, panic, hearing voices or seeing visions and suicide threat were observed in 23 percent of the cohort. In determining treatment, comorbidity must be considered.

Dr. Hagerman explained that animal studies have helped to determine what medications might be most helpful for FAS patients. Animal studies that model FAS showed lower neurotransmitter levels in alcohol-exposed animals. Decreased dopamine and norepinephrine levels are associated with ADHD. Reduced serotonin levels are related to depression, anxiety, obsessive-compulsive behavior, aggression, suicidal ideation, and suicide.

The stimulants most commonly used with FAS patients are methylphenidate or Ritalin, Dexedrine, and Adderall. Adderall is metabolized slower than Ritalin, and patients appear to suffer fewer side effects. The stimulant medications are look-alike drugs for dopamine and norepinephrine. The drugs improve neurotransmission by blocking reuptake of the neurotransmitter, stimulating release in higher doses, or stimulating receptors. The dopamine system has three components, and the mesolimbic system appears to be most affected in FAS patients. Dr. O'Malley's data suggest that Dexedrine is more effective for the mesolimbic system than Ritalin. The norepinephrine system involves the cerebellum, a known problem area in FAS patients.

The response rate to stimulants is 80 percent to 90 percent in ADHD patients with normal IQ and approximately 60 percent in patients with developmental disabilities. Stimulants improve vigilance, reaction time, inhibition, short-term memory, learning, attention, distractibility, and sensory motor integration problems. Improvement is observed also in peer interactions, family relationships, and social standing. There can be a synergistic effect between interventions (e.g., social skills training and psychopharmacological management).

Positron emission tomography (PET) scan studies with ADHD patients revealed that areas of decreased metabolism-frontal region, striatum, and parietal areas—can improve with stimulant medication. PET scan data also show improvement in the cerebellum after methylphenidate treatment. The effect of medication on metabolic activity in the brain tissue of FAS patients remains undocumented.

Dr. Hagerman reviewed the survey of response rates to psychotropic medications based on 66 medication trials with 22 FAS patients. The trials were for the treatment of ADHD, aggression, mood swings, depression, anxiety, sleeplessness, and seizure disorder. The survey revealed the following: (1) Children under 5 years of age often do not respond to stimulants and frequently suffer from side effects. Medications should be retried when the patient is 7 or 8 years old. (2) Approximately 63 percent of patients with FAS spectrum disorders responded well to stimulants. (3) Approximately 88 percent of patients showed mild to marked improvement with mood stabilizers. (4) Mild to marked improvement with selective serotonin reuptake inhibitor (SSRI) agents was observed in 80 percent of patients. FAS patients may exhibit an increased incidence of mania with SSRI treatment. (5) Tricyclics are not particularly helpful, but the study cohort was limited. Antipsychotic drugs are needed for aggression or psychosis. Risperidone appears promising as it triggers fewer side effects. (6) ARND patients showed a better response rate than FAS patients, although the study sample was too small to be statistically significant. However, the observation may indicate that response rate decreases with increased brain pathology.

Future research should explore several areas. Motor therapy improves inhibition actions. Possible carryover to inhibition-related activities in cognitive functioning should be investigated. Controlled medication studies with a detailed neuropsychological test battery are needed. Cholinergic agents should be investigated. Alzheimer patients, who have frontal lobe deficits and ADHD-like problems, show improvement with cholinergic drugs. Lastly, the use of assisted technology and computer programming should be explored, for example, replacing deficit frontal lobe activities with an external structure.

**Discussion**

Dr. Nitkin inquired about the problem in maintaining FAS patients on medication regimes for years. Dr. O'Malley replied that animal studies have shown that chronic amphetamine administration affects the DI dopamine system. Dr. Hagerman noted that studies of ADHD patients with normal IQ indicated that individuals medicated appropriately experience better outcomes in adult life. Dr. O'Malley added that the natural history of untreated FAS patients is bleak. The secondary disabilities study showed that the majority of FAS adults encountered trouble with the law. Medication can control impulsivity and alter the natural history of the illness. The risk/benefit ratio for long-term medication regimes appears to tilt in favor of medication for FAS patients.

Dr. Streissguth announced that the CDC printed 10,000 copies of the secondary disabilities study. Participants interested in obtaining a copy can contact the Department of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine (206 543-7155).

Dr. Riley commented that recent studies indicate that N-methyl-D-aspartate (NMDA) receptors are affected by extremely low levels of prenatal alcohol exposure. He asked if glutamatergic treatments

had been tried. Dr. O'Malley replied that this treatment had not been tried but warrants investigation. Dr. Riley added that approximately 50 percent of his FAS patients on Ritalin stopped taking the medication even if they showed improvement. He wondered if Dr. O'Malley observed a similar scenario. Dr. O'Malley stated that the secondary disability study revealed a similar incidence of noncompliance. The same problem is observed in adolescent ADHD patients. Combining family therapy with psychopharmacology has been recommended as a means to address noncompliance.

Dr. Floyd noted that the FAS population is not homogeneous. Identifying the medications that work best for different subsets might provide a quantum leap in pharmacotherapy and the establishment of standard of care.

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## INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SYNDROME

# INTERVENING WITH CHILDREN AFFECTED BY PRENATAL ALCOHOL EXPOSURE

## September 10-11, 1998

# FINAL COMMITTEE LIST


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## INTERAGENCY COORDINATING COMMITTEE ON FETAL ALCOHOL SYNDROME

# INTERVENING WITH CHILDREN AFFECTED BY PRENATAL ALCOHOL EXPOSURE

## September 10-11, 1998

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