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Substance Abuse

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Strengthening the Web:  
Teaching People with Fetal Alcohol Syndrome or Fetal  
Alcohol Effect.

Carol L. Johnson, M.Ed

## Abstract

A survey of literature about research and practice in the fields of learning disabilities and of Fetal Alcohol Syndrome/Effect (FAS/E) revealed parallels between the two populations, both in learning characteristics and recommended teaching strategies. These parallels suggested that strategies that have been successful with students with learning disabilities may also be effective for students with FAS/E, and that research to document the effectiveness of these strategies with students with FAS/E is recommended. Emerging medical research highlights a connection between physiological damage resulting from prenatal exposure to alcohol and learning and behavior problems in affected individuals. An experienced tutor, trainer, and psychometrician discusses practical approaches to working with students with FAS/E, based on her training and experience in the field of learning disabilities.

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## Résumé

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## Executive Summary

Teaching people with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE) is a challenging task. This challenge is attributable to the complexity and variety of learning, attention, and behavior problems in the population of people with FAS/FAE. Current research and literature revealed similarities in the recommended interventions and teaching strategies for people working with either FAS/E or Learning Disabilities (LD) populations.

While those with FAS/E or LD are heterogeneous groups with inter-student and intra-student differences, general recommendations found in the literature for both groups are similar. Some of these recommendations include the following principles: structure in environment and routines; consistency in rules, environment and communication; brief and concrete communication; repetition and practice to over-learning; multisensory teaching and reinforcement; minimize distractions in the environment; teach to the skill level and need of each student; and provide immediate concrete feedback on success and errors.

In addition to general recommendations, this paper explores reading, writing and spelling teaching strategies that can be implemented by practitioners working with FAS/E populations. An elaborate intertwining of teaching strategies are needed in order to implement reading, writing, and spelling curriculums for individuals with FAS/E or LD. This complex and responsive process requires flexibility as well as patience and respect for the student. Other key factors include awareness of the neurological damage that alcohol may have caused on the brain and awareness of the distinct needs of the person. This awareness and acceptance needs to be present in the home, school, and in the community. Recommendations for policy and practice accentuate the need for policy that demonstrates a willingness to support the individuals with FAS/E's needs, and thus a willingness to support the community that supports all those with Fetal Alcohol Syndrome or Fetal Alcohol Effects.



## Introduction

“Like having a broken spider web in my brain” is the way one woman describes having Fetal Alcohol Syndrome. She says that trying to do everyday things is like pushing her way through a spider’s web. Sometimes she can push through and succeed, but sometimes when she can’t do a task she was able to do the day before, she drops out through the holes in the broken web (Kleinfeld, 2000a, p. 3). Turning that web with its holes and gaps into a strong and resilient safety net is a challenge for parents, caregivers, and professionals.

Teaching individuals with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE) is a challenging task because of the complexity and variety of learning, attention, and behavior problems in this population, as well as because of variability within the individual (Kleinfeld, 1993; Malbin, 1999; Morse, 2000). Especially in northern Canada, where prevalence of FAS/E is higher (Schmidt & Turpin, 1996), there is a need for effective teaching approaches and appropriate social support for these individuals. Professional development and client access to medical care or other forms of treatment are also limited in the less densely populated areas of northern Canada, due to great distances between services, lack of public transit, or high travel costs (Turpin & Schmidt, 1999).

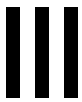
Although observations about the effects of maternal drinking on a fetus have been made since Biblical times, the characteristics of Fetal Alcohol Syndrome were first identified in France in 1968, and the term FAS was coined in the United States in 1973 (Malbin, 1999; Morse, 2000). Research into FAS/E is a new field, which draws on literature and practical experience not only in education, but in medicine, psychology, and social work as well. A key question is whether this field of research in the area of education is totally new, or whether it can borrow and learn from the study of learning disabilities (LD). Parallels between the learning problems in both groups suggest that similar teaching interventions may be appropriate (Johnson & Lapadat, 2000). Furthermore, some statistics indicate that there may be an overlap in the two populations. Of students identified with

LD, 35% drop out of high school. Up to 60% of adolescents in treatment for substance abuse have LD. Of females with LD, 50% will become mothers (many of them single) within three to five years of leaving high school (Ellis & Cramer, 1996). According to these statistics, it is likely not unusual to see students whose learning is affected by both FAS/E and inherited LD (Johnson, 2000).

As a tutor, trainer, and psychometrician who works with children and adults with FAS/E or learning disabilities, I wanted to learn how I could best work with these individuals. My focus is on teaching reading, writing, and spelling, so I reviewed literature about issues relating to FAS/E, LD, interventions that are recommended for students with FAS/E or LD, and teaching written language. This review revealed many similar patterns of learning problems and of recommended interventions in individuals with FAS/E and with LD. It also demonstrated the importance of teachers', parents', and caregivers' awareness of the physiological basis for the behaviors and learning problems of individuals with FAS/E (Johnson, 1999; Malbin, 1999).

Because this field of investigation is so new, there is only a small body of research to advise practice. To a large extent, teachers, counselors, and social workers depend on what Judith Kleinfeld calls "wisdom of practice" (2000b). In the absence of adequate generalizable research about teaching students with FAS/E, the results of anecdotal reports and preliminary studies may provide practical suggestions for those working with individuals affected by FAS/E (Johnson, 1999). As stressed by Morse, "the needs of children and their families demand that interventions be tested now" (1993, p. 24).

As a practitioner with experience with people with FAS/E or LD, I have gathered information from literature as well as from "wisdom of practice" stories shared by other parents, caregivers, and educators (see Kleinfeld, 2000b). This paper suggests implications for practice, and therefore for policy supporting and governing practice, as well as recommendations for further research.



## Overview of Fetal Alcohol Syndrome and Effect and Learning Disabilities

### A. Fetal Alcohol Syndrome and Effect

#### *Definition and Diagnosis or Identification*

Alcohol is “one of the most powerful teratogens” or substances that cause birth defects (Morse, 1993, p. 24). The diagnosis of Fetal Alcohol Syndrome (FAS) depends on three conditions being observed in a child born to a mother who has consumed alcohol during her pregnancy. Impaired growth, changes in facial structure, and central nervous system abnormalities must all be present for the label of FAS to be applied (Burgess & Streissguth, 1992; Morse, 2000). However, in the case of Fetal Alcohol Effect (FAE), identification is made when one or two of these three signs appear in such a child (Malbin, 1999; Morse, 2000; Riley, 2002).

In this young field of research, new terminology is emerging. This includes terms such as alcohol-related neurodevelopmental disorder (ARND), prenatal exposure to alcohol (PEA) (Mattson, Schoenfeld, & Riley, n.d.), alcohol related birth defects (ARBD) (May & Gossage, n.d.), fetal alcohol related conditions (FARC) (LaDue, Schact, Tanner-Halverson, & McGowan, 1999), Fetal Alcohol Spectrum Disorder (FASD) or partial Fetal Alcohol Syndrome (pFAS). As a convenience, this report refers to individuals affected by prenatal exposure to alcohol as having FAS or FAE when the distinction is known, or FAS/E when the distinction is unknown. Also as a convenience, it refers to students with FAS/E or LD as female. This is simply to avoid confusion and awkward language in the report, and does not suggest gender differences in these populations.

FAS is the leading cause of mental retardation in the western world, and the particular tragedy of this is that it is preventable (Burgess & Streissguth, 1992; Morse, 2000; Riley, 2002). Estimates of prevalence of FAS/E are difficult to obtain, partly because of lack of identification or diagnosis in many cases (Burgess & Streissguth; Morse), or because of high death rates in alcohol-affected

infants, which reduces the number of surviving children who have been affected (Robinson, Conry, & Conry, 1996). In addition, different methods of collecting data, such as passive surveillance systems, clinic-based records, or active case ascertainment approaches, provide different statistics (May & Gossage, n.d.). Considering the variety of data-collection methods, May and Gossage estimated that FAS occurs in about 0.5 to 2 of 1000 live births in the United States, and FAE occurs about in about 10 per 1000 births. This proportion may be identified as being higher in some areas, such as some communities in Alaska, First Nations reservations in the U.S. or First Nations reserves in Canada (LaDue, Schact, Tanner-Halvorson, & McGowan, 1999). A key question is whether more rigorous identification of FAS/E or higher incidence or a combination of both provides these data.

Certainly, the site of data collection influences the identification of cases of FAS/E. For example, the proportion is 10 times higher in low-income African-American or American Indian populations than it is in sites with predominantly Caucasian middle class populations (May & Gossage, n.d.). Even though imperfect research methods might exaggerate the degree of impact of FAS/E in First Nations communities in Canada, it is apparent that this impact is more significant than in most other communities (Hart, 1999).

The proportion of individuals with FAS/E in a community may also be affected by the migration of skilled workers away from the area in search of better jobs. These jobs are usually not available to adults with FAS/E so they may be less likely to leave their communities. Therefore the concentration of individuals with FAS/E in a community could increase with the departure of less-affected or unaffected adults (LaDue et al., 1999).

Although it may be tentatively identified by educators, parents, social workers, teaching assistants, or other people working with affected individuals, Fetal Alcohol Syndrome is a medical diagnosis. Noting the imprecise nature of this diagnosis, Burgess and Streissguth (1992) said that it must be made by a medical doctor who has specific training in recognizing the often subtle intricacies of this type of birth defect (See also Hay, 1999; Morse, 2000). However, Morse described a 1992 study of

234 pediatricians, in which 10 percent stated that they were skeptical that FAS existed as a syndrome, and 57 percent stated that they were not knowledgeable enough to appropriately support families affected by FAS/E. Particularly in communities in the north of Canada or outside of large urban areas, expertise in diagnosis and treatment is limited (Lindsay & Preston, 1999; Turpin & Schmidt, 1999). Hay stated that clinicians in the north are on the “front lines of the FAS/E war”, and they need to use whatever tools they have, in the absence of easier access to expertise that might be found in more urban centers (p. 26). She provided a “clinician’s atlas” to diagnosing FAS/E based on information from medical literature as well as from her practice as a pediatrician in northern British Columbia (p. 27). This may not be a perfect tool, she said, but it could help patients and their families to understand the special needs resulting from FAS/E, and to have these needs met according to the services available in the community.

Further contributing to imprecise diagnosis is the fact that recognition of craniofacial abnormalities is a subjective process, particularly because of possible ethnic differences in facial characteristics (Robinson et al., 1996). Other factors to be considered are genetics, metabolism, lifestyle, nutrition during pregnancy, the number of previous pregnancies, maternal characteristics including IQ, and the possibility of prenatal exposure to other drugs as well (Morse, 2000). The effects of the consumption of a combination of drugs and alcohol on the developing fetus is unknown (Morse; Smitherman, 1996). Malbin added that diagnosis is also complicated because the nature and severity of the effects observed in a child after fetal exposure to alcohol is impacted by dose and by the stage of pregnancy when the alcohol was consumed (1999). A longitudinal study of the effects of prenatal alcohol exposure on 500 children followed from birth to age 14 suggested that binge drinking and drinking early in the pregnancy as opposed to mid-pregnancy had the most serious consequences in the form of neurobehavioral deficits (Streissguth, A.P., Barr, H.M., Kogan, J., & Bookstein, F. L., 1994). Emerging brain imaging research suggests that the developing corpus callosum is most sensitive to alcohol damage in the first trimester, while the developing cerebellum is most sensitive shortly before or after birth (Mattson, Schoenfeld, & Riley, n.d.; Riley, 2002).

Fetal Alcohol Effect is a descriptive term for individuals who had prenatal exposure to alcohol but

do not display the full range of physical manifestations of FAS (Burgess & Streissguth, 1992; Malbin, 1999; Morse, 2000; Riley, 2002). Accuracy of identification at present varies with the experience and skill of the practitioner, the completeness of the family and medical history, and the particular professional discipline involved, which could include medicine, social work, education, mental health, or the justice system. Accuracy of identification is also affected by the variety of factors that complicate diagnosis of FAS, noted above.

Early research into the nature of brain damage in FAS/E relied on autopsies of brains of deceased individuals, which was limited not only by the number of brains available for autopsy, but also by the probability that these brains were more severely damaged than most (Mattson et al., n.d.; Riley, 2002). These autopsies revealed that children with FAS had smaller brains than would be expected, with a variety of abnormalities. However, exciting new research using technologies such as Magnetic Resonance Imaging (MRI) and positron emission tomography (PET) more accurately documents the underlying neurological damage that is at the root of learning and behavior problems in individuals with FAS/E. It is important to note that these technologies can demonstrate variations in the size of brain structure, but not efficiencies of function of these structures (Riley, 2002).

Emerging research using functional Magnetic Resonance Imaging (fMRI) supports a link between damage to brain structure and how the brain functions, as do studies examining the functioning of individuals with FAS/E on a variety of neuropsychological tests (Mattson et al., n.d.). Current studies looking at areas of brain damage in individuals with FAS/E show that children with FAS have about 13% less brain volume than unaffected children, and children with FAE have about 5 or 6% less volume. In general, their brains are less symmetrical, and are distorted in shape (Riley, 2002).

However, specific areas in the developing brain seem to be more sensitive to prenatal alcohol exposure. For example, the cerebellum is usually reduced in size, more than would be expected even with the reduced brain volume. Specific areas are more severely affected, with the overall

damage probably relating to difficulties with attention, balance, and learning (Riley, 2002).

Similarly, the corpus callosum, which connects the two sides of the brain, appears to be very sensitive to the effects of prenatal alcohol exposure, especially in the first trimester. In particularly severe cases, the corpus callosum is absent because it never has developed, but in most cases it is smaller, and often is displaced to a different part of the brain from unaffected brains. This damage is believed to be associated with problems with attention, intellectual functioning, reading, learning, verbal memory, and executive and psycho-social functioning. (Mattson et al., n.d.; Riley, 2002).

The basal ganglia are involved with both motor and cognitive abilities, but prenatal exposure to alcohol seems to affect the cognitive area more significantly. Problems with concept formation, problem solving, and behavior inhibition may rise from this damage (Riley, 2002).

In addition to the reduced volume and displacement of specific areas of the brain, another effect of prenatal exposure to alcohol seems to be a greater proportion of gray matter and a smaller proportion of white matter in the brain. It is suggested that this damage leads to slower communication abilities. Also, damage in the area of the frontal lobes is implicated in problems with executive function and problem solving (Mattson et al., n.d.; Riley, 2002).

These data about physiological brain damage have been replicated in animal studies, which proves that it is only the effect of prenatal exposure to alcohol that is causing the damage, and not other factors such as abuse, neglect, or multiple foster placements (Riley, 2002). Riley also emphasized that this imaging research has found the brains of children with FAE to be physiologically more similar to the brains of children with FAS than they are to the brains of unaffected children. Functionally, few qualitative differences have been found between individuals with FAE and those with FAS, suggesting that there are few real-life differences between the learning and behavior of the two groups, despite a different diagnosis (Mattson et al., n.d.). Therefore, it is important that FAS should not necessarily be considered to be more severe than FAE, because there is often little difference between the cognitive and behavioral characteristics of individuals with these two

conditions (Burgess & Streissguth, 1992; Malbin, 1999; Mattson et al., n.d.; Riley, 2002). A student with FAE may not look disabled, but may struggle with the same cognitive or behavioral weaknesses as a student who qualifies for special help because of physical manifestations of FAS (Burgess & Streissguth; see also Mattson, Riley, Gramling, Delis, & Jones, 1998).

In addition to neurological damage, facial morphology, and impaired growth, several important chemical, endocrine, and immunological functions of the fetal brain can also be affected by prenatal exposure to alcohol (Weinberg, 1997). Other physical abnormalities which may point to the effect of a mother's alcohol consumption during pregnancy may be seen in the ears, eyes, mouth, heart, liver, skeletal system, and urogenital systems. Their impact upon the child can be significant. It is crucial that significant prenatal exposure to alcohol be confirmed because these associated abnormalities may also result from factors other than alcohol consumption during pregnancy (Hay, 1999; LaDue et al., 1999; Lasser, 1999; Morse, 2000).

Of the many kinds of damage caused by prenatal exposure to alcohol, problems resulting from central nervous system changes have the greatest potential to affect a growing child (Morse, 2000). Extreme irritability and restlessness seen in infancy may present as hyperactivity and sleep problems in childhood and adolescence. Learning disabilities, slow language processing, memory deficits, intellectual limitations, perseveration, inappropriate social behavior, and fine and gross motor abnormalities significantly affect the social and academic success of a child with FAS or FAE. Faced with feeling inadequate because of the many motor, academic, and social challenges resulting from their prenatal exposure to alcohol, people with FAS/E are at high risk for low self-esteem (Caldwell, 1993; Hinde, 1993; Lasser, 1999; Lutke, 1993;). To further complicate the picture, Morse described the variability in the performance of individuals with FAS/E, with them often performing a particular task successfully one day but being unable to complete it the next (see also Olson et al., 1997; Weinberg, 1997).

There are no biochemical tests (Morse, 1993) or statistical testing measures (Burgess and Streissguth, 1992) that can definitively diagnose FAS or FAE. However, many researchers now

recommend routinely collecting information on possible prenatal exposure to alcohol when any child displays cognitive impairment of unknown etiology (Mattson et al., 1998; Weinberg, 1997). To help identify individuals who may have FAS/E, questionnaires have been developed, such as the FASNET Assessment Tool for Children and the FASNET Assessment tool for Adults (see Hales, D. & G., 2000), and the Fetal Alcohol Behavior Scale designed by Streissguth et al (1996) for use in their study on secondary disabilities in this population. Questionnaires such as these provide a non-medical means of starting the process of identification or diagnosis of FAS/E, and may provide useful information for a physician if it is determined that medical evaluation is appropriate (LaDue et al., 1999).

Psycho-educational testing is an essential tool in assessment, providing measurements of a person's functional capabilities, and identification of her learning strengths and weaknesses. It is particularly important to include tests of adaptive behavior in assessment, because often individuals with FAS/E have poor understanding of social situations that is not expected when considering only their levels of intelligence (Williams, 1999). Current clinical research suggests that individuals who have had prenatal exposure to alcohol tend to have impairments in both cognition-based and emotion-based executive functioning (Kodituwakku, Kalberg, & May, n.d.). Given the importance of executive or cognitive functioning in the process of daily planning, guiding, predicting, setting goals, and decision-making, it is critical when assessing an individual with FAS/E to have an estimate of whether this functioning is effective or if it is impaired.

Also critical in an assessment is an awareness of the developmental level of the individual. Malbin (1999) described a typical scenario of an adolescent whose chronological age is 18, but his expressive language is at age 23, his social maturity is at age 12, his math skills are at age 8, his reading decoding is at age 14, and his reading comprehension is at age 9 (p. 26). She suggested that the caregiver "think younger" when dealing with inappropriate behavior in an individual with FAS/E, considering that the behavior may be based in a developmental age that is lower than chronological age. Awareness of problems with executive functioning or widely varied developmental capabilities and how these affect adaptive living skills are key to identifying the

supports that are necessary for success for each individual with FAS/E.

Most primary care professionals such as doctors, social workers, and educators have limited experience with patients with FAS/E (Hay, 1999; Morse, 2000; Turpin & Schmidt, 1999). Because much educational literature for physicians is based only on severe cases, doctors may overlook the condition when their patients are less severely affected. Many physicians say they are reluctant to diagnose FAS, particularly with diagnostic criteria being so imprecise. They have expressed concern that the diagnosis might label a child in school and in society, which may not be useful as long as there is little in theory and research that can suggest successful interventions (Morse, 1993). Because of the stigma this may place on the mother, the diagnosis of FAS/E may be problematic when she has not admitted to drinking during pregnancy and is attempting to provide support for a child (Alexander & Short, 1999; Lasser, 1999; Jones, 1999).

However, the label of FAS or FAE can be hugely important in the support that could be available to an individual (Hay, 1999; Morse, 2000). For example, it is critical that the distinction be made between ordinary ADHD and the attention problems that are often part of FAS/E because of the cognitive deficits that usually go along with the prenatal damage from alcohol. Similarly, access to funding for special services is likely to be less readily available for a child with non-specified behavior and learning problems than for a child with the diagnosis of FAS or even FAE. Further, an accurate diagnosis of FAS/E should result in more realistic expectations for an individual's behavior or academic accomplishments, and also more realistic expectations for parents, caregivers, educators, and other professionals who are trying to support her. Kellerman (2000) used the analogy of a baby bird, saying that as a parent she encouraged her son to "fly" while accepting the limitations imposed by his disability. She said this approach helped her son to stay "balanced between dreams and reality" (p. 359). Finally, and perhaps most importantly, the label of FAS/E should shift the perception that an individual **won't** follow rules or learn a task to the awareness that maybe she **can't** because of prenatal damage to her brain (Malbin, 1999; Morse).

Because of the complexity of problems in children and adults with FAS/E, community awareness

and sharing of information among various disciplines is necessary (Burgess, Lasswell, & Streissguth, 1992; Jones, 1999; Malbin, 1999; Schmidt & Turpin, 1996b; Weinberg, 1997). Streissguth et al (1996) stressed the importance of families, clients, and agencies working together when dealing with mental health, education, criminal justice, social work, alcohol and drugs, and life skills issues.

### *State of Research into FAS/E*

As noted above, heterogeneity in the profiles of students with FAS/E is one factor which makes it difficult to design rigorous research that is generalizable to other students (Weinberg, 1997). A second factor affecting the generalizability of research results is the difficulty in diagnosing FAS/E, which leads to inconsistency in classification. Third, the psycho-social complications of identifying drinking mothers influence availability and accuracy of perinatal histories (Alexander & Short, 1999; Lasser, 1999; Jones, 1999; Weinberg). A fourth factor to consider is the widely varying circumstances in which children with FAS/E grow up. Children with FAS/E who remain with their birth mothers are at high risk for abuse, neglect, and poverty, particularly if the mother is still abusing alcohol or other substances (Jones, 1999; Kleinfeld, 1993; Schmidt & Turpin, 1996a; Weinberg, 1997). If a child was living with any of those risks, it would be difficult to tell whether ongoing problems or problems on any particular day were a result of FAE, learning disabilities, poor nutrition, stress from home, or other factors. When these risk factors do occur they must be seen as having significant effects on a child, and thus as being significant variables in rigorous study. Because many other similarly damaged children are in homes that provide optimal care, nutrition and support, this is particularly important to consider when evaluating research.

The most important factors in the success of a student with FAS/E are the intervention and advocacy of the family, whether this family is biological or otherwise (Morse, 1993). Factors that appear to be protective against the development of secondary disabilities for an individual with FAS/E include living in a stable and nurturant home for over 72% of her life, being diagnosed before the age of 6, not having been subjected to violence, and having basic needs met for at least

13% of her life. Secondary disabilities, those the child is not born with, could include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behavior, substance abuse problems, and problems with employment and living independently in adulthood (Streissguth et al., 1996).

Although their functioning is significantly affected by physical damage as a result of prenatal exposure to alcohol, people with FAS/E have many strengths, and it is important to celebrate these strengths and support the weaknesses (Kleinfeld, 2000b). Kleinfeld said she sees courage and inventiveness in the way many adolescents with FAS/E face the ups and downs of everyday life. Cindy is artistic, persistent, realistic about her limitations, and a compassionate art teacher (Gere & Gere, 2000). Antone is honest, trustworthy, compassionate, and sensitive (Caldwell, 2000). Lutke stressed that her children all have conscience, empathy, and compassion “when circumstances allow them to understand the situation” (2000, p.19). She described two of her children as hard workers at their jobs, and another as artistic and active on her student council.

With the diagnostic categories of FAS/E first identified in the United States in 1973 (Morse, 2000), it is not surprising that definitive research has not yet been produced about successful interventions in such a new field of study. When other factors such as the imprecise nature of diagnosis (Weinberg, 1997), the heterogeneity and variability of the symptoms (Olson et al., 1997), and the extreme differences in living circumstances (Kleinfeld, 1993; Weinberg, 1997) are also considered, it is even more understandable that rigorous intervention studies with generalizable results have not been forthcoming.

Awareness of the neurological basis for learning and behavior problems in individuals with FAS/E is essential (Malbin, 1999; Morse, 2000), even though support of these individuals is largely educational. Early intervention and support are critical factors in the learning and life success of children with FAS/E (Kleinfeld, 2000; Morse).

## B. Learning Disabilities

### *Definition and Diagnosis or Identification*

The definition of learning disabilities (LD) is no more precise and no more easily operationalized than the definitions of Fetal Alcohol Syndrome or Fetal Alcohol Effect. Stanovich (1993) noted that different definitions serve different purposes, whether for research, delivery of service, or advocacy work. Because diagnostic criteria differ, so do prevalence rates, ranging from 2.4% in one part of the USA to 9.6% in another (Torgeson, 1991). Zigmond (1993) added that for each child identified with LD, there is a child with similar learning characteristics who is not identified.

A report from the National Joint Committee on Learning Disabilities (NJCLD) to the International Dyslexia Association (IDA) provided this definition, which was first published in 1990 following extensive multidisciplinary discussion:

Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical skills.

These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not, by themselves, constitute a learning disability.

Although learning disabilities may occur concomitantly with other disabilities (e.g., sensory impairment, mental retardation, serious emotional disturbance), or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences. (NJCLD, 1997, p. 29)

Dyslexia, difficulty with different forms of language, is the most prevalent type of LD and affects at least 80% of the LD population. Dyslexia is better verified by comparing reading age to chronological age or by comparing reading ability to academic performance in other areas, than by reference to previously acceptable discrepancy between IQ and reading levels (Lyon, 1995). Dickman (1996) claimed that identifying LD through a discrepancy between IQ and achievement identifies a result rather than a cause of LD. However, Stanovich (1993) claimed that measuring the discrepancy between listening comprehension and reading ability would be more useful to educators than measuring the discrepancy between IQ and reading levels. Further, he noted that statistical means are often used to identify students with LD without consideration of whether their learning has been adversely affected by other factors, such as sociocultural differences or lack of adequate instruction.

More than one ability-achievement discrepancy should be considered to increase validity when identifying a student as dyslexic, and it would be useful to apply regression equations to the difference between reading achievement and expected reading skills as predicted by intelligence testing (Pumphrey & Reason, 1992). Moats and Lyon (1993) added that although the IQ-reading levels discrepancy model is not desirable in classifying a student as dyslexic, it may be relevant in predicting useful instructional approaches or long-term outcomes.

According to Ellis (1993), dyslexia is more like obesity than like the measles. He said that you either have measles or you don't, but the diagnosis of obesity is more arbitrary, based on a continuum that is affected by various factors, such as bone structure, gender, age, and proportion of muscle to fat. Similarly, the diagnosis of dyslexia is based on a continuum that is affected by several factors, such as apparent intelligence, type of literacy experiences, support for literacy in the home and school, or social or emotional influences on the individual. This continuum was recognized and described by Orton as long ago as 1928 (Henry, 1998).

While scientists from various disciplines debate causes, definitions, and diagnostic criteria, parents, teachers and students cope daily with the manifestations of LD. The "unexpected" problems with

listening, speaking, reading, writing, reasoning, or mathematical skills as defined above by the NJCLD present only part of the complex picture of LD. Many other learning characteristics contribute to a common profile of students with LD, with some or all of these characteristics being consistent and persistent in each individual. In my tutor training workshops I illustrate the elements of this profile by drawing an umbrella, showing each of these characteristics as a drip from the umbrella. An individual with LD may display five of these characteristics, or nine, or 11, and they may be large drips or small ones, depending on the severity of the characteristic.

Most students with LD are poor at organizing (Hallahan, Kauffman, & Lloyd, 1996; Henry, 1998; Hornsby, 1984; Lyon, 1996), including steps of a task, or their ideas, time, or possessions. They may be slow to process language (Lahey & Bloom, 1994) and may have problems with word retrieval (Alexander, Gray, & Lyon, 1993; Catts, 1991b; German, 1994; Roth & Spekman, 1991), comprehension (Roth & Spekman, Pumphrey & Reason, 1992), abstract reasoning (Roth & Spekman; Bender, 1992), and understanding of idioms (Milosky, 1994; Roth & Spekman). Students with LD often have difficulty with metacognitive strategies (Bender; Wong, 1991), generalization of learning (Pumphrey & Reason; Swanson, 1993), and transitions between activities or environments (Bender; Hornsby). They may be distractible, with poor selective attention, and many have problems with handwriting, copying, and sequencing (Bender; Hornsby). Individuals with LD often demonstrate low self-concept (Bender), and are at risk for development of secondary problems such as depression, anxiety, and substance abuse (Pumphrey & Reason; Torgeson, 1994). To further confuse this complex picture, there is often variability within the individual (Pumphrey & Reason; Zigmond, 1993), with performance being successful one day, poor the next, and successful again the third day.

Given the heterogeneity among individuals and the difficulties in providing consistent definitions for identifying LD in general or dyslexia in particular, it is difficult to recommend one-size-fits-all interventions or to design research that has consistent and practical applications.

### *State of Research into Learning Disabilities*

As with FAS/E, definitive research into the area of LD is still fairly new, with this category of disability having been recognized in the United States only since 1968 (Lyon 1996). The phrase was coined by Kirk, who said that LD represented a discrepancy between an individual's achievement and her apparent capability to learn (Zigmond, 1993). Complicating the understanding of LD is the multidisciplinary nature of research in the field, which includes psychology, education, neurology, neuropsychology, psychiatry, speech-language pathology, and optometry, each with only a partial understanding of the complex manifestations of LD (Lyon). Inadequate definitions and classification systems fail to provide educators or researchers with the information they need to guide their practice, and guiding practice is presumably an important reason for having definitions and classifications (Moats & Lyon, 1993). Wong (1997) recommended stronger links between research and teaching practice as a means of encouraging practical research that is more likely to be used by teachers in the field.

Because some research has suggested that the educational approaches usually recommended for teaching students with LD are also useful with students that Torgeson (1991) described as "garden-variety poor readers" (p. 27), many educators question the necessity for identification of LD in a student. Wallach and Butler (1994) suggested that too much attention given to causes and categories of LD detracts from intervention time (see also Ellis, 1993; Pumphrey & Reason, 1992). Disagreement about classification or categorization for students with LD creates a dilemma similar to that faced by physicians described above who are reluctant to diagnose FAS because of the imprecise nature of the diagnosis as well as lack of research on appropriate interventions (Morse, 2000).

Just as the heterogeneity in students with FAS/E makes it difficult to provide a clear operational definition or generalizable research, so does the heterogeneity in students with LD. Lack of consistency in classification due to conflicting views of what qualifies as a learning disability leads to problems in identifying samples of similar subjects, and this variability in sample characteristics

limits rigorous replication of studies and generalization of results (Catts, 1991a; Lyon, 1996; Moats & Lyon, 1993; Pumphrey & Reason, 1992; Torgeson, 1994; Williams, 1988). Describing the difficulty of producing generalizable research about students with LD, Dickman (1993) compared studies using inconsistent classification of students with LD to studies that investigated the link between balls and broken windows without considering the difference between baseballs, basketballs, and golf balls. It is impossible to generalize across studies when this difference between types of balls is not considered, and it is impossible to predict how one ball will behave by studying a different kind of ball, he said. Similarly, generalization across studies is not advisable when the criteria for including students in the samples differ, and an intervention that is useful for students of one classification may not be useful for students who are identified by different characteristics.

“The nature of the problem dictates the nature of the intervention” (Moats, 1996; p. 88). Current neuropsychological research suggests that it may be more effective for students with LD to be taught to use their strengths to compensate for their weaknesses rather than to try to correct their weaknesses, although this suggestion is only tentative and more research in this area is required (Lyon, Newby, Recht, & Caldwell, 1991). Dickman (1993) added that diagnostic profiles are often complicated by co-morbidity of various kinds of learning problems along with intrinsic problems such as mental health disorders or extrinsic factors including socioeconomic status, school failure, and adoptive status. Identifying a student with only one condition when others co-occur gives an inaccurate picture of that child’s learning needs. “The fashion of sorting children into separate and distinct diagnostic pigeonholes is a bureaucratic convenience with no scientific or pedagogic merit,” he said (p. 221).

There is little rigorous, empirically-based research on effective interventions to use with students with LD, particularly students in high school (Ehren, 1994; Scruggs & Mastropieri, 1994). Researchers seldom have control in their investigations of interventions used with students with LD, whether in the classroom or a laboratory, and it is difficult to provide ideal research conditions (Pumphrey & Reason, 1992; Scruggs and Mastropieri). Englert (1996) claimed that traditional

quantitative research is inappropriate for investigating teaching of strategies because of the complexity of factors that affect the teaching-learning process, and that rich data from qualitative research is more useful. Pumphrey and Reason added, however, that research must not wait for perfect research conditions, but that “perfect is the enemy of the better. If you have an idea on how to alleviate SpLD [specific learning disabilities], try it out” (p. 125). Just be aware, they said, that claims of efficacy of an intervention may be undermined by less than ideal research conditions. Single-subject case studies using a pre-posttest, no-control-group design may provide valuable insights (Pumphrey & Reason), and begin to shed light on interventions for individuals and suggest directions for larger studies. Because developments in the field of LD in special education are more political and social than scientific (Torgeson, 1991) and more financial than educational (Pumphrey & Reason), it is difficult to carry out systematic research on effective interventions or to implement research recommendations.

Research in the fields of both FAS/E and LD is chronologically young, and beset by problems with imprecise definitions, unclear means of classification, unproven interventions, and heterogeneity of populations, making design and generalizability difficult.

### **C. Comparing FAS/E and Learning Disabilities**

The presence of Fetal Alcohol Syndrome or Fetal Alcohol Effect in an individual with LD complicates an already complex picture. The literature seems to distinguish the learning problems associated with FAS/E from those associated with LD (Burgess & Streissguth, 1992; Kleinfeld, 1993; Morse, 1993), presumably on the basis of the differing neurological etiologies of the learning problems. Perhaps it is because research in both areas is so chronologically young that the similarities and differences in their manifestation and in successful interventions do not appear to have been investigated. Although LD are mentioned in FAS/E literature as characteristic in individuals with FAS/E, there is little reference to research about LD, and there are few references to FAS/E in literature about LD (see Bender, 1992). To clarify the similarities and differences described in the literature, parallels in problems seen in students with FAS/E and in students with

LD are summarized in Table 1.

Table 1

Problems in Children with FAS/E and Children with Learning Disabilities

FAS/E	Learning Disabilities
	Diagnosis
Based on prenatal history and physical examination by trained physician.	Usually based on number of years behind peers in school reading and spelling, or discrepancy between IQ and performance, as measured by a psychologist.
	Physical manifestations
Growth retardation, central nervous system involvement, facial dysmorphology, physical anomalies in eyes, ears, mouth, heart, liver, skeletal, and urogenital systems. Hypo- or hypersensitive to touch.	Suggestion of higher incidence of left-handedness or uncertain hand preference, and autoimmune disorders such as arthritis, diabetes, or allergies.
	Familial tendencies
Not inherited, but may run in families because of familial pattern of alcohol abuse.	Thought to be inherited in most cases.
	Etiology
Neurological and physiological damage from prenatal alcohol exposure.	Possible neuro-anatomical differences.
Intrinsic to individual; not developmental.	Intrinsic to individual; not developmental.
	Learning problems
IQ range 20-130.	IQ range same as normal population.
Slow development of early language, including articulation.*	May have slow development of early language, including articulation.
Problems with sound/symbol relationships and phonological awareness.*	Problems with sound/symbol relationships and phonological awareness.
Problems with storage and retrieval of information.*	Problems with storage and retrieval of linguistic information.
Slow to process language.*	May be slow to process language.
Problems with spelling, reading, writing, and math.*	Problems with spelling, reading, writing, and sometimes math.

(table continues)

FAS/E	Learning Disabilities
Difficulty with abstract concepts.*	May have difficulty with abstract concepts.
May be able to decode but struggle with comprehension.*	May be able to decode but struggle with comprehension.
Poor cognitive processing, especially executive and strategic processes.*	May have poor cognitive processing.
Not known.	May have reversals in reading and writing.
Poor selective attention.*	May have difficulty with selective attention.
Impulsive; lack of awareness of consequences.*	May be impulsive; may show lack of awareness of consequences.
Problems organizing ideas, things, time.*	Problems organizing ideas, things, time.
Poor short and/or long term memory.*	Poor short and/or long term memory.
Poor sequencing, especially instructions.*	Poor sequencing, especially instructions.
Problems generalizing from one activity or situation to another.*	Problems generalizing from one activity or situation to another.
Transitions between activities are often difficult, and may cause child to withdraw or be disruptive.*	Transitions between activities may be difficult.
Poor communication skills, especially pragmatics of language.*	May have poor communication skills, including pragmatics of language.
Variability; marked difference between "good days" and "bad days."**	Variability; may show marked difference between "good days" and "bad days."
At risk for developing secondary problems such as depression, anxiety, substance abuse, trouble with the law.*	At risk for developing secondary problems such as depression, anxiety, substance abuse.

Note. \*Problems may be more severe than in students with learning disabilities.  
Sources: Ellis & Cramer, 1996; Hornsby, 1984; Lapadat, 1991; Malbin, 1999; Morse, 1993; Pumphrey & Reason, 1992; Smitherman, 1996; Streissguth et al., 1996; Vellutino, 1987; Zigmund, 1993.

It is essential for the parent, caregiver, or practitioner to understand what some of these behavior and learning problems look like in everyday life. Because they are usually more severe or puzzling in people with FAS/E than in people with LD, the following examples are drawn from anecdotal reports about people with FAS/E. Some behaviors may be rooted in physical problems that are not immediately obvious. For example, one mother tells of her son, who was very picky about what he ate. She thought it was his emotional immaturity that led him to actively avoid crisp or hard foods and choose those that were soft and mushy. However, his first visit to the dentist revealed that the enamel on his teeth had not formed completely, and eating almost anything was painful for him. Although this particular child may have been too young at the time, sometimes asking, "What's it like for you?" gives us answers about the basis for behavior or learning problems (Malbin, 1999).

There are many manifestations of problems with storage and retrieval of information, which can be related to an inability to generalize from one situation to another (Morse, 2000). In northern British Columbia, a mother of several alcohol-affected children uses one dramatic example to illustrate how difficult it can be for these individuals to transfer learning to different situations. She talks about teaching her daughter to tie her shoelaces, a complex sequence of operations for any six year-old, but especially for one who sometimes has problems with motor skills and memory. Pleased and surprised at the speed with which her daughter learned to tie her shoes, this mother went out and bought a pair of brightly-colored laces as celebration of the child's success. To the dismay of both mother and daughter, she was unable to apply her new skill to the colorful laces. To her, it was an entirely different task from tying the old white ones. If she has problems transferring her learning from white laces to bright ones, imagine how hard it is for her to transfer learning from home situations, to school, to Grandma's, to the doctor's office, and to the public swimming pool, or from books to real life.

An individual who is slow to process language needs instructions given succinctly in small increments, and probably would benefit from "think time" before responding to an instruction (Lutke, 1993). During a math lesson, a young boy said to his teacher, "Shut up and talk to me." He was so overwhelmed by the words of the lesson that he was unable to pay attention to the

message (Murphy, 1993, p. 198). This child was also easily overwhelmed by noises in his environment, and often coped with lively class activities by putting his fingers in his ears to reduce the stimulation to a more manageable level for himself. Adults who care for individuals with FAS/E learn to watch for cues about what is affecting their learning and their behavior, in order to be able to support them more effectively.

Difficulty with abstract concepts such as time, ownership, anger, or humor may look like willful disobedience (Malbin, 1999; Morse, 2000). Making the abstract concrete can be helpful in many situations. For example, time is an abstract concept that is a minefield for people with FAS/E. Richard Laplante was a worker in a residential facility in British Columbia, and his adult client with FAS had problems understanding the passage of time. To make it easier for the client to understand that 4 a.m. is time for sleep and not activity, whether he is awake then or not, Laplante developed a linear clock (Kleinfeld, 2000a). One little girl in northern BC was always in trouble at school because she liked to go through everyone's lunch boxes and take what she wanted. Numerous attempts at stopping this "stealing" had been unsuccessful. Possession is an abstract concept, and telling her what **not** to do didn't work, so the teacher decided to tell her what she **should** do. He made the situation more concrete by giving her a box in which to store her lunch and other possessions, and teaching her that she could touch things only in her box. That box moved with her to each classroom, and reduced the problem significantly. Both of these examples illustrate how much more helpful it is to tell a person with FAS/E what she should do ("Hang your coat up.") rather than what she shouldn't do ("Don't leave your coat on the floor.").

Poor cognitive processing manifests in many different ways. Problem solving, predicting, or thinking about consequences are related to cognitive processing (Morse, 2000). Deborah Evensen, an educator in Alaska, tells the story about a girl going sledding with her father on a hill where the road ran parallel to the sled run, then crossed the run at the foot of the hill. The girl was at the top of the hill, and at the bottom, her father waved and pointed to let her know that a truck was coming down the road beside the sled run. She waved back to let him know that she saw the truck, got on her sled, came down the hill – and slid under the truck and out the other side. Her

father was breathless with shock, and asked her if she hadn't seen the truck coming. She had, she said, but "I didn't know it was going to go there." If this child could not predict that a truck coming down the road was going to follow the road across the bottom of her sledding track, how could she predict the hundreds of events that happen in her life every day? What will happen if she goes out in the cold without a jacket? Or if she plays instead of eating lunch at lunch time? Or if she spends her monthly allowance or disability cheque during the first week? Or if she has sex without protection? Understanding this inability to predict, even when an individual has experienced something time and time again in daily life, is key to understanding what may seem like willful disobedience in people with FAS/E.

Transitions or changes are usually very problematic for people with FAS/E (Warner, 1999). This might be as simple as having the same seat on the bus every day, and feeling disoriented or out of control when this does not happen. A father tells about the time he rearranged the family living room while his son was at school. When the boy arrived home from school, he was confused and frightened by the changes. The same furniture was there, the same television, the same toy box, the same carpet and drapes – but to him, it was like walking into someone else's home and being lost. A similar feeling of disorientation may occur if a child returns to his classroom to find that his creative teacher has regrouped the desks, hung all new art work on the walls, and moved her workspace to a different corner. Without guidance through changes such as these, people with FAS/E often act out or withdraw because they find it difficult to adapt quickly. Similarly, transitions between activities are usually more successful if the individual has been prepared beforehand, by some form of explanation, demonstration, or notification by a teacher, parent, or other caregiver.

Communication skills of people with FAS/E are often deceiving, and Lasser (1999) claims that language disabilities are the most pervasive of the neurological effects of FAS/E. Usually the expressive language of people with FAS/E is superior to their receptive language, and they sound more knowledgeable than they really are (LaDue et al., 1999; Lasser; Malbin, 1999; Ten Eyck, 2000). Their pragmatic use of language is often not as effective as it might appear (see Lapadat, 1991). There may be gaps in their understanding that are masked by their level of conversation.

One young mother with FAE was being supported by a social services organization in learning to live independently and to care for her infant. This articulate woman could stand in a grocery store and in her head, calculate which of four cake mixes was the best buy per ounce. Based on her demonstration of capable behaviors such as this, the assumption was that she understood fairly complex details. However, when her baby was given a prescription for an ear infection with a dosage of three times a day, she gave the baby the medication three times in the first morning. She did not understand how the dosage should have been given, and had no idea how dangerous this was for the baby. A guiding principle when working with people with FAS/E is that you assume nothing, and take steps to clarify important instructions and provide support to ensure that they are followed.

Variability in performance in a person with FAS/E is confusing and frustrating for both the individual and for those around her. On a good day, Jane might be able to sit quietly in class and work effectively. But the next day, or even later that same day, she may be agitated, hyperactive, or even withdraw totally, particularly if she is hungry, excited, upset, or tired. Fatigue or hunger are factors often implicated in breakdown of learning or behavior (Malbin 1999). Picture the web described in the opening paragraph of this report (Kleinfeld 2000a). A person with FAS/E struggles all day, every day, to succeed with a brain that sometimes works and sometimes doesn't, and that is exhausting. An eight year-old may need a nap after lunch, or at least a quiet respite, in order to gather up enough energy to complete an afternoon at school. It is not unusual for children to need a snack or a sleep when they get home from school in order for them to be able to cope with dinner and evening activities. For an adult, part-time work may be all she can handle. Lutke (2000) described how her 21 year-old daughter Karen is most successful when she works 15 to 20 hours a week. When she works more than that, she develops migraine headaches. For her, paying attention, thinking, processing, and remembering all the details involved in her job consume so much energy that she can not do her job effectively if she works longer hours.

When I first recognized the parallels illustrated in Table 1, I wondered if the approach to teaching language that is effective for teaching most of my students with LD would also be effective for

students with FAS/E. Johnson (1999) has begun to address the question of whether similar symptoms of learning problems in students with FAS/E and with LD would respond to similar interventions.

## **IV** Teaching Students with FAS/E or Learning Disabilities

### **A. General Recommendations**

Students with FAS/E and students with LD are both heterogeneous groups, with inter-student and intra-student differences. However, the similar symptoms listed in Table 1 are reflected in similar general recommendations in the literature for working with both groups. These recommendations are summarized in Table 2 (found on the following page).

Table 2

Recommended Interventions for Students with FAS/E and Students with Learning Disabilities

FAS/E	Learning Disabilities
Structure in environment, routines, etc.*	Structure in environment, routines, etc.
Consistency in rules, environment, communication.*	Consistency in rules, environment.
Brevity in communication; make it as concrete as possible.*	Brevity in communication. May benefit from concrete presentation.
Variety in communication, using visual and auditory input, singing, and demonstration.*	Variety in communication, using visual and auditory input, singing, and demonstration.
Repetition and practice to overlearning.*	Repetition and practice to overlearning.
Multisensory teaching and reinforcement.*	Multisensory teaching and reinforcement.
Teach to the skill level and need of each student.*	Teach to the skill level and need of each student.
Adapt environment to minimize distractions.*	May be necessary to adapt environment to minimize distractions.
Immediate constructive feedback on successes and errors.*	Immediate constructive feedback on successes and errors.
Teaching reading: conflicting anecdotal reports of progress and of problems with both whole language and with explicit instruction in sound-symbol relationships.	Teaching reading: research recommends explicit instruction in sound/symbol relationships along with connected reading, meaning, and other language instruction.
Not known.	Integrate teaching of reading, writing, and spelling.
Not known.	Writing helps to improve reading.

Note. \*More important for students with FAS/E than for students with LD.

Sources: Adams, 1990; Gere, 1993; Hallahan et al., 1996; Henry, 1998; Hornsby, 1984; Lahey & Bloom, 1994; Lutke, 1993; Malbin, 1999; Morse, 1993; Tanner-Halverson, 1993.

We need to try differently rather than harder when we teach people with FAS/E, because their learning and behavior problems are rooted in neurological damage (Malbin (1999). Lasser cautioned that “students with learning challenges cannot afford to have any time when their

teachers do not know, understand, or consider their special needs” (1999, p. 41). She commented that some teachers prefer to begin a school year uninfluenced by records from past years. However, she stressed that when a teacher has expectations of a student that the child is unable to meet because of the physical handicap of FAS/E, the student’s frustration and damaged self-esteem can lead to behavior problems that might have been minimized if expectations had been more appropriate.

The literature gives five consistent guiding principles for intervention with students who have FAS/E. These were summarized by Tanner-Halverson (1993) as structure, consistency, brevity, variety, and persistence (see also Lasser, 1999). Describing the need for structure, Lutke (1993) explained, “Structure creates the form that holds us together, like the pail around a bucket of sand. Alcohol-affected children do not have internal structures to hold themselves together. In effect, they are the sand, and we must attempt to be the pail” (p. 75). Similarly, Malbin emphasized that because Fetal Alcohol Syndrome and Effect (FAS/E) are physical handicaps, modifications to environment should be made for FAS/E as they would for any other physical handicap. She said this could include modifications to attitudes, perceptions, physical layout, sensory stimuli, timelines, expectations, and processes, suggesting that these modifications could support greater student success. Lutke agreed, recommending structure in environment, routine, rules, and possessions. For students with distractibility or problems with attention, this structure and modification of environment often makes the difference between successful learning and acting out or shutting down in reaction to overstimulation (Malbin, 1999). Structure may also reduce the cognitive load required by decision-making, which is often difficult for people who have a problem with executive functioning as a result of prenatal exposure to alcohol (Kodituwakku et al., n.d.)

Structure is also important for students with LD (Hallahan et al., 1996; Lyon, 1996), even though they do not usually require the degree of structure that is often necessary for students with FAS/E. Students with LD tend to struggle with organization, whether of their personal effects, their homework, their time, or their ideas, and they usually benefit from direct instruction in and practice of skills to improve their organization in all areas (Henry, 1998). Environmental considerations

such as reducing distracting sights and sounds, seating at the front of the room near the teacher, or maintaining consistency in location of classroom supplies can be helpful to students with LD (Hornsby, 1984).

In effect, consistency is a form of structure, ensuring that rules and routines are established and reinforced the same way every time. Children with FAS/E do not adapt easily to change, and inconsistency causes change, which is stressful to them (Lutke, 1993). Morse (1993) agreed, suggesting that consistency would help them to focus on their learning. Both students and teachers benefit when the student “can rely on a ritual rather than internal organization” (Soby, 1994, p. 86). Co-operation between home and school, so that the same key phrases or strategies are used in both places, is a strong support for children with FAS/E (Warner, 1999). When change in rules or routine is necessary, children with FAS/E should be prepared in advance in order to facilitate a smoother transition (Tanner-Halvorsen, 1993; Warner).

Similarly, children with LD benefit from consistency in scheduling, in recording homework assignments, or even in the people they interact with (Bender, 1992; Hornsby, 1984). Changes in routines, rules, or teaching staff tend to be disturbing for children with LD, as they are for children with FAS/E. Children with LD usually benefit from help with transitions, such as reminders that there are five minutes left before recess, or that this afternoon Mrs. Brown will be away but Mr. Jones will be taking care of the class.

Addressing the need for brevity when communicating with children with FAS/E, Lutke (1993) claimed, “The more you talk, the less likely they are to grasp the point” (p. 85). Sentences should be short, precise, and concrete. She said that too many stimuli, whether verbal, visual, or environmental, seem to overwhelm these children and make it more difficult for them to sort out the information they need. Malbin (1999) concurred, adding that slow cognitive pace may be based in slow processing of auditory or visual stimuli or slow production of expressive language (see also Weinberg, 1997). This slow cognitive pace means that children with FAS/E may need longer to process information than other children. If they are not allowed this time they may become

overloaded and be unable to cope with the learning or communication task, which they might be capable of performing if they are given the time they need. They may react to stimulus overload by withdrawing or by acting out with disruptive behaviors (Malbin). In the midst of a lengthy list of instructions, one young man told his mother, "Mom, I can't hear anymore. That's enough words." His mother said that she learned that if she kept talking, he would shut down because he could not absorb any more information at that point. Her strategy was to try to be more brief, but if that was not possible, to come back to the subject at another time (Canney, 2000. p. 51).

Slow language processing is also a problem for many students with LD. They need time to think about an instruction, or to process the language in a question before they can begin to think about the answer (Lahey & Bloom, 1994). Many struggle with word retrieval, which makes it difficult for them to answer quickly, even when they know the content of what they want to say (Catts, 1991a; German, 1994; Roth & Spekman, 1991). Note-taking from a lecture is difficult for students who process language slowly, and they are often unable to summarize an idea and write it down before the teacher has gone on to another topic (Hornsby, 1984; Lahey & Bloom). Sharing notes with a selected classmate or being provided with a copy of the teacher's notes can be useful accommodations for these students. Taped lectures are another possible strategy, but in my experience, most students find re-listening to a whole lecture too time-consuming for study purposes.

Variety in communication with children with FAS/E can be accomplished by incorporating visual representations such as picture labels, or singing, physical demonstrations, exaggerated vocal variety, and exaggerated expressive body language (Lutke, 1993). Eye contact can help to ensure that the child knows that a particular instruction is for her and not for anyone else in the room (Groves, 1993; Lutke, 1993; Murphy, 1993). For some children, it may even be necessary to give the rules to the class and to later name the child personally and give them again, as discovered by Lutke (2000) when her son was suspended from school for breaking a rule. After the offense, she read the rules to him one by one, putting his name in front of each rule. When she came to the one he had broken, he seemed surprised, and said to her and to his teacher, "I didn't know you meant

me.” (p. 34). It is important to be aware that children with FAS/E can often “talk the talk but not walk the walk,” perhaps being able to repeat an instruction or tell a peer what to do, but not being able to apply it to their own behaviors (Malbin, 1999). For this reason, they may need to be led through the steps of instructions for them to succeed, and they may need this in different settings so that they can begin to generalize. Because children with FAS/E tend to take communication literally, Lutke (1993) suggested avoiding idiomatic expressions such as “put a lid on it” (p. 85).

Similarly, variety in communication is important for students with LD, although they may not have the intellectual limitations or the depth of weaknesses of students with FAS/E. A consistent recommendation in the literature about LD is for a multisensory approach to teaching (Henry, 1998; Lyon et al., 1991; Pumphrey & Reason, 1992) and multisensory choice in student presentation of assignments as a means of accommodating students’ different strengths and weaknesses (Pumphrey & Reason). As for students with FAS/E, rhythm or singing are often useful learning tools, particularly for learning material such as the alphabet or mathematical facts by rote. Also like most children with FAS/E, many students with LD take communication literally, often missing the point of idiomatic expressions (Milosky, 1994; Roth & Spekman, 1991).

Persistence is essential in working with children affected by FAS/E (Kerns, Mateer, & Streissguth, 1997). Lutke (1993) described repetition in teaching routines for learning new skills in school and at home, including such basic tasks as dressing, bathing, making sandwiches, and doing chores. Chores and skills must be explained in simple language and demonstrated and practiced step-by-step, with immediate tactile and visual rewards for the accomplishment of each step (see also Phillpot, 1993). Learning is most effective when it is integrated with experience (Murphy, 1993). This experience should occur in a variety of situations because children with FAS/E have difficulty with generalization and memory, and for them, “every day is a new day -- every minute a new minute” (Soby, 1994, p. 93). For children with FAS/E who often lack the ability to conceptualize, comprehend, sort out, retain, and apply abstract information, it is usually necessary to provide repetition and concrete, visual representation of instructions, rules, concepts, and sequences (Kerns et al.; Lutke; Soby). Teachers should use a multisensory approach to teaching, using

visual, auditory, and tactile-kinesthetic input (Lasser, 1999; Malbin, 1999; Morse, 1993; Phillipot; Soby), activity-based teaching (Morse; Soby), and repetition to the point of overlearning (Malbin).

Multisensory reinforcement to the point of overlearning is also a crucial component of teaching most students with LD (Greene & Enfield, 1982; Hallahan et al., 1996; Henry, 1998; Pumphrey & Reason, 1992; Sheffield, 1991; Vellutino, 1987), usually to a lesser degree than for students with FAS/E. While the need for concrete representation of instructions or learning material may not be as critical for students with LD as it is for many students with FAS/E, concrete presentation can be effective for those students who struggle with abstract ideas. I have found manipulative materials to be useful for explaining abstract concepts such as affixes, sentence structure, spelling rules, or number place values to students who are otherwise puzzled by these concepts. For example, manipulating plastic letters to demonstrate the effect of adding an “e” to words like “fin” and “mat” is usually more effective than simply explaining and demonstrating with paper and pencil.

The general recommendations for structure, consistency, variety, brevity, and persistence in teaching students with FAS/E apply to teaching students with LD as well. The need for such support is usually greater for students with FAS/E than for students with LD, and this may be related to more serious neurological damage in students with FAS/E.

## **B. Teaching Reading, Spelling, and Writing**

Eighty per cent of students with LD have problems with language and reading (Ellis & Cramer, 1996). This statistic does not distinguish students with FAS/E from other students with learning difficulties, but presumably a similar percentage of students with FAS/E have problems with written language. The above general principles for teaching students with FAS/E and LD must be considered when teaching them written language, but it is also important to consider current research on teaching reading, writing, and spelling to students in general. Various approaches to teaching reading have been used in our schools in recent years, including whole word or meaning-based and code-emphasis approaches. Language experience approaches emphasize the

interdependence of oral and written language, utilizing beginning readers' memory and oral language skills as well as visual configuration of words and context clues. A socio-cultural process involving the student, teacher, and peers produces a vocabulary of sight words that are relevant to students' interests (Bos & Vaughn, 1994). The whole language approach focuses on students' construction of meaning, functional language that is relevant to individual students, the use of authentic literature, emphasis on the writing process, co-operative student work, and the importance of student motivation, enthusiasm, and interest. Most whole language teachers believe that students should not be taught reading skills in isolation using segmented texts and worksheets (Bergeron, 1990). On the other hand, code-emphasis instruction, whether analytic or synthetic, emphasizes explicit teaching of reading skills such as segmenting and sound-symbol relationships as part of a larger program of reading and writing (Adams, 1990).

In her 1990 review of current research on learning to read, Adams concluded that fluency and comprehension in reading English depend on thorough knowledge of sound-symbol relationships and spelling. Further, she found that most children do not learn these relationships unless they are explicitly taught. Lyon (1996) described the importance of a beginning reader's phonological awareness, of being able to distinguish the overlapping sounds in speech as discrete sounds which are represented by symbols in written language. Current research demonstrates conclusively that effective reading instruction includes explicit instruction in writing the symbols representing the sounds in speech, in addition to an emphasis on connected reading, meaning, and language instruction (Adams, 1997; Blachman, 1996; Chall 1997; Henry, 1998; Moats, 1996; Pumphrey & Reason, 1992; Stanovich, 1980; Vellutino & Scanlon, 1991). However, Chall (1991) made the distinction that phonology is the critical feature of teaching beginning reading, while language and meaning become more important as reading develops.

Is this approach to teaching reading also appropriate for students with FAS/E or LD? Adams (1997) maintained that structured explicit instruction in orthophonemic or sound-symbol relationships along with connected reading and direct teaching in other aspects of language were effective in teaching all but 1% to 3% of children to read. Further, she claimed that this approach

was particularly effective for students who were at risk for reading problems, although she did not directly address its usefulness for students with FAS/E. With reference to teaching students with LD, Adams' position has been supported by others in the field (Blachman, 1996; Chall, 1997; Greene & Enfield, 1982; North, 1992; Pumphrey & Reason, 1992; Sheffield, 1991; Vellutino, 1987), but these provided little reference to students with FAS/E.

Effective instruction both for students with FAS/E and for students with LD must include multisensory reinforcement (Henry, 1998; Morse, 1993; Philpott, 1993; Pumphrey & Reason) and repetition (Lutke, 1993; Malbin; Pressley & McCormick, 1995) with constructive feedback on errors (Lutke; Pressley & McCormick; Hallahan et al., 1996). Pumphrey and Reason contended that these approaches would be useful in teaching literacy to any student, but that teaching students with dyslexia differs in "the degree of structure, detail, assessment, systematic teaching, record-keeping, and overlearning that characterized the specialized approaches.... There is no quick fix, no magic method, no panacea" (p. 118) in working with students with LD. However, they cautioned that it is difficult to determine whether learning success results from direct instruction or from program content, suggesting that the combination may be more effective than each of its parts. To the critics who have called this approach boring and involving too much overlearning for the student, Pumphrey and Reason replied that it is effective, while less structured approaches have consistently failed to help students with dyslexia to become literate. The effectiveness of this approach for teaching students with FAS/E has not been thoroughly and rigorously investigated.

There is less literature describing effective approaches for teaching reading to students with FAS/E than for students with LD, and to date, it is anecdotal in nature. Referring to the debate about the teaching of reading as it relates specifically to children with FAS/E, Tanner-Halverson (1993) said that her school found that these students had difficulties with instruction in sound-symbol relationships and were more successful with what she called a whole language approach. She attributed this to students' problems with auditory processing, analysis, and synthesis, which she said are required by what she called the phonics approach. On the other hand, Philpott (1993) claimed that structured multisensory instruction in sound-symbol relationships was more effective

than a literature-based approach for her students with FAS/E. Gere (1993) commented that contextual prediction was her daughter Cindy's strength, while decoding as taught in the Distar Program was her weakness.

This debate brings up several questions. The first is whether what is helpful for one will be helpful for others. This must be asked for each student, given the heterogeneous profiles of students with FAS/E and with learning disabilities, as well as the inconsistent levels of performance often displayed by each student. The second question is whether to remediate or to compensate for a weakness, such as Cindy's weakness with decoding, as mentioned above. A third question concerns the quality of teaching used when an approach has been unsuccessful. An experienced teacher with domain-specific knowledge about the structure of language and related problem-solving skills (Mayer, 1987) is more likely to provide effective instruction than a teacher who does not have this knowledge, even when they are both presenting the same program.

Current research strongly supports direct instruction in phonemic awareness for reducing reading difficulties (see also Adams, 1990; Blachman, 1994; Moats, 1988). My professional preference in tutoring is to provide both remediation and compensatory techniques for my students' weaknesses, and I have found situations where after intensive but unsuccessful attempts at remediation I have decided that continued remediation is counterproductive. Difficulty in learning mathematical facts by rote is an example of a weakness that can be readily compensated for with use of a calculator (Lasser, 1999).

In my experience, reading instruction is most effective when it is responsive to the needs of the student as to whether or how much orthophonemic instruction is involved (see Alberta, 1997; Lasser, 1999). Pumphrey and Reason (1992) emphasized the importance of teaching to individual needs of students with LD, so that a student who appears to benefit more from a top-down approach would progress from general learning to specific, with word recognition skills following the reading of a story. On the other hand, a student who struggles with phonological awareness may need to strengthen specific decoding skills before progressing to reading and writing

sentences and stories. This responsive teaching is difficult to accomplish across a classroom but more feasible in a small group or tutoring situation, where the teacher or tutor has an opportunity to not only observe individual learning strengths and needs, but to respond to them as well (see Englert, 1996).

Practice with immediate constructive feedback helps the student to analyze and correct errors, which is more effective than practice with feedback that simply classifies answers as right or wrong (Hallahan et al., 1996; Pressley & McCormick, 1995). For example, immediate constructive feedback helps a student to correct her spelling errors rather than practice incorrect spelling (Gelzheiser & Clark, 1991). Lutke (1993) described the benefits of immediate feedback and rewards when teaching her children with FAS/E.

The course of a lesson plan changes when the teacher or tutor is able to respond immediately with constructive feedback, seeing a student error or confusion as what is often called a “teachable moment.” Many other factors call for adjustment of a responsive lesson plan, including what the student already knows, what she needs to know, whether her prior knowledge is sufficient to support the development of a new cognitive strategy, and whether she has the appropriate receptive or expressive language for effective communication of new learning (Englert, 1996). Given the variability in performance of students with FAS/E and students with LD, what the student knows or is capable of may change from day to day or hour to hour, so it is seldom possible to design a lesson plan ahead of time and follow it exactly.

Pumphrey and Reason (1992) discussed whether phonemic awareness was a prerequisite or a consequence of learning to read, and concluded that probably a reciprocal interaction existed. They suggested that as phonemic awareness increased, reading improved, and as reading was practiced and improved, phonemic awareness increased still more (see also Blachman, 1994; Kamhi, 1991; Stanovich, 1993; Wong, 1991). Because the learning of students with FAS/E has not been thoroughly investigated, it is not known if this reciprocal interaction is also typical for them.

In her review of the literature on beginning reading, Adams (1990) noted that an emphasis on writing activities consistently resulted in improvements in reading achievement. As children learn to write, they come to “the most important reading insights of all” (p. 103), that the purpose of writing is to communicate, and therefore the purpose of reading is to be a part of that communication. Further, she argued that both theory and research confirm the importance of integration of reading, writing, and spelling in productive education (see also Pumphrey & Reason, 1992). The importance of creative writing in this process was stressed as well (Greene & Enfield, 1982; Sheffield, 1991; Williams, 1991). Many teaching approaches, such as Slingerland, Project Read, Reading Mastery, the Spaulding Road to Reading, and Orton Gillingham include an emphasis on multisensory instruction, structure, phonetics, and direct teaching of reading, spelling, handwriting, and creative writing (Adams, 1990; Greene & Enfield, 1982; Pumphrey & Reason, 1992; Sheffield, 1991; Williams, 1991).

Research has demonstrated that teaching spelling is an effective component in teaching reading (Adams, 1990; Henry, 1998; Williams, 1991). Spelling instruction gives practice in analysis of the phonemes that make up words and exposure to the orthographic or visual representation of the words, both of which are essential to good reading (Adams, 1997; Williams, 1991). Spelling also gives multisensory practice involving motoric, auditory, and visual reinforcement (Pumphrey and Reason, 1992) to support automaticity in reading. Automaticity in reading feeds comprehension rather than competing with it (Adams, 1990). Teaching strategies for spelling is also useful in teaching writing (Adams, 1997). Englert (1996) claimed that students with LD need to understand that strategies are tools for learning and knowledge, and they need to be provided with guided practice across the curriculum for effective transfer of their skills.

Most students with learning disabilities struggle with writing. Problems with the mechanical aspects of spelling, grammar, and handwriting tend to interfere with the cognitive processes of organizing, coming up with ideas, using variety in vocabulary, and revising for the purposes of effective communication. Current research supports the process approach to teaching writing, which includes instruction in the recursive, non-linear process of planning, drafting, revising and

editing, emphasizes the social context of writing as communication, and requires responsive interaction between teacher and student as the text develops. In addition to process instruction, some teaching of basic skills such as grammar, spelling, and handwriting is also important for the development of good writing (Graham, Harris, MacArthur, & Schwartz, 1991; Kamhi & Catts, 1991; Stanovich, 1993; Wong, 1991).

It is important to note that none of the above suggestions for strategies for teaching students with FAS/E has been the subject of thorough rigorous research. I found little research literature discussing whether students with FAS/E are likely to be successful with these approaches, but I suspect that in some cases their success may be compromised by intellectual limitations as well as learning problems as a result of their prenatal exposure to alcohol.

Although research into teaching students with LD has been more extensive than for students with FAS/E, it has been beset by methodological problems as described above, and may not be sufficiently rigorous for generalizability of results. Many suggestions for interventions come from the anecdotal reports of practitioners and parents searching for effective teaching strategies for working with students affected by FAS/E or by LD. However, as Morse (1993) emphasized, the needs of children with FAS/E and their families demand that the development of learning and coping strategies should not wait for medical research to thoroughly identify and explain the neurological or physiological basis for these needs. Wong (1991) made a similar recommendation with reference to practice and research related to learning disabilities.

### **C. Secondary Disabilities**

Students with FAS/E are at risk for developing secondary disabilities such as mental illness, school problems, and trouble with the law (Streissguth et al., 1994), and to a lesser degree this is also true for students with LD (Dickman, 1996; Pumphrey & Reason, 1992; Torgeson, 1994). Because students with FAS/E (Malbin, 1999) and students with LD (Bender, 1992) frequently have problems reading social cues, they often benefit from instruction in appropriate social behavior and related

support to ensure healthy self-esteem (Cramer, 1996). Attention to life skills and self-esteem in individuals with LD is important to their quality of life (Moats, 1996). For students with FAS/E in particular, life skills instruction and support are important because of the extent and nature of their neurological damage (Alberta, 1997; Lutke, 2000).

Burgess and Streissguth (1992) actually discouraged producing a curriculum specifically for working with students with FAS/E, citing the dramatic variation of abilities of students. They said that instead, academic skills must be complemented by functional skills for these students, claiming that the greatest area of deficit for these students is in adaptive living skills. Teaching strategies should arise from the educational needs of each student, rather than from the diagnosis of FAS/E (Alberta, 1997). Kleinfeld (1993) noted that much research, such as early work by Streissguth, involved the most severely damaged children, including those still living with their birth parents in high risk conditions. However, many students with FAS/E have a much higher potential, particularly when they grow up in conditions that recognize, remediate, and accommodate their weaknesses (Kleinfeld; Malbin, 1999; Morse, 1993; Streissguth et al., 1996).

Morse claimed that the most important factors in determining the success of children with FAS/E are the intervention and advocacy provided by the family, whether that is the birth family or a foster or adoptive family. As reported above, environmental factors such as a stable nurturing home and safety from violence protect children with FAS/E from developing secondary disabilities and contribute to their academic and social success (Streissguth et al.).

Students with LD are also at risk for secondary problems such as low self-esteem, depression, social problems, and anxiety (Dickman, 1996; Lyon, 1996; Pumphrey & Reason, 1992; Torgeson, 1993), although their risk appears to be lower than that for students with FAS/E (see Burgess & Streissguth, 1992; Lutke, 1993; Streissguth et al., 1996).

“To wait until the experts have agreed on methods of diagnosis and effective means of intervention is to condemn many children to illiteracy” (Pumphrey & Reason, 1992, p. 90). The statistics quoted

above by Ellis and Cramer (1996) suggested the possibility that FAS/E and LD could often coexist in students, so this particular complexity of learning problems is a reality in teaching practice, making it an important issue to address.

# V

## Discussion and Recommendations

Fetal Alcohol Syndrome and Fetal Alcohol Effect are medical diagnoses (Morse, 2000), but support for individuals with these conditions is multidisciplinary because of their impact on learning and behavior (Alberta, 1997; LaDue et al., 1999; Lasser, 1999; Malbin, 1999). Although the initial focus for this study was on educational manifestations of learning and behavior problems in people with FAS/E, application of the principles for teaching can be practical in other fields as well.

Recognition that learning and behavior problems in people with FAS/E stem from neuropathology rather than psychopathology should support a shift from a focus on changing behaviors to supporting a physical handicapping condition (Malbin, 1999).

### A. Implications for Teaching Practice

The cause of learning disabilities is now assumed to have a neurological basis but the treatment is educational (Ellis & Cramer, 1996; Henry, 1998). This is even more true for FAS/E (Morse, 1993), and effective treatment requires teachers who are experts in domain-specific knowledge as well as problem-solving (see Mayer, 1987). As a tutor, trainer, and psychometrician, my focus in this study has been on the learning and behavior problems of individuals with FAS/E, as well as appropriate interventions and support. Recognition of the similarity of learning problems in individuals with Fetal Alcohol Syndrome or Effect and those with learning disabilities (see Table 1) prompted investigation of whether similar teaching strategies would be useful for individuals from both groups (see Table 2). A review of the literature supported multisensory, structured, direct instruction for students with Fetal Alcohol Syndrome or Effect (FAS/E) (Alberta, 1997; Lasser, 1999; Lutke, 1993) and for students with learning disabilities (LD) (Henry, 1998; Joshi, Dahlgren, & Boulware, 2002). Little research specifically discussed teaching reading, writing, and spelling to students with FAS/E, and anecdotal reports were inconclusive in that some supported the use of the whole language approach and others recommended code-emphasis instruction. However, Adams (1997) recommended explicit instruction in sound-symbol relationships as well as in connected reading,

meaning, and other aspects of language for teaching written language to all but 1% to 3% of beginning readers.

Johnson (1999) described the elaborate intertwining of teaching strategies that appeared even when the intended focus of teaching was simply on spelling or reading. If tutoring of a single student was this complex, how complex must be the teaching of this student in a classroom situation, where the teacher is responsible for managing and teaching 20 or 30 students with their myriad strengths, weaknesses, and behaviors? Recognizing this complexity, Stahl (1994) described good teachers of language arts as “flexible, eclectic pragmatists” (p. 140) who look for teaching strategies that work and then apply them flexibly as needed by different students and different classes. Teaching or tutoring students with LD is a complex, responsive process that must consider the individual learning needs of different students (Englert, 1996; Lasser, 1999). When teaching written language, decoding and encoding are only a start for working with students with FAS/E or LD. Strategies for writing, organization, memory, and comprehension (Henry, 1998), self-monitoring and metacognition (Wong, 1991), and self-advocacy (Swanson & Cooney, 1991) are also important.

Patience and respect for their students as individuals are important attributes for teachers working with students with FAS/E. It is crucial that teachers of students with FAS/E be aware of the effects of alcohol-related brain damage in their students (Alberta, 1997; Lasser, 1999; Malbin, 1999; Morse, 2000). Adaptation of environment, concrete representations of teaching, awareness of some students’ inability to generalize or predict, their need for structure and consistency, possible limitations in their communication, and behavioral manifestations of overstimulation must all be considered when teaching students with FAS/E. Because of the neurological damage they have suffered as a result of prenatal exposure to alcohol, many students with FAS/E would benefit significantly from small structured classes with minimal disruption in environment, routine, and staff (Lasser, 1999; Lutke, 1993; Malbin, 1999; Morse, 2000).

Greater public and professional awareness of the unique learning requirements of students with

FAS/E is essential so that families, educators, social workers, and other practitioners can advocate more effectively for appropriate support and intervention (Streissguth et al., 1996). The absence of physical manifestations of prenatal alcohol exposure does not eliminate the possibility of cognitive manifestations, and these cognitive problems may be as severe in an individual with FAE as in an individual with full FAS (Burgess & Streissguth, 1992; Malbin, 1999; Mattson et al., 1998). Given that learning problems may exist in a child who has no physical markers of prenatal exposure to alcohol, many researchers suggest that the possibility of FAS/E be considered for all children who have learning problems of unknown etiology (Lasser, 1999; Mattson et al.; Weinberg, 1997). It is particularly important that the neurological basis for learning and behavior problems associated with FAS/E be accepted at home, in school, and in the community (Lasser; Malbin). Recognition of the condition and appropriate support should be provided as early as possible to prevent the development of secondary problems such as depression, anxiety, school problems, employment problems, and trouble with the law (Malbin, 1999; Streissguth et al.).

## **B. Implications for Policy and for Practice in General**

The effects of FAS/E are pervasive in the individual, and significant in the community. Government policy needs to demonstrate a willingness to support the individual according to her needs, and thus a willingness to support the community that supports her and others with FAS/E.

Understanding the neurological basis of the manifestations of FAS/E shifts emphasis from behaviors to the structure and function of affected brains (Malbin, 1999; Riley, 2002). This shift in understanding impacts policy and practice at a fundamental level.

### Clear Definitions and Consistent Diagnostic Guidelines

Inconsistency in definitions or diagnostic criteria for FAS/E further complicate a picture that is already complicated enough (Kleinfeld, 2000; Morse, 2000; Weber, Floyd, Riley, & Snider, 2002). Clear, concise diagnostic criteria would provide physicians and other professionals with a consistent means of determining whether a patient has FAS or FAE. Rather than being reluctant to

label a patient when the diagnosis is unclear, a physician would feel more confident in making a diagnosis of FAS/E if there were consistent guidelines to support this decision (Morse, 1993). Once a child has a diagnosis, she could have access to early intervention services to deal with the physical, neurodevelopmental, neurobehavioral, and psychiatric manifestations of this “chronic, lifelong disabling condition” as well as access to lifelong support if necessary (Hay, 1999, p. 27).

### Funding Support as Affected by Complexity of Problems in People with FAS/E

Identification and diagnosis of FAS/E in an individual should involve professionals from many disciplines, such as medicine, education, social work, counseling, public health, psychology, and vocational planning (Jones, 1999). To be useful, diagnosis must demonstrate the abilities, estimated intellectual capacity, and adaptive living skills of an individual (Williams, 1999), as well as describe the limitations in executive function as they affect everyday planning and decision-making (Kodituwakku et al., n.d.). Malbin (1999) emphasized the uneven development of people with FAS/E, and pointed out that an individual’s developmental level may vary significantly from one ability to another. All of these factors must be considered when funding for support is being allocated, because their impact on the life skills of the individual are significant. IQ alone gives an incomplete picture of the capabilities of people with FAS/E, and basing funding decisions on IQ alone is not appropriate (see Williams, 1999).

### Public Awareness

Increased public and professional awareness of the pervasive influence of prenatal exposure to alcohol is a first crucial step towards supporting people with FAS/E, their families, and their communities (Morse, 2000; Weber et al., 2002). Part of this awareness should include emphasis on de-stigmatizing FAS/E, both for the affected individual and for the parent (Alexander & Short, 1999; Jones, 1999; Kleinfeld, 2000b). It seems that many public awareness promotions are run or instigated by a variety of non-profit groups whose mandates include care for mothers, children, students, people with intellectual limitations, people in trouble with the law, or people with mental

health issues, rather than by government agencies. For example, the a bylaw of City Council in Prince George, British Columbia has supported placement of posters about drinking during pregnancy in bar and restaurant washrooms, but the initiative for this bylaw came from the non-profit group "Healthiest Babies Possible" rather from city authorities.

### Training for Professionals and for Families

"Better diagnosis through training, increased awareness, and improved medical school curricula could benefit all affected children" (Morse, 2000). 74 percent of 234 pediatricians in a 1992 study recognized that specific training in this area would be useful to their practice (Morse). While Morse referred to training of physicians, basic curricula in many other professions should provide more thorough grounding in the field of FAS/E (Weber et al., 2002). This initial education should be followed up in the field for new practitioners in the areas of medicine, public health, mental health, education, social work, counseling, and the justice system, as well as for experienced workers who have had no access to such training. In a study conducted in British Columbia, Turpin (1996) found that fewer than 10 per cent of child protection workers could describe the main features of FAS/E, which points to the need for continuing education in their field.

Limited training may already exist, but practitioners may benefit from more active circulation of this training. For example, the Ministry of Education in British Columbia has produced a manual to guide teachers working with students with FAS/E (British Columbia, 1996). However, to my knowledge, dissemination of this publication and its information is by request only. It would be far more effective if a government publication such as this were accompanied by compulsory professional development workshops for all teachers and school administrators and counselors, with further training and more staff support available in locations where the incidence of FAS/E is particularly high. Needless to say, this training would be most useful if it could be backed with appropriate funding to carry out the recommendations (see Turpin & Schmidt, 1999). Although this funding may be costly in the short term, it would be more cost-effective in the long term because of

the value of early intervention and continued support as necessary throughout the life of an individual with FAS/E (Alberta, 1997; Kleinfeld, 2000b; Streissguth et al., 1996).

Each school in a district should have a Resource Kit for working with students with FAS/E. This kit could include information about the learning and behavior problems of students with FAS/E, teaching materials, reference lists, contact numbers for local resource people with experience in this field, and information about professional development opportunities in a particular school district (Lasser, 1999). A similar kit would be an appropriate form of support within any agency dealing with individuals with FAS/E, whether in social work, health care, mental health, vocational planning, or the justice system.

Better awareness and more training among professionals should lead to better training and support for families with children or adults with FAS/E. This support could improve the stability of families, resulting in fewer foster placements for children whether they are living with the birth mother or a foster family (Morse, 2000). Better support for families could also reduce the need for families to relinquish their affected adolescents or adult children to therapeutic group homes or the justice system in order to provide them with better access to services that can support and protect them effectively (Kleinfeld, 2000b; Streissguth et al., 1996).

#### Effective Prevention and Treatment for Women at Risk

Because the irreversible effects of FAS/E are preventable, prevention of drinking in pregnant women is critical, as is treatment for women who struggle with alcohol abuse (Weber et al., 2002). However, it is important to understand that supporting the pregnant woman is more complex than it would at first seem, involving family, friends, school, the workplace, and her whole community. Non-judgmental support is more likely to be successful, and often harm-reduction rather than abstinence is all that can be achieved (Alexander & Short, 1999). Poverty, unstable families, or abuse are often issues for women who drink, and women seldom drink alone. Therefore support of their living conditions and their partners must be part of the picture of prevention and treatment

(Alexander & Short, 1999; Turpin & Schmidt, 1999). Preventive programs are particularly important for individuals with FAS/E who are at risk for substance abuse themselves (Streissguth et al., 1994) and who may also have limited cognitive resources for preventing unwanted pregnancies (Johnson, 1999).

#### Provision of Appropriate Educational and Social Supports for People with FAS/E

Because of the difficulty of conducting generalizable research, our knowledge about appropriate teaching approaches and behavior supports for people with FAS/E is currently based largely on what Kleinfeld calls "wisdom of practice" (2000a). Although this knowledge is based on the experience of practitioners in the field rather than research, it provides a strong framework of principles for teaching and working with children and adults with FAS/E. With better training of professionals, as above, implementation of these principles should be part of "best practices" for all relevant professionals and should provide a nation-wide standard of care (see Weber et al., 2002).

#### Provision of Therapeutic Homes for People with FAS/E

Support and advocacy of the family is one of the most important factors in the success of individuals with FAS/E (Morse, 1993; Streissguth et al., 1996). However, at times the needs of the affected individual go beyond the capabilities of the family, and a therapeutic home is necessary for her protection or support (Kleinfeld, 2000b). Kleinfeld said that when she researched what would be a desirable group home for adolescents and adults with FAS/E, parents consistently described the same kind of facility. It should be small and function much like a family would, and it should be geographically close to the individual's family. It should provide the structure that she needs, and it should not be situated in an urban area where she has access to situations that are too difficult for her to handle successfully. It should include a variety of activities, and many of those activities should be productive, so that she feels useful. This ideal group home should not include peers who model behaviors that are inappropriate for her. It is key to understand that parents may at

times need to relinquish a child, adolescent, or adult in order that she have access to services that the family is unable to provide, but that the family should still be able to be involved if they wish.

### Potential Areas for Further Research

Despite the difficulty of obtaining generalizable results from research on FAS/E, further study in the field of education is important for treatment of individuals with this problem. One factor that interferes with the generalizability of research in this area is the inter- and intra-personal variability in learning characteristics of people with FAS/E. Inconsistent diagnoses or definitions provide further complications for this research (Johnson, 1999; Morse, 2000). Perfect conditions for studying effective teaching or behavioral approaches are very difficult to establish. However, even in the absence of these perfect conditions, repeated documentation of claims of effective interventions may provide a basis for implementing teaching and support strategies as well as for further research (Johnson; Morse, 1993; Pumphrey & Reason, 1992). The collective results of several such studies can demonstrate patterns that in turn provide hypotheses to be tested further. Longitudinal qualitative and quantitative studies of a large cohort of individual subjects over a number of years would be ideal. However, it is not feasible to expect to be able to control for variables such as subjects moving away, family crises, changes in professional support, or health problems (Johnson).

Also in the field of education, study of the development and support of self-esteem and of the prevention of secondary disabilities (Streissguth et al., 1996) could impact on case management of people with FAS/E. Further, it may be useful to extend research into co-morbid conditions such as attention deficit disorder, and into similarities between learning disabilities and FAS/E. Particularly as clinical research becomes more sophisticated in the area of neurological variations, this field is open for development of new insights (Riley, 2002; See Johnson & Lapadat, 2000).

Emerging scientific research into the neurological foundations of the learning and behavior problems of people with FAS/E is encouraging (see Riley, 2002). However, such research

currently deals with small numbers of subjects, and will be more useful as its results are replicated with more subjects in a variety of locations. This research should look at maternal and fetal susceptibility to prenatal exposure to alcohol from a clinical point of view, and this clinical work should also consider how the clinical findings are related to function in affected individuals (Weber et al., 2002).

Wide dissemination of the results of rigorous clinical research in this area has potential as a source of scientific and moral support for practitioners in the field. As this research more clearly demonstrates the neurological basis for the puzzling strengths and weaknesses in people with FAS/E, it will be more evident that the nature of appropriate treatment should be based on brain function rather than behaviors and traditional learning theory (Malbin, 1999). This shift in perception of appropriate treatment and support should affect policy and funding, as physical disability comes to be understood to be as the root of problem behaviors.

# VI

## Conclusion

The literature review for this study provided a concise picture of the similarities and differences between learning problems of students with FAS/E and students with LD, as well as a summary of the similarities and differences between recommendations for intervention and support for each group. The parallels between learning problems and teaching recommendations for the two groups indicate that students with FAS/E may benefit from being taught according to research recommendations for students with LD, but with particular consideration of the behavior and learning problems that result from neurological damage as a result of prenatal exposure to alcohol.

It is important for teachers and other professionals to consider the neurological basis for learning and behaviors in people with FAS/E. These students benefit from expert teaching in small structured classes, with consistency in routine and communication, as few distractions as possible, direct multisensory instruction with extensive reinforcement and practice, and modification of requirements for reading materials, assignments, and exams. Their performance and behavior are variable, and are often limited by impulsiveness, inability to predict consequences, and shallow communication skills. Because these limitations are based in neurological damage, teaching for these students must include environmental adaptations and realistic expectations, as well as support from other professionals in the fields of medicine, social work, and counseling. The key to this support is to treat FAS/E as a physical handicapping condition rather than a behavior problem. The appropriate support of individuals and their communities is critical.

## **About the Author**

Carol Johnson has been tutoring children and adults with learning disabilities or fetal alcohol spectrum disorder since 1987, and providing training for parents, tutors, teachers, and other professionals since 1992. She obtained her Bachelor of General Studies degree from Simon Fraser University in 1994, and her Master of Education degree from the University of Northern British Columbia in 1999. She has been working as a psychometrician since 2000. She has been active on the boards of Literacy BC, Project Literacy Prince George, and the Prince George Dyslexic Support Society, and is on the advisory board to the B. C. Branch of the International Dyslexia Association. She feels fortunate to be able to do a job she loves, make a difference in peoples' lives, and to be paid for doing it.

## References

- Adams, M.J. (1990). *Beginning to read: A summary*. Urbana-Champaign: University of Illinois Center for the Study of Reading.
- Adams, M.J. (1997). The great debate: Then and now. *Annals of Dyslexia*, 47, 265-276.
- Alberta (1997). *Teaching students with Fetal Alcohol Syndrome and possible prenatal alcohol-related effects*. Edmonton, AB: Ministry of Education.
- Alexander, D., Gray, D.B., & Lyon, G.R. (1993). Conclusions and future directions. In G.R. Lyon, D.B. Gray, J.F. Kavanagh, & N. Krasnegor (Eds.), *Better understanding learning disabilities: New views from research and their implications for education and public policies* (pp.343-350). Baltimore, MD: Paul H. Brookes.
- Alexander, J. & Short, P. (1999). The Role of the Community Health Nurse in Dealing with FAS/E. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 56-61). Halifax, NS: Fernwood Publishing.
- Bender, W.N. (1992). *Learning disabilities: Characteristics, identification, and teaching strategies*. Toronto, ON: Allyn and Bacon.
- Bergeron, B. (1990). What does the term whole language mean? Constructing a definition from the literature. *Journal of Reading Behavior*, 22 (4), 301-329.
- Blachman, B.A. (1994). Early literacy acquisition: The role of phonological awareness. In G.P. Wallach and K.G. Butler (Eds.). *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 253-274). Toronto, ON: Maxwell Macmillan Canada.
- Blachman, B.A. (1996). Preventing early reading failure. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. 65-70). Baltimore, MD: Paul H. Brookes.
- Bos, C.S. & Vaughn, S.(1994). *Strategies for teaching students with learning and behavior problems*. Toronto, ON: Allyn and Bacon.
- British Columbia (1996). *Teaching Students with Fetal Alcohol Syndrome/Effects: A resource guide for teachers*. Victoria, BC: Ministry of Education, Special Programs Branch.
- Burgess, D., Lasswell, S.L., & Streissguth, A.P. (1992). *Educating children prenatally exposed to alcohol and other drugs: Planning for Learning Project*. Seattle, WN: University of Washington.
- Burgess, D. & Streissguth, A.P. (1992). Fetal Alcohol Syndrome and Fetal Alcohol Effects: Principles for educators. *Phi Delta Kappan*, 74 (1), 24-30.

- Caldwell, S. (1993). Nurturing the delicate rose. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds! Experiences in educating children with Fetal Alcohol Syndrome* (pp. 97-130). University of Alaska Press.
- Caldwell, S. (2000). Fantastic Antone is growing up. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. xiii-xvi). Fairbanks: University of Alaska.
- Canney, M.L. (2000). Ryland's gift: How my son taught me to be a good mother. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 45-60). Fairbanks: University of Alaska.
- Catts, H.W. (1991a). Early identification of reading disabilities. *Topics in Language Disorders*, 12(1), 1-16.
- Catts, H.W. (1991b). Phonological processing deficits and reading disabilities. In A.G. Kamhi & H. W. Catts (Eds.), *Reading disabilities: A developmental language perspective* (pp.101-132). Toronto, ON: Allyn and Bacon.
- Chall, J. (1991). American reading instruction: science, art, and ideology. In W. Ellis (Ed.), *All language and the creation of literacy* (pp. 20-25). Baltimore, MD: The Orton Dyslexia Society.
- Chall, J. (1997). Are reading methods changing again? *Annals of Dyslexia*, 47, 257-263.
- Cramer, S.C. (1996). Looking to the future. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. 297-304). Baltimore, MD: Paul H. Brookes.
- Dickman, G.E. (1996). The link between learning disabilities and behavior. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. 215-228). Baltimore, MD: Paul H. Brookes.
- Ehren, B.J. (1994). New directions for meeting the academic needs of adolescents with language learning disabilities. In G.P. Wallach and K.G. Butler (Eds.), *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 393-417). Toronto, ON: Maxwell Macmillan Canada.
- Ellis, A.W. (1993). *Reading, writing, and dyslexia: A cognitive analysis*. Hove, UK: Lawrence Erlbaum.
- Ellis, W. & Cramer, S.C. (1996). Introduction. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. xxvii-xxxi). Baltimore, MD: Paul H. Brookes.
- Englert, C.S. (1996). Instructional issues in conducting intervention research at the elementary level. In S. Vaughn & C. Bos (Eds.), *Research issues in learning disabilities: Theory, methodology, assessment, and ethics* (pp.109-129). New York:

Springer-Verlag.

- Gelzheiser, L.M. & Clark, D.B. (1991). Early reading and instruction. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp. 261-281). San Diego, CA: Academic Press.
- Gere, A.R. (1993). Cindy's story. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds! Experiences in educating children with Fetal Alcohol Syndrome* (pp. 55-68). Fairbanks: University of Alaska Press.
- Gere, A. R. & Gere, C. (2000). *The Graduate: College for students with FAS/E*. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 61-84). Fairbanks: University of Alaska.
- German, D.J. (1994). Word finding difficulties in children and adolescents. In G.P. Wallach and K.G. Butler (Eds.), *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 323-347). Toronto, ON: Maxwell Macmillan Canada.
- Graham, S., Harris, K.R., MacArthur, C., & Schwartz, S. (1991). Writing Instruction. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp. 309-343). San Diego, CA: Academic Press.
- Greene, V.E. & Enfield, M.L. (1982). *Project Read reading guide: Phase 1, Volume 1*. Bloomington, MN: Bloomington Public Schools.
- Groves, P.G. (1993). Growing with FAS. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 37-54). University of Alaska Press.
- Hales, D.A. & G.S. (2000). Annotated bibliography of resources. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 375-398). Fairbanks: University of Alaska.
- Hallahan, D.P, Kauffman, J.M., & Lloyd, J.W. (1996). *Introduction to Learning Disabilities*. Toronto, ON: Allyn & Bacon.
- Hart, M.A. (1999). Support for First Nations to address Fetal Alcohol Syndrome and Effects. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 94-101). Halifax, NS: Fernwood Publishing
- Hay, M. (1999). A practical roadmap for the imperfect but practical-minded clinician. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 26-43). Halifax, NS: Fernwood Publishing.
- Henry, M.K. (1998). Structured, sequential, multisensory teaching: The Orton legacy. *Annals of Dyslexia*, 48, 3-26.

- Hinde, J. (1993). Early intervention for alcohol-affected children: Birth to age three. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds! Experiences in educating children with Fetal Alcohol Syndrome* (pp.131-148). University of Alaska Press.
- Hornsby, B. (1984). *Overcoming dyslexia: A straightforward guide for parents and teachers*. Scarborough, ON: Prentice-Hall Canada.
- Johnson, C.L. (1999). *An adolescent student with Fetal Alcohol Effect and learning disabilities: Tutoring in written language*. Unpublished Master's thesis, University of Northern British Columbia. Prince George, British Columbia, Canada.
- Johnson, C.L. (2000). *Less different than you would think: Teaching students with Fetal Alcohol Syndrome and students with Learning Disabilities*. Paper presented at the annual meeting of the Canadian Society for the Study of Education, Congress of the Social Sciences and Humanities, Edmonton, AB.
- Johnson, C. & Lapadat, J. (2000). Parallels between learning disabilities and Fetal Alcohol Syndrome/Effect: No need to reinvent the wheel. *Exceptionality Education Canada*, 10(3), 65-81.
- Jones, K. (1999). The Ecology of FAS/E: Developing an interdisciplinary approach to intervention with alcohol-affected children and their families. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 80-87). Halifax, NS: Fernwood Publishing.
- Joshi, R.M., Dahlgren, M, & Bouware-Gooden, R. (2002). Teaching Reading in an Inner City School through a multisensory teaching approach. *Annals of Dyslexia*, 52, 229-242.
- Kamhi, A.G. (1991). Causes and consequences of reading disabilities. In A.G. Kamhi and H.W. Catts (Eds.). *Reading disabilities: A developmental language perspective* (pp. 67-100). Needham Heights, MA: Allyn & Bacon.
- Kamhi, A.G., & Catts, H.W. (1991). Language and reading: Convergences, divergences, and development. In A.G. Kamhi and H.W. Catts (Eds.). *Reading disabilities: A developmental language perspective* (pp. 1-34). Needham Heights, MA: Allyn & Bacon.
- Kellerman, T. (2000). Broken beaks and wobbly wings. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 355-362). Fairbanks: University of Alaska.
- Kerns, K.A., Don, A., Mateer, C.A., & Streissguth, A.P. (1997). Cognitive deficits in nonretarded adults with Fetal Alcohol Syndrome. *Journal of Learning Disabilities*, 30 (6), 685-693.
- Kleinfeld, J. (1993). Introduction. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 1-20).

University of Alaska Press.

- Kleinfeld, J. (2000a). Introduction: The roller coaster ride of life with FAS/E. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 1-16). Fairbanks: University of Alaska.
- Kleinfeld, J. (2000b). Conclusion: What the wisdom of practice teaches us about FAS/E at adolescence and young adulthood. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 325-354). Fairbanks: University of Alaska.
- Kodituwakku, P.W., Kalberg, W., & May, P.A. (n.d.). *The effects of Prenatal Alcohol Exposure on Executive Functioning*. Retrieved September 3, 2002, from National Institutes of Health, National Institute on Alcohol Abuse and Alcoholism Web Site: <http://niaaa.nih.gov/publications/arh25-3/192-198.htm>
- Lapadat, J. (1991). Pragmatic language skills of students with language and/or learning disabilities: A quantitative synthesis. *Journal of Learning Disabilities, 24* (3), 147-158.
- LaDue, R.A., Schacht, R.M., Tanner-Halverson, P., & McGowan, M. (1999). *Fetal Alcohol Syndrome: A training manual to aid in vocational rehabilitation and other non-medical services*. Flagstaff, AZ: Northern Arizona University.
- Lahey, M. & Bloom, L. (1994). Variability and language learning disabilities. In G.P. Wallach and K.G. Butler (Eds.), *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 354-372). Toronto, ON: Maxwell Macmillan Canada.
- Lasser, P. (1999). *Challenges and opportunities: A handbook for teachers of students with special needs with a focus on FAS and pFAS*. Vancouver, BC: Vancouver School Board.
- Lindsay, A. & Preston, D. (1999). FAS and FAE in classrooms: Strategies for educators. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 94-101). Halifax: Fernwood Publishing.
- Lutke, J. (1993). Parental advocacy for alcohol-affected children. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 62-72). University of Alaska Press.
- Lutke, J. (2000). Works in progress: The meaning of success for individuals with FAS/E. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 19-44). Fairbanks: University of Alaska.
- Lyon, G.R. (1995). Toward a definition of dyslexia. *Annals of Dyslexia, 45*, 3-27.

- Lyon, G.R. (1996). The state of research. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. 3-61). Baltimore, MD: Paul H. Brookes.
- Lyon, G.R., Newby, R.E., Recht, D., & Caldwell, J. (1991). Neuropsychology and learning disabilities. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp. 376-407). San Diego, CA: Academic Press.
- Malbin, D.B. (1999). *Fetal Alcohol Syndrome and Fetal Alcohol Effects: Trying differently rather than harder*. Portland: FASCETS, Inc.
- Mattson, S.N., Riley, E.P., Gramling, L., Delis, D.C., & Jones, K.L. (1998). Neuropsychological comparison of alcohol-exposed children with or without physical features of Fetal Alcohol Syndrome. *Neuropsychology*, 12(1), 146-153.
- Mattson, S.N., Schoenfeld, A.M., & Riley, E.P. (n.d.). *Teratogenic effects of alcohol on brain and behavior*. Retrieved September 3, 2002, from National Institutes of Health, National Institute on Alcohol Abuse and Alcoholism: <http://www.niaaa.nih.gov/publications/arh25-3/185-191.htm>
- May, P. A. & Gossage, J.P. (n.d.). *Estimating the prevalence of Fetal Alcohol Syndrome: A Summary*. Retrieved September 3, 2002, from National Institutes of Health, National Institute on Alcohol Abuse and Alcoholism: <http://www.niaa.nih.gov/publications/arh25-3/159-167.htm>
- Mayer, R. E. (1987). *Educational psychology: A cognitive approach*. Toronto, ON: Little, Brown, and Company.
- Milosky, L.M. (1994). Non-literal language: Seeing the forest for the trees. In G.P. Wallach and K.G. Butler (Eds.). *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 275-303). Toronto, ON: Maxwell Macmillan Canada.
- Moats, L.C. (1988). The missing foundation in teacher education: Knowledge of the structure of written and spoken language. *Annals of Dyslexia*, 44, 81-102.
- Moats, L.C. & Lyon, G.R. (1993) Learning disabilities in the United States: Advocacy, science, and the future of the field. *Journal of Learning Disabilities*, 26(5), 282-294.
- Moats, L.C. (1996). Implementing effective instruction. In S.C. Cramer & W. Ellis (Eds.), *Learning disabilities: Lifelong issues* (pp. 87-94). Baltimore, MD: Paul H. Brookes.
- Morse, B.A. (1993). Information processing. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 23-36). University of Alaska Press.
- Morse, B.A.(2000). Diagnosis and thereafter: What we know now and where we are going. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up:*

- Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 301-324). Fairbanks: University of Alaska.
- Murphy, M. (1993). Shut up and talk to me. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 189-200). University of Alaska Press.
- National Joint Committee on Learning Disabilities (1997). Operationalizing the NJCLD definition of learning disabilities for ongoing assessment in schools. *Perspectives*, 23 (4), 29-31. Baltimore, MD: The International Dyslexia Association.
- North, M.E. (1992). The writing road to reading: From theory to practice. *Annals of Dyslexia*, 42, 110-123.
- Olson, H.C., Streissguth, A.P., Sampson, P.D., Barr, H.M., Bookstein, F.L., & Thiede, K. (1997). Association of prenatal alcohol exposure with behavioral and learning problems in early adolescence. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36 (9), 1187-1194.
- Phillipot, B. (1993). Setting up the Learning Center. In J. Kleinfeld & S. Wescott (Eds.), *Fantastic Antone Succeeds: Experiences with educating children with Fetal Alcohol Syndrome* (pp. 233-244). University of Alaska Press.
- Pressley, M. & McCormick, C.B. (1995). *Cognition, teaching and assessment*. New York: HarperCollins College Publishers.
- Pumphrey, P.D. & Reason, R. (1992). *Specific Learning Difficulties (dyslexia): Challenges and responses*. London, UK: Routledge.
- Riley, E.P. (2002). *Keynote Address*, Paper presented at Fetal Alcohol Syndrome Summit, Anchorage, Alaska.
- Robinson, G.C., Conry, J., & Conry, R. (1996). Clinical and community studies: Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. In G. Schmidt & J. Turpin (Eds.), *Fetal Alcohol Syndrome/Fetal Alcohol Effects: A resource manual* (pp. 12-18). Prince George, BC: University of Northern British Columbia.
- Roth, F.P. & Spekman, N.J. (1991). Higher-order language processes and reading disabilities. In A.G. Kamhi & H. W. Catts (Eds.), *Reading disabilities: A developmental language perspective* (pp. 159-198). Toronto, ON: Allyn and Bacon.
- Schmidt, G. & Turpin, J. (1996a). Introduction. In G. Schmidt & J. Turpin (Eds.), *Fetal Alcohol Syndrome/Fetal Alcohol Effects: A resource manual* (pp. 1-4). Prince George, BC: University of Northern British Columbia.
- Schmidt, G. & Turpin, J. (1996b). Towards a case management model with FAS/E children in northern and remote communities. In G. Schmidt & J. Turpin (Eds.), *Fetal*

- Alcohol Syndrome/Fetal Alcohol Effects: A resource manual* (pp. 52-60). Prince George, BC: University of Northern British Columbia.
- Scruggs, T.E. & Mastropieri, M.A. (1994) Issues in conducting intervention research: Secondary students. In S. Vaughn & C. Bos (Eds.), *Research issues in learning disabilities: Theory, methodology, assessment, and ethics* (pp. 130-145). New York: Springer-Verlag.
- Sheffield, B. (1991). The structured flexibility of Orton Gillingham. *Annals of Dyslexia*, 41, 41-54.
- Smitherman, C.H. (1996). The lasting impact of Fetal Alcohol Syndrome and Fetal Alcohol Effects on children and adolescents. In G. Schmidt & J. Turpin (Eds.), *Fetal Alcohol Syndrome/Fetal Alcohol Effects: A resource manual* (pp. 5-11). Prince George, BC: University of Northern British Columbia.
- Soby, J.M. (1994). *Prenatal exposure to drugs/alcohol: Characteristics and educational implications of fetal alcohol syndrome and cocaine/polydrug effects*. Springfield, IL: C.C. Thomas.
- Stahl, S. (1994). Is Whole Language "the real thing"? Advertisements and research in the debate on Whole Language. In C.B. Smith (Moderator), *Whole Language: The debate* (pp. 124-142). Bloomington, IN: EDINFO Press.
- Stanovich, K.E. (1980). Toward an interactive-compensatory model of individual differences in the development of reading fluency. *Reading Research Quarterly*, 1, 32-71.
- Stanovich, K.E. (1993). The construct validity of discrepancy definitions of reading disabilities. In G.R. Lyon, D.B. Gray, J.F. Kavanagh, & N. Krasnegor (Eds.), *Better understanding learning disabilities: New views from research and their implications for education and public policies* (pp. 273-307). Baltimore, MD: Paul H. Brookes.
- Streissguth, A.P., Barr, H.M., Kogan, J., & Bookstein, F.L. (1996). *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) (Final Report)*. Seattle: University of Washington School of Medicine, Dept. of Psychiatry and Behavioral Sciences.
- Swanson, H.L. (1993). Learning disabilities from the perspective of cognitive psychology. In G.R. Lyon, D.B. Gray, J.F. Kavanagh, & N. Krasnegor (Eds.), *Better understanding learning disabilities: New views from research and their implications for education and public policies* (pp. 199-298). Baltimore, MD: Paul H. Brookes.
- Swanson, H.L. & Cooney, J.B. (1991). Learning disabilities and memory. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp.104-129). San Diego, CA: Academic Press.
- Tanner-Halvorsen, P. (1993). Snagging the kite string. In J. Kleinfeld & S. Wescott

- (Eds.), *Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome* (pp. 210-222). University of Alaska Press.
- TenEyck, M. (2000). Living independently: A mother's tale. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 85-102). Fairbanks: University of Alaska.
- Torgeson, J. (1991). Learning disabilities: Historical and conceptual issues. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp. 3-37). San Diego, CA: Academic Press.
- Torgeson, J. (1994). Learning disabilities theory: Issues and advances. In S. Vaughn & C. Bos (Eds.), *Research issues in learning disabilities: Theory, methodology, assessment, and ethics* (pp. 3-21). New York: Springer-Verlag.
- Turpin, J. (1996). *Fetal Alcohol Syndrome/Fetal Alcohol Effects: What do Child Protection Workers Know?* Unpublished M.S.W. thesis, University of Northern British Columbia.
- Turpin, J. & Schmidt, G. (1999). Case management with FAS/E children in northern and remote communities. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 94-101). Halifax: Fernwood Publishing.
- Vellutino, F.R. (1987). Dyslexia. *Scientific American*, 256 (3), 34-41.
- Vellutino, F.R. & Scanlon, D.M. (1991). The effects of instructional bias on word identification. In L. Rieben & C. Perfetti (Eds.), *Learning to read: Basic research and its implications* (pp.189-203). Hillsdale, NJ: Lawrence Erlbaum Assoc.
- Wallach, G.P. & Butler, K.G. (1994). Creating communication, literacy, and academic success. In G.P. Wallach and K.G. Butler (Eds.), *Language learning disabilities in school-age children and adolescents: Some principles and applications* (pp. 2-26). Toronto, ON: Maxwell Macmillan Canada.
- Warner, K. (1999). Parenting Children with Fetal Alcohol Syndrome. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 14-25). Halifax: Fernwood Publishing.
- Weber, M.K., Floyd, R.L., Riley, E.P., & Snider, D.E. (2002). *National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect: Defining the national agenda for Fetal Alcohol Syndrome and other prenatal alcohol-related effects*. Retrieved April 4, 2003, from Centers for Disease Control Web Site:  
<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5114a2.htm>
- Weinberg, N.Z. (1997). Cognitive and behavioral deficits associated with parental alcohol use. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36 (9), 1177-1186.

- Williams, J.P. (1988). Educational treatments for dyslexia at the elementary and secondary levels. In W. Ellis (Ed.), *Intimacy with language: A forgotten basic in teacher education* (pp. 24-32). Baltimore, MD: The Orton Dyslexia Society.
- Williams, R. J. (1999). The role of psychological tests in FAS/E. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 44-55). Halifax: Fernwood Publishing.
- Wong, B.Y.L. (1991). The relevance of metacognition to learning disabilities. In B.Y.L. Wong (Ed.), *Learning about learning disabilities* (pp. 231-258). San Diego, CA: Academic Press.
- Zigmond, N. (1993). Learning disabilities from an educational perspective. In G.R. Lyon, D.B. Gray, J.F. Kavanagh, & N. Krasnegor (Eds.), *Better understanding learning disabilities: New views from research and their implications for education and public policies* (pp.251-272). Baltimore, MD: Paul H. Brookes.