

**Behavioral Self-Management: A Curriculum for
Those Affected by a Prenatal Exposure to Alcohol**

by

**Andre Lacabanne
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**A Thesis submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements of the Degree
Masters of Education**

**Faculty of Education
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Andre Lacabanne

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree**

of

MASTER OF EDUCATION

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Abstract

Fetal alcohol syndrome (FAS), a unique constellation of physical and intellectual impairments, occurs as a consequence of prenatal exposure to the teratogenic effects of alcohol. The connection between exposure of the fetus to alcohol and birth defects was confirmed by Lemoine (Lemoine, Harousseau, Borteyu, & Menuet, 1968) and Jones and Smith (Jones, Smith, Ulleland, & Streissguth, 1973). With confirmation of maternal alcohol consumption, diagnosis is organized around a triad of criteria: growth delay, particular cranio-facial dysmorphology, and evidence of central nervous system (CNS) damage. When dysmorphology is minimal or absent but evidence for CNS damage and growth delay is present, the term fetal alcohol effects (FAE) may be used. Intellectual decrements and social and response inhibition deficits frame the life experiences of those affected. Reaching a level of functional self-management necessary for employment and independence is difficult (Streissguth, 1997). To attain long-term goals such as employment and independence, it is essential to delay gratification and endure adversity (Skinner, 1971; Mischel, 1974; Kanfer, 1977). Drawing from various resources, a curriculum featuring both cognitive and behavioral strategies (Thoresen & Mahoney, 1974) was designed for the improvement of self-regulatory behavior of adolescents affected by prenatal alcohol exposure. It was proposed that long-term controlling behaviors which favor independence and employment can be developed using a structured curriculum of skill development in which delay of gratification and tolerance of adversity are employed to attain specified goals. The attainment of outcomes—and the experience of their benefits—was intended to be contingent on a capacity to

tolerate a measure of adversity and delay of gratification. In a single case study, using a 12-year-old male diagnosed with alcohol related neurological disorder (ARND), three goals were selected for development. Goal Attainment Scaling (Kiresuk, Smith, & Cardillo, 1994) was used to structure and interpret the intervention. The subject performed at or near the expected outcome. Further investigation into the efficacy of this approach is suggested.

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Introduction and Literature Review

The teratogenic effects of prenatal exposure to alcohol have now been well documented. The word teratogenesis—the resultant embryonic malformation due to contact with a causative agent—is derived from the Greek word *terato* which, in literal translation, means *to form a monster* (Webster, 1970). Throughout the ages, people have expressed an intuitive concern regarding the harmful effects of alcohol upon offspring. However, it was only late in the twentieth century that the damaging effects of alcohol upon the developing fetus were confirmed.

In 1968, Lemoine (Lemoine, Harousseau, Borteyru, & Menuet, 1968) had made note of a distinct pattern of dysmorphology (the study of patterns of malformation) in 127 cases of the children of alcoholic mothers. Somewhat later, in Seattle Washington, Ulleland studied a “failure to thrive” phenomenon in the offspring of alcoholic mothers whose infant children failed to improve in spite of adequate hospital care (Ulleland, Wennberg, Igo, & Smith, 1970). Ulleland et al. felt that there was a relationship between the mother’s alcoholism and their children’s failure to thrive symptoms. Dysmorphologists Jones and Smith (1973) made note of the striking similarities in Ulleland’s unrelated patients and, in the June 9, 1973 issue of *Lancet* magazine, presented the tentative conclusion that it was the mother’s consumption of alcohol during pregnancy that had led to the conditions observed in these children (Jones, Smith, Ulleland, & Streissguth, 1973). Although their work was published subsequent to Lemoine’s, it is Jones and Smith who are generally credited with having brought the attention of the scientific community to the constellation of distinctive physical and intellectual impairments

associated with maternal consumption of alcohol during pregnancy now known as fetal alcohol syndrome (FAS).

Although an entirely preventable condition, incidence of the syndrome has been estimated between 0.5 and 3.0 for every 1,000 live births, affecting people of all races and socioeconomic status (Institute of Medicine, 1996). The greatest incidence of the fetal alcohol syndrome has been found among Native Americans with rates of 1.33 to 10.0 per 1000 live births having been recorded for various groups (May, Hymbaug, Aase, & Samet, 1983). Some problems associated with presenting an accurate picture of incidence and trends in frequency include regional variations reflective of varying hospital protocols, differences in physician's practices in reporting the syndrome, and the increasing accuracy of reporting over time which would result in higher rates recorded when compared with earlier less accurate records (Cordero & Floyd, 1994).

In hindsight, the relationship between maternal alcohol consumption and consequent birth defects seems obvious. It is almost inconceivable that this connection should have eluded us for so long. Particular periods of history have been characterized by their liberal consumption of alcoholic beverage, most notably the Roman and Medieval time periods, and the people of the time should have been afforded the opportunity to observe firsthand the effects of alcohol on their offspring. Although credit is frequently given to the people of the ancient and medieval worlds for having knowledge of the adverse consequences to offspring due to maternal consumption of alcoholic beverage, Abel (1984) asserts that this was not the case. He maintains that in the numerous historic references to alcohol

consumption—descriptions of people's drinking behaviours and proscriptions regarding the consumption of alcoholic beverage no doubt coloured by the particular motive or virtue of the writers of the time—none of the conclusions arrived at ever point to the teratogenic effects of alcohol as we know them today. Abel (1984, p. 1) explains:

I believe that a critical examination of the evidence will show that nearly all the statements investing the ancient and medieval past with precognition of this disorder are wrong. Most are simply repetitions of what has been written before, thus perpetuating the error. In those instances when there does seem to be an awareness of "fetal alcohol effects" in the ancient and medieval world, the emphasis is almost entirely on the father. Moreover, these comments are not based on empirical evidence but are deductive—arising from alcohol's observable effects on sperm production and libido.

It was only toward the end of the nineteenth century that researchers were beginning to question a possible link between maternal alcohol consumption and "sickly and feeble-minded" children. Yet, in spite of a growing awareness of a problem, mid twentieth century dialogue on the topic still attempted to explain away any plausible connection through perpetuation of a notion that alcoholics came from "bad stock". Alcohol was not seen as a cause of problems, but rather it was thought that alcoholism was the consequence of a family's weak lineage (Haggard & Jellinek, 1942). As late as the mid-1960's, Ashley Montague (1965, p. 114) must have felt safe in writing:

It can now be stated categorically, after hundreds of studies covering many years, that no matter how great the amounts of alcohol taken by the mother—or by the father, for that matter—neither the germ cells nor the development of the child will be affected . . .

As to why the connection proved elusive to us for so long, Abel (1984, p. 2) says, "The answer, is that the evidence prior to Jones and Smith was far from convincing, and in some cases it was interpreted as showing that fetal damage was generally a good thing for mankind as a whole!"

The true history of fetal alcohol syndrome began with Lemoine (1968), Ulleland (1970), and Jones and Smith (1968) and their establishment of a connection between maternal alcohol consumption and birth defects. Subsequent to this discovery, a considerable body of knowledge has been compiled regarding the syndrome, including its etiology, the physical and cognitive impairments the syndrome can bring to those affected, and consequent outcomes regarding behaviour and life adjustment issues. We may draw from this body of knowledge as we work toward understanding the issues and developing meaningful interventions in this area.

Primary Features of the Syndrome

A fundamental element to complete a diagnosis of FAS is confirmation of maternal consumption of alcohol during pregnancy. Further, the diagnostic process is organized around a triad of criteria: prenatal and/or postnatal growth deficiency, a pattern of cranial-facial dysmorphologies peculiar to the syndrome, and evidence of central nervous system (CNS) damage (Jones, Smith, Ulleland, & Streissguth, 1973).

As Streissguth has noted, the postnatal growth deficiency is frequently accompanied by what is called a failure to thrive (cf. Landesman-Dwyer, Ragonzin, & Little, 1981)—feeding difficulties, weak suckling, and an irregular sleep pattern.

There is evidence to show that impairment of overall cell proliferation as a consequence of the prenatal alcohol insult may explain observed deficiencies in weight gain and growth (Abel, 1984).

As illustrated in Figure 1, salient features of cranial-facial dysmorphism include short palpebral fissures (eye slits), flattened midface, a short up-turned nose, and a smooth or long philtrum (the ridges which run between the nose and upper lip) (Majewski & Goecke, 1982). In addition, the lip line may be thin giving an appearance “. . . as though they were pursing their lips even when they were not smiling” (Streissguth, 1997, p. 3).

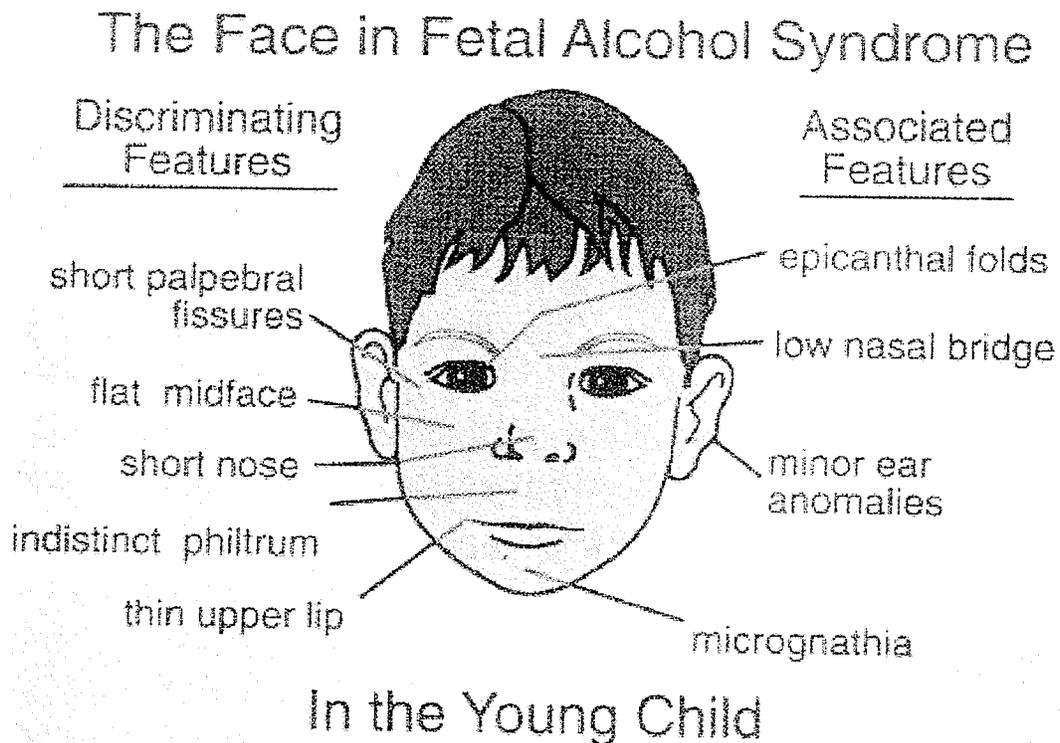


Figure 1. Diagram of FAS facial characteristics in young child. (From Streissguth & Little, 1994). Reprinted by permission.

Primary evidence of CNS damage includes microcephaly (lower than average head circumference) and neuropsychological symptoms, which may manifest around developmental stages (Majewski & Goecke, 1982; Streissguth, 1997). CNS impairments include "tremors, hyperactivity, fine or gross motor problems, attentional deficits, learning disabilities, intellectual or cognitive impairments, or seizures" (Streissguth, 1997; pp. 18-19).

As the study of FAS expanded, examples were documented which did not strictly conform to the triad of diagnostic criteria. Cases were described which included evidence for CNS impairment and at least some of the facial dysmorphologies but apparently normal growth. Fetal Alcohol Effect (FAE) is a term often used to describe such cases (Streissguth, 1997). Lamana (1982) also provides a description of individuals whose symptoms place them outside of the traditional criteria: intellectual functioning in the normal range, but facial or other physical irregularities associated with FAS, poor work habits, low school achievement, fidgety behaviour, hyperactivity, impulsivity, attention deficits, and delayed development. He points out that, except for the descriptor of physical anomaly associated with the syndrome, this description may fit students who eventually end up being placed in a special education context. The implication is that the true source of their difficulties may be missed.

In addition to the salient dysmorphologies already mentioned, there are numerous others, which may manifest as a consequence of exposure to alcohol in utero. These include cleft or arched palate, the hypoplasia (underdevelopment) of the midface that may extend to the maxillary region of the head. This, and a

hypoplasia of the lower jaw, may result in dental problems due to insufficient space for proper alignment of incoming secondary teeth. There are anomalies to the eye, which include ptosis (drooping eyelid), underdeveloped neural pathways, myopia, strabismus, tortuosity of the retinal vessels, and even blindness. Hearing decrements and abnormalities of the brain stem, auditory cortex, and corpus callosum may be associated with the central auditory processing disorders that are common to the syndrome. Skeletal anomalies may include spine and/or joint malformation and fusion as well as crooked or shortened fingers and toes. Also, anomalies of the heart, genitals, and internal organs of the body have been noted. A more complete description of these matters is available elsewhere (Majewski & Goecke, 1982; Abel, 1984; Streissguth, Clarren, & Jones, 1985; Streissguth, 1997; Stromland & Hellstrom, 1996; Smith, 1997).

The choice of terminology is an important factor to consider when attempting to bring clarity and accuracy to diagnostic classification of the syndrome. There is general agreement with the use of the term FAS as originally defined by Jones and Smith (Jones, Smith, Ulleland, & Streissguth, 1973), in which prenatal exposure to alcohol is confirmed and a complete triad of diagnostic criteria is presented—the growth delay, the evidence of CNS impairment, and the presentation of the characteristic dysmorphologies. However, the application of descriptively accurate terminology becomes difficult when diagnostic classification is unclear—where prenatal exposure to alcohol is unconfirmed and/or presentation of diagnostic criteria is incomplete or obscure.

Possible Fetal Alcohol Effects (PFAE) (Clarren & Smith, 1978) is a term that has been suggested for use when physical characteristics are not clearly presented but evidence for CNS impairment exists. Its use becomes problematic, however, with its ambiguous reference to either the possibility of prenatal exposure to alcohol or the possibility of effects.

Prenatal Exposure to Alcohol (PEA) is another term found in the literature. It has been used to classify those cases in which fetal exposure to alcohol is confirmed but facial dysmorphologies are minimal or lacking entirely and growth reduction and microcephaly are not obvious (Mattson, Riley, Gramling, Delis, & Jones, 1997).

The term that has found the most widespread acceptance and clinical application is Fetal Alcohol Effects (FAE) (Clarren & Smith, 1978). It also is used to classify those cases where a clear presentation of the diagnostic criteria is lacking: prenatal exposure to alcohol is confirmed and evidence for CNS impairment is presented, but distinctive facial characteristics are less apparent and growth could be considered normal.

The Institute of Medicine (IOM) (1996) attempts to manage the diagnostic problem of confirmed and unconfirmed exposure with a five-tiered system for categorizing degree of effect from prenatal exposure to alcohol. FAS categories one and two include those cases where diagnosis of FAS is deemed appropriate regardless of confirmed or unconfirmed prenatal exposure to alcohol. Category three, or Partial FAS, requires that exposure be confirmed and that only one of three criteria are present (growth delay, evidence of CNS developmental

abnormality, or a particular pattern of behavioural or cognitive abnormalities deemed inconsistent with the individual's developmental level and unexplained by environmental and family background). The fourth and fifth levels require confirmation of prenatal alcohol exposure and focus on congenital anomalies (alcohol-related birth defect [ARBD]) and alcohol's impact on the CNS respectively (alcohol-related neurodevelopmental disorder [ARND]). Although the IOM's system proposes that a diagnosis of FAS may be made without confirmation of maternal alcohol consumption, where one or more of the diagnostic criteria are incomplete, confirmation is required.

Central Nervous System Effects

The developing nervous system appears to be particularly sensitive to the teratogenic effects of alcohol. Although human physiology is generally quite resilient and capable of rebound, it would appear that the damage to the architectural foundations of the central nervous system brought about by alcohol's insult during gestational growth is permanent (Guerri, 1998). Microcephaly is perhaps the most obvious indicator of the CNS damage associated with the syndrome. Magnetic resonance imaging studies of children with FAS, compared to those of non-exposed children, show smaller cerebral and cerebellar vaults and greater amounts of fluid space proportionate to brain tissue overall (Mattson, Riley, & Jernigan, 1994).

Although an overall underdevelopment may be evident, not all areas of the brain are affected equally by the prenatal exposure to alcohol. The developing basil ganglia, neo-cortex, hippocampus, cerebellum, and corpus callosum all seem

particularly vulnerable to alcohol's insult. A disruption of orderly cell proliferation, site migration, and cell death has been observed (Streissguth, 1997; Guerri, 1998; Roebuck, Mattson, & Riley, 1994). The basal ganglia, which consist of a cluster of neural body systems, lie deep within the cerebral hemispheres and are associated with posture control and movement (Noback & Demarest, 1972). Developmentally reduced volume in the basal ganglia and their related structures has been noted in those having had prenatal exposure to alcohol. It is hypothesized that the balance deficits observed in these individuals are related to this compromise to basal ganglia development (Roebuck, Simmons, Richardson, Mattson, & Riley, 1998).

The neo-cortex comprises the voluminous and convoluted outermost layers of the brain and is parceled into areas governing sensory, motor, and psychical functions. It is linked with functions of perception, motor programming, memory, language, and reasoning (Noback & Demarest, 1972; Singer, 1996). Overall volume of this important structure is significantly compromised by prenatal exposure to alcohol due to decreased neural and glial cell proliferation (Miller, 1992).

The hippocampus, a subsystem to the larger limbic system, sits astride the brain stem deep within the overall brain structure (Noback & Demarest, 1972). Associated with memory, specifically contextual memory, it helps in understanding the emotional significance of events (Goleman, 1997). It is thought that learning and memory impairments observed in children exposed to alcohol's teratogenic effects may be attributed to the specific neurochemical, neuropsychological, and anatomical changes that may occur in the hippocampus (Gianoulakis, 1990; Riley,

Barron, & Hannigan, 1986; Streissguth, Barr, & Sampson, 1990; Streissguth et al., 1994).

The cerebellum, located posteriorly and below the cerebral hemispheres, is another structure of the brain affected by gestational alcohol exposure. It functions as a modulator of coordination and timing to muscles and is important to the maintenance of muscle tone (Fiez, 1996; Robinson, 1995). Developmentally, the overall volume of the cerebellum is reduced through alcohol insult, most notably during the third trimester when a growth spurt of the brain takes place (Jacobson, Jacobson, Sokol, Martier, & Ager, 1992; Streissguth, Barr, & Sampson, 1990). Delays in motor development, difficulties with fine motor tasks, ataxia (lack of overall muscle coordination), and an unusual gait have been noted in children who have suffered exposure to alcohol's teratogenic effects (Streissguth, Barr, & Sampson, 1990; Streissguth & Martin, 1983).

The corpus callosum is a bundle of nerve fibers, which connects the left and right hemispheres of the brain. Abnormalities to the corpus callosum have been noted all along in the study of fetal alcohol syndrome, initially from autopsy (Jones & Smith, 1973) and more recently utilizing magnetic resonance imaging through which abnormality of size and shape of the corpus callosum—or its absence altogether—was found (Riley, Mattson, & Sowell, 1995). Hyperkinetic and attentional disorders that are frequently diagnosed in FAS/FAE children may be associated with these abnormalities. When the corpus callosa of FAS subjects were compared to those of children diagnosed with attention deficit hyperactivity

disorder (ADHD), a similar pattern of abnormal configuration was revealed (Hynd et al., 1991).

Early studies were based on autopsy and those most profoundly affected. Now, magnetic resonance imaging has uncovered examples of children who are functionally FAS but who lack apparent brain anomalies (Roebuck, Mattson, & Riley 1998). These findings further our understanding regarding the relationship between alcohol damage to the architecture of the brain and functional outcomes. What we have grown to understand is that the syndrome may be conceived of as a continuum of effects ranging from severe to those that are currently beyond physiological detection. It can safely be said that development of the brain can be disrupted in any of its phases, and that cognitive, intellectual, motor, and behavioural impairments are a likely consequence of in utero exposure to alcohol (Clarren & Smith, 1978; Streissguth & Martin, 1983).

Intellectual Functioning

In a general sense, all tests of intelligence purport to measure ability in some fashion. Since innate intelligence is impossible to measure in isolation, all measures of intelligence reflect the learning experiences of the individual (Wesman, 1968). Factors included when measuring intelligence are abstract thinking, the acquisition of knowledge and problem solving, adaptations to the environment, creativity, overall knowledge, linguistic and mathematical competence, memory, and mental speed (Snyderman & Rothman, 1987).

Studies of alcohol's teratogenic effects on intellectual functioning characteristically find lower Intelligence Quotient (IQ) scores for FAS affected

subjects compared to normal controls. Although intelligence tests are “standard equipment” in educational and medical settings, their validity in general has been questioned: some consider them more as a predictor of overall school success than as a measure of innate intelligence (Feuerstein, Rand, & Hoffman, 1979; Gardner, 1983; McCluskey & Walker, 1986). Results of IQ testing must be interpreted in context. Standardized tests are typically normed from data gathered across large populations, making the validity of results questionable when measurements have been obtained from an un-normed subgroup. Perhaps IQ results are best used and interpreted flexibly to understand the relative strengths and weaknesses of an individual, and to guide programming (McCluskey & Walker, 1986).

It was first believed that cognitive impairment was the defining feature of FAS, above even that of dysmorphology (Abel, 1980). Clarron and Smith (1978) noted that studies of the time indicated that 80% of those affected by FAS were cognitively impaired. More recently, more representative populations have been examined and it has been shown that IQ decrements are not as great as once thought. A study by Streissguth et al. (1991) found IQ scores for a sample including FAS/FAE subjects (N = 61) to be 68 with only 58% of this group testing at 70 or below. Mean scores for the FAS and FAE groups were 66 and 73 respectively. Further, standardized intelligence testing of a large sample (N = 473) of FAS/FAE subjects studied over a 23 year period (Streissguth, Barr, Kogan, & Bookstein in Streissguth, 1997) found that the mean IQ was 79 for the FAS subjects and 90 for the FAE subjects, with considerable overlap of scores. Only 25% of the FAS

subjects had IQ's below 70, and only 10% of those identified as FAE would have been considered to be cognitively impaired. In the early studies, individuals with severe cognitive impairments were over represented simply because it was those most profoundly affected who came to the attention of researchers.

Full-scale IQ scores are an insufficient measure of a connection between a prenatal exposure to alcohol and intellect. For example, when 87 children (aged 6.5 to 18.5) referred for special education services were examined for prenatal exposure to alcohol, 15 had been exposed to heavy (undefined) maternal consumption of alcohol during pregnancy (Shaywitz, Cohen, & Shaywitz, 1980). All 15 exposed students displayed, to some degree, the constellation of features that characterize FAS. Overall growth and head circumference were below normal and at least two facial dysmorphologies were found in each student in this group. All of these students had attentional and self-regulation problems and had experienced early school failure, yet their IQ test scores fell within normal range.

Another study (Mattson, Riley, Gramling, Delis, & Jones, 1997) revealed factors that appear to set apart alcohol-exposed children from the non-exposed population, independent of the physical markers that are considered to be essential for diagnosis. When 47 alcohol-exposed children, 34 of whom met traditional criteria, were compared to normal controls on measures of intelligence, performance of the exposed group was significantly lower overall than that of the normal controls. Although the performance of the children lacking the full triad of diagnostic criteria was marginally better than the FAS group, these two groups showed similar patterns of subtest scores, which Mattson and his colleagues felt set

them apart from the normal controls. A functional commonality emerged that seemed to go beyond matters of IQ alone.

A later study, also by Mattson, Riley, Gramling, Delis, and Jones (1998), undertook neuropsychological evaluations of language, verbal learning and memory, academic skills, fine motor speed, and visual-motor integration. It was found that FAS subjects, and subjects in the Prenatal Exposure to Alcohol (PEA) group, shared a common cognitive profile which set them apart from normal control subjects. Although the PEA subjects were less impaired overall (mean IQ 83.6) than their FAS counterparts (mean IQ 74.5), the researchers found that the degree of cognitive deficit may be independent of the presence or absence of the physical markers consistent with the syndrome—that children who are essentially normal in appearance can carry with them all of the cognitive deficiencies of FAS. Most striking was a similarity of deficits in the alcohol-exposed groups in verbal learning and the memory. As investigators state:

The effects of prenatal alcohol exposure fall on a continuum, with prenatal death as the most severe outcome. Although lesser amounts of alcohol may cause less severe behavioral and cognitive consequences, the absence of physical markers does not preclude the possibility of significant cognitive deficits (Mattson, Riley, Gramling, Delis, & Jones, 1998, p. 152)

Findings such as these suggest that physical markers alone are insufficient for identification of alcohol-affected children.

Threshold of the Effects of Exposure to Alcohol In Utero

Attempts have been made to determine a teratogenic threshold level of alcohol's effects to the fetus. In a study of African American infants, no evidence of

cognitive impairment was found below an amount of .5 ounces of absolute alcohol (AA) per day (one drink per day) (Jacobson, Jacobson, Sokol, & Ager, 1998). Above this amount, as consumption increased, cognitive function was increasingly affected.

Larroque and Kaminski (1998), investigating psychomotor development, neurological state, growth, and facial features of pre-school age children in Roubaix, France, measured significant effects when alcohol consumption was 1.5 ounces of AA per day (3 drinks) or greater. Outcomes were inconclusive at levels less than this amount.

There are adverse effects of alcohol to offspring that may be detected only through population studies. For example, IQ decrements and learning problems were noted in offspring of mothers whose alcohol consumption would be considered within the realm of social drinking (Streissguth, Barr, & Sampson, 1990). Heavy drinkers to abstainers were selected from a stratified sample (N = 482) drawn primarily from middle class white women; to control for potential confounding effects, smokers to non-smokers were selected as well. Alcohol consumption for this group was 1.84 drinks per day prior to pregnancy recognition and 1.71 thereafter to term. Overall, performance for the offspring of this sample was satisfactory—they appeared to be a somewhat above average group of children with a mean IQ of 107.6. However, within this group, children whose mothers consumed approximately two drinks (1 ounces of AA) per day or more revealed average IQ, 6.7 points lower than those of children whose mothers consumed less than that amount. These decrements corresponded with lowered academic and

behavioural performance most notably in reading and arithmetic skill development and in impulsive/attentional concerns affecting ability to work in cooperative group activities.

Naturalistic observations of children suggest the occurrence of behavioural effects due to prenatal exposure to alcohol through the ingestion of as little as an average of .45 ounces of AA per day throughout pregnancy. In a study of middle class white women (N = 128) and their four-year-old children (Landesman-Dwyer, Ragozin, & Little, 1981), youngsters whose mothers consumed this moderate amount (when compared to mean amounts of .07 ounces of AA per day consumed by occasional drinkers or those who abstained) of alcohol during their pregnancy were observed during mealtimes to be more fidgety, less compliant, and less attentive than their counterparts whose mothers abstained or were occasional drinkers. Both the observers and the principal researchers were unaware of the alcohol consumption patterns of these mothers during the data collection time period. The mothers of the seemingly affected children did not perceive that their children were different in some respects from other children. The amount of .45 ounces AA per day represents the lowest figure found in the present literature search to produce effects in the offspring of mothers who consumed alcohol during pregnancy.

Factors confounding to establishment of a defined threshold are binge drinking and pregnancies that occur toward the end of reproductive age. Both of these factors have been shown to increase the risk and severity of impairment (Jacobson, Jacobson, Sokol, & Ager, 1998; Streissguth & LaDue, 1987). Overall, it

would appear that alcohol's teratogenic effects are dose dependent—risk of impairment to the unborn increases in proportion to the amount of alcohol consumed (Jacobson, 1998).

Life Adjustment Issues

Those affected by FAS/FAE are confronted with specific impairments that may help to explain why their life adjustment problems seem to go beyond those that would be expected from factors of IQ alone. As Jacobson (1998, p. 313) notes:

Recent findings from longitudinal follow-up studies of adolescents and adults with FAS in the United States, Germany, and France, however indicate that, whereas some of the facial anomalies diminish with age and there is catch-up growth for weight during adolescence (particularly among girls), microcephaly and specific intellectual problems persist; and behavioral, emotional, and social problems become more pronounced, even when the home environment changes for the better.

Streissguth (1997) has proposed the concepts of primary disability and secondary disability to help provide an understanding of the parameters of functional ability for those affected by prenatal exposure to alcohol. IQ tests and measures of social adaptation were administered to a large sample of FAS/FAE subjects (N = 473) ranging in age from 3 to 51 years. Primary disabilities were defined through the IQ and social adaptation scores. Secondary disabilities were identified through a life history interview. Keeping in mind a score of 100 is the norm for both intelligence and adaptive living measures, those diagnosed with FAS (N = 178) were found to have an average IQ of 79 and an adaptive living score of 61. Those categorized as FAE (n = 295), tested with an average IQ of 90 and an

adaptive living score of 67. Six significant secondary problem areas or disabilities emerged for subjects with FAS/FAE who ranged in age from 6 to 51 (N = 415). Specifically, for those in the sample 12 and over, 90 % had mental health problems, 60% had disrupted school experience, 60% had trouble with the law, 50% had been incarcerated, 50% exhibited inappropriate sexual behaviour, and 30% had alcohol and drug problems. These issues framed the life experiences of this group. As a measure of adult self-sufficiency for those subjects 21 and older, two additional secondary disabilities were studied: dependent living and problems with employment. Of the 90 adults in the sample, only seven were able to live independently and with problem-free employment.

A higher IQ does not necessarily correspond with a higher level of performance. FAE individuals with IQs greater than 70, demonstrated higher rates in all secondary disabilities excepting that of mental health problems (Streissguth, 1997). Although their comparably higher IQ's may have helped with their superior performance in the workplace, the adults with FAE experienced as much difficulty with issues of independent living as those with FAS. Factors that tended to prevent or ameliorate secondary disabilities were a stable nurturing home experience, diagnoses of FAS/FAE prior to age six, and not having experienced violence. The important outcome of this study has been the recognition that proactive intervention goes a long way in the management of secondary disabilities (Streissguth, Barr, Kogan, & Bookstein, 1997).

The negative impact of in utero alcohol exposure on the developing CNS translates to a broad range of functional disabilities across the life span. Poor

judgment, attention deficit, difficulties with arithmetic reasoning, memory impairment, difficulty with abstracting, disorientation in time and space, and impulsivity adversely effect the executive functions of forming, planning, and carrying out tasks (Streissguth, 1997; Jacobson, 1998).

Poor judgment may lead to easy victimization (Streissguth, 1997). Impulsivity and attentional problems provoke unfocused, distractible behaviour and perserveration of error (repetition of mistakes) that do not allow for the self-reflection required for effective self-regulation (Barkley, 1994). Memory and abstract thinking impairments create difficulties with learning from experience and understanding consequences (Lutke, 1997). Disorientation in time and space prevents the recognition of social cues through which one regulates social behaviour. Difficulties with arithmetic reasoning lead to any number of functional difficulties, from the handling of money to telling time (Streissguth, 1997).

Each stage of life brings problematic issues for those affected by exposure to alcohol in utero. Noted as early evidence of CNS dysfunction, tremulousness, irritability, weak suckling, and even seizures have been reported as symptomatic of exposed neonates (Clarren, Bowden, & Astley, 1985; Streissguth & LaDue, 1985). Discomfort with sensory stimulation of any kind often is apparent. Linked with these symptoms are issues of habituation and arousal. Habituation may be seen as our first attentional task in life as we learn to filter out redundant stimuli and respond only to those that most directly relate to our needs. The habitation difficulties observed in infants exposed to the teratogenic effects of alcohol may be but an early manifestation of the response inhibition deficits that come to frame their lives.

Importantly, amounts of alcohol consumed maternally were found to be directly related to degree of difficulty with habituation to irrelevant light, bell, and rattle stimuli (Streissguth, Barr, & Sampson, 1990; Streissguth, Barr, Martin, 1983). Also, as Streissguth, Martin, and Barr found in 1977, the low threshold of arousal to stimuli in general by neonates exposed to alcohol in utero was directly related to amounts consumed (cf. Abel, 1981).

We can follow the thread of CNS dysfunction into pre-school years when three prominent characteristics emerge: cognitive impairment, hyperactivity, and poor or delayed motor development (cf. Abel, 1981; Clarren & Smith, 1978; Spohr & Willms, 1993). In addition to hyperkinetic and attentional issues, problems of social competency are issues for this age group (Steinhausen, Willms, & Spohr, 1993). These children are described as inappropriately affectionate, overly tactile, demanding of attention, and as having poorly developed peer relations. Even though children affected by FAS/FAE may be quite sociably engaging at this stage, because of their difficulty in following directions, issues of compliance and emotional control may become problematic (LaDue, 1989; Streissguth, 1997).

Children of school age continue to exhibit the hyperkinetic and attentional deficits characteristic of FAS/FAE and to show the lack of social competency that first emerged in early childhood (Steinhausen & Spohr, 1998). Streissguth (Burgess & Streissguth, 1992; Streissguth & LaDue, 1987) described these children as impulsive, hyperactive, and as having a poor attention span. It was observed that they showed a lack of inhibition, overly friendly and inquisitive natures, and the tendency to enter into inappropriate or dangerous situations because of their lack of

judgment and social awareness. Due to their sociability, they may appear to have more ability than they in fact possess, and they frequently will associate with younger children to find their level of social and intellectual comfort. As well, this is the stage where issues of behavioural control may become a focus of concern due to such non-compliance issues as lying, stealing, and defiance of authority (LaDue, 1989).

The lack of social skills is a problem for alcohol-affected children. A study by Thomas, Kelly, Mattson, and Riley (1998), in which school-aged children (5.5 to 13 years) with FAS ($n = 15$) were assessed with the Vineland Adaptive Behavior Scales (VABS) (Sparrow, Ball, & Cicchetti, 1984)¹ is worth examining in some detail. Adaptive behaviour is defined as "the ability to perform daily activities required for personal and social sufficiency" (Sattler, 1992, p. 384). Two equal-sized, non-exposed control groups were selected: the first of these had Verbal IQs matched to the FAS group, while the second had average to above average Verbal IQs. Children in the FAS group showed a great discrepancy between their chronological age and VABS scores typically expected for their age group. Their matched IQ counterparts, although somewhat delayed, displayed a pattern more closely resembling that of the normal control group. The scores of FAS-affected children were what one might expect from children four to six years of age. These results suggest that social abilities for those affected by FAS are arrested in their development, not merely delayed.

¹ The VABS (Sparrow, Ball, & Cicchetti, 1984) are tools for assessing the social competence of both handicapped and non-handicapped individuals from birth through 19 years of age.

In adolescence, the demands and expectations of daily living increase dramatically in intensity and complexity. Formulating an effective self-identity (Erikson, 1963) and finding guidance through the crafting of flexible moral judgments (Kohlberg, 1963) would seem contingent on having attained sufficient capacity for abstract reasoning and thought (Piaget, 1954). The findings of Thomas, Kelly, Mattson, and Riley (1998) suggest that adolescents affected by prenatal exposure to alcohol, may end up facing the issues of peer group, independence, and sexuality—which all teen-agers must face—with their social abilities rooted in an earlier age. Handicapped in this way, adolescence may become a time of particular difficulty.

There is evidence to support the notion that, for adolescents, IQ alone does not fully explain the life adjustment difficulties presented by prenatal exposure to alcohol. The degree to which secondary disabilities (e.g., mental health problems, disrupted school experience, trouble with the law and confinement, inappropriate sexual behaviour, and alcohol and drug problems) appear during adolescence gives testimony to the profound handicap created by this exposure. In a study by Olson, Feldman, Streissguth, Sampson, and Bookstein (1998) using the Wechsler Intelligence Scale for Children—Revised (WISC-R) (Wechsler, 1974)² as the overall indicator of function, three groups of adolescents were compared on measures of cognitive and behavioural performance: (a) non-cognitively impaired teenagers with

² The WISC-R (Wechsler, 1974) was standardized based on the 1970 census using a representative sample of 2,200 American children. It was revised from the original WISC (Wechsler, 1949), which in turn had been developed for use with children from adult intelligence tests by adding easier items to the beginning of the subtests. In contrast to the WISC, the standardized sample for the WISC-R included proportionate representation of non-white minorities.

FAS (N = 9), with a mean IQ of 91.1 and a range from 70 - 118; (b) those minimally or non-exposed to alcohol in utero (N = 174); (c) and, from this second group, a subgroup whose IQ scores fell within the range of the group of FAS subjects (N = 52). Although considerable diversity in aptitude was represented in the FAS group, the performance of the teenagers affected by FAS was lower overall on aspects of attention, memory, and cognitive flexibility (planning) relative to the other two groups. The behavioural problems and social competencies of the FAS group, as rated by the Child Behavior Checklist (Achenbach & Edelbrock, 1986)³ in this study, fell below the clinical cut-off point for boys and in the borderline range for girls. Ratings were within normal limits for the other two groups. Socialization VABS scores were 68.2 for FAS subjects—below the clinical cut-off of 70. No comparison of VABS measures was provided for the other two groups.

Although the discrepancies between the ability those affected and society's expectations for performance widen in adolescence, some level of competency becomes mandatory to function as an adult (Streissguth, 1997). The themes that emerged in adolescence continue into adulthood and impairments to intellect and cognition appear to remain stable over time (Kerns & Don, 1997). For example, substantial deficits in both auditory and visual attention have been recorded in adults who were exposed to alcohol in utero (Connor, Streissguth, Sampson, Bookstein, & Barr, 1999). Further insight into their difficulties as adults may be

³ The Child Behavior Checklist (Achenbach & Edelbrock, 1986) consists of a list of competencies and behavioural problems that are rated by parents or parent-surrogates. Ratings are based on a three-point scale—not true, somewhat or sometimes true, and very true or often true.

gained through examination of their performances on the VABS; their scores on communication and socialization skills were, on average, comparable to those expected for a child of seven years of age (Streissguth et al., 1991). Because of their particular social and academic deficits, adults who are affected by prenatal exposure to alcohol are open to exploitation by others. They remain at risk for poor judgment and unpredictable, impulsive behaviour. They carry the added burden of the societal expectation that they will obtain and maintain employment and manage their personal affairs. Withdrawal and marginalization may follow failure in these important areas (LaDue, 1989; Streissguth, 1997). Reflecting on the long-term outlook, it is clear that, "Fetal alcohol syndrome is not just a childhood disorder, there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management" (Streissguth et al., 1991, p. 45).

Habituation deficits appear to be a fundamental and pervasive aspect of the syndrome. The modulation of incoming stimuli remains problematic throughout the life span: from the adaptive difficulties of the neonate, to the hyperkinetic and attentional issues of childhood, across adolescence, and into adulthood where hyperactivity diminishes but attentional deficits and problems of over stimulation and emotional overload remain. A particularly insightful comment from an individual affected by FAS described his difficulties with sensory modulation and his attempts to manage the problem in a public context:

When I go into a supermarket, I feel overwhelmed with the sights, the sounds, and the smells . . . I color code everything. I make my shopping list on a small note pad and write each item on a separate page. That way I only have to attend to one item at a time—when

that item has been found, I tear off that page and go to the next item I see, otherwise, the market is just too overwhelming (Streissguth, 1997, p. 157).

Diagnostic Considerations

Given the powerful implications for individuals and their families stemming from a diagnosis of being affected by a prenatal exposure to alcohol, the importance an accurate diagnosis cannot be overstated. The diagnostic process requires that alternative explanations for symptoms be eliminated, leaving prenatal alcohol exposure as the only plausible explanation. However, diagnostic difficulties may occur when an attempt is made to eliminate alternative explanations for symptoms. CNS impairments may be caused by alcohol, but are not necessarily unique to alcohol (Streissguth, 1997). Outside of the triad of criteria, there is diagnostic ambiguity due to the non-specific nature of symptoms that could also be descriptors of other conditions. Such lack of diagnostic clarity is illustrated an example presented by Aase (1994): a three-year-old girl, weight and head circumference measuring at the 5th percentile, hyperactive and a short attention span; her mother drank four bottles of beer a day during early pregnancy but stopped drinking altogether halfway to term. It is the facial and physical characteristics (not mentioned in above case) as hallmark features of the syndrome, along with confirmation of maternal consumption of alcohol during pregnancy, that draw together symptoms which otherwise may be given an alternative explanation. Regarding diagnostic difficulties surrounding fetal alcohol syndrome, Aase (1994, p. 9) states:

. . . the physical features of FAS are nonspecific, whereas their overall pattern is unique. Similarly, the pattern of learning and behavioral characteristics may have diagnostic value in affected children. The brain is the organ most sensitive to the prenatal damage caused by alcohol. If that damage resulted in a unique, unmistakable psychological profile, FAS could be diagnosed reliably with reliance on the variable and subtle clinical features. As yet, no such distinctive profile has been ascertained . . .

In order to arrive at an accurate assessment of alcohol's teratogenic effects, we must also consider the variables of environmental influences. There is evidence to show that, although the alcoholic household may exacerbate problems while healthy surroundings ameliorate them to some degree, the neuropsychological deficits retain their essential character regardless of environment. In one study in which children of alcoholic mothers were assessed for alcohol effects during their pre-school years and again at 12 to 14 years, some mitigating influences were achieved through changes in the living arrangements (Aronson & Hagberg, 1998). However, there were aspects that endured regardless of environment. Specific problems that continued into pre-adolescence included attention deficits, problems of motor control, learning disorders, and a degree of cognitive impairment. It was the researchers conclusion that:

Early fostering did not appear to eliminate the harmful effects of exposure to alcohol in utero. However, our clinical impression not yet supported by systematic study, suggest that placement in a foster home leads to improved performance and a better quality of life for affected children, but normalization does not occur. (Aronson & Hagberg, p. 323)

In a study of children of alcoholic mothers, Spohr and Willms (1993) report on the stability of affects overtime as well. Regarding measures of intelligence,

they found that the socio-environmental circumstances of the affected individual made little or no difference.

The question may be asked as to the feasibility of identifying from within the general population only those individuals who have been affected by a prenatal exposure to alcohol. Benefits to be gained from such a screening could include early identification of and referral for appropriate intervention services as well as aid in the identification and intervention with mothers at risk for bearing further exposed children (Clarren & Astley, 1998). Two models representing different approaches to this topic are presented below.

Burd and Cox (1999) present a screening tool, conceptually organized around the traditional triad of diagnostic criteria. Their goal was to develop an instrument that would feature ease of administration, economic feasibility, and utility over a range of contexts. Taking approximately 15 minutes per session, their test was designed to screen children of school age (4-18) and to be administered by teachers and paraprofessionals. In their study, 1013 children were assessed at a cost of \$13.00 each. Of the 65 children with a positive screening score, 6 were eventually diagnosed as FAS. This screening tool meets acceptable performance criteria with its sensitivity in correctly identifying those with the condition (100%) and its specificity in correctly excluding those without the condition 94.1%. The screen's positive predictive value (the probability of those identified for further evaluation ultimately being diagnosed with the condition) was 9.1%.

Streissguth, Bookstein, Barr, Press, and Sampson (1998) also developed a tool for identifying individuals exposed to alcohol in utero from a population at large.

In contrast to Burd and Cox, their model proposes to identify affected individuals through what is described as “the behavioral essence” of the syndrome. It is felt that the Fetal Alcohol Behavior Scale (FABS) (Streissguth, Bookstein, Barr, Press, & Sampson, 1998), with its focus on behavioural descriptors only, achieves independence from factors of dysmorphology, IQ, age, race, culture, and socio-economic status. From a list of 68 behavioural descriptors, 36 items were eventually chosen for their correlative values across age groups. These items were believed to detect the consequences of exposure to alcohol in utero and not the consequences of the alcoholic environment. A scoring on the FABS was obtained through a tally of “yes” answers to the descriptors that most fit the behaviour of the individual. For example, such items as overreacting, chats with no content, demanding of attention, unaware of consequences for actions, and incompleteness of tasks were chosen for inclusion in the FABS, while fearlessness, tantrums, low self-esteem, difficulty learning, and poor school attendance were not.

A reference population of FAS/FAE subjects (N = 472) used in the development of the FABS revealed an average score of 20.3 out of 36 (Streissguth, Bookstein, Barr, Press, & Sampson, 1998). A detection study, targeting prison inmates, was able to identify individuals who later confirmed that their mothers had problems with alcohol. In a normative study, parents in a waiting room of a general practice clinic were asked to voluntarily complete a FABS survey on one of their children chosen at random. Again, elevated FABS scores were an indicator of a maternal alcohol problem. As well, elevated FABS scores were found to be an

accurate predictor for dependent living among adults with FAS/FAE. As Streissguth (1997, p. 130) states:

Growth and facial features are not really the essence of FAS—they are just early markers that, in combination with CNS effects, embody the constellation of features that characterize the syndrome. The real long-term disability in FAS is the CNS dysfunction—the brain damage—that compromises the development of the affected person.

Interventions

The interventions that take place in the lives of those affected by in utero exposure to alcohol may or may not include recognition of their condition. For example, a child may be removed from an unsuitable home environment with no consideration being given to a referral for a diagnostic evaluation for the syndrome. Consequently, the prenatal effects of alcohol exposure can remain undifferentiated from the effects of environment, and the mother's problematic drinking may remain unrecognized, leaving subsequent children at risk for exposure to alcohol's teratogenic effect. The children so affected also may remain undiagnosed and, consequently, untreated for their condition (Clarren & Astley, 1998).

Removal from the home, with or without a diagnosis of FAS/FAE, may be a frequent occurrence due to the existence of unsuitable domestic environments that may be exacerbated by the difficulties inherent in caring for an alcohol-affected child. Most children affected by the syndrome do not receive a proper diagnosis of their condition until problems surface later in life (Streissguth, 1997). In a study (Aronson & Hagberg, 1998) of 24 alcohol-affected children aged 12 to 14, 16 were in foster placement, while 8 were with their biological parent(s). Eleven of the children in foster care had been removed from their home before 18 months of age.

All apprehensions were due to unsuitable domestic environments that may have been created by alcoholic households. However, only five of these children had been identified at birth as having been affected by the syndrome.

A similar pattern of removal from the birth home and delayed diagnosis of the condition is found in a study by Steinhausen and Spohr (1998). In this investigation (N = 158), a diagnosis of FAS occurred at various ages, and a lifespan assessment revealed that only 26% of the subjects lived continuously with biological parent(s).

Following the history of living arrangements for individuals affected by FAS/FAE into adolescence and adulthood (N = 61), Streissguth et al. (1991) found that the primary caregiver for these individuals had changed an average of five times during their lives. Fully one third of them had been abandoned or given up for adoption at birth. Of further significance was that, by adolescence, 69% of the biologic mothers were dead from a variety of causes, including the health consequences of their alcoholism, suicide, homicide, and accidental death.

Given that many cases of children affected by alcohol prenatally remain undetected from an early age, the school may play a part in the intervention process. When a student is showing obvious signs of difficulty academically and behaviourally, a more formal response may be needed, including taking steps to secure a medical confirmation of the syndrome (Manitoba Education, Training and Youth [METY], 2001).

As previously discussed, early diagnosis and intervention can lead to more favourable outcomes. Weiner and Morse (1994, p. 67) state:

In the field of child development there is a general view that early intervention and a facilitating environment can help to maximize every child's potential, no matter what the problem. However, children without learning disabilities or behavior problems can thrive without such interventions, whereas children such as those with FAS need interventions to approach normalcy.

For Streissguth, Barr, Kogan, and Bookstein (1996), the benefits of early diagnosis and intervention are irrefutable—lower incidences of secondary disabilities are noted when the syndrome is identified prior to six years of age. Such diagnoses allow for the setting of appropriate and realistic expectations, so that attention can be focused on the skills and attributes that the alcohol-affected person does possess and on objectives that are achievable.

For the individual affected by a prenatal exposure to alcohol, obstacles to normal development are presented at each stage of life. A corresponding set of interventions may be employed to help offset those deficits (Streissguth, 1997; LaDue, 1989). Interventions for infants and pre-schoolers centre on support provided for the primary caregiver(s) and environmental considerations for the child. For caregivers, education regarding the requirements of caring for affected children is recommended, as well as respite when needed. The assignment of a case manager for the coordination of services is also important. Recommendations for affected children include the close monitoring of their health and physical development and the creation of secure and predictable home environments. The implementation of concrete expectations and limits is suggested, along with the adaptation of the environment (to assist with the moderation of stimuli and to attend to issues of habituation).

From school entry to the pre-teen years, Streissguth (1997) suggests that the caregiver(s) support include assistance in setting realistic expectations and goals for the child, together with continued respite and support-group membership. In addition to acting as liaison between parents and health care providers and social services, the scope of the case manager's responsibilities is usually expanded to include school (Streissguth, 1997). To maintain safety, structure, and stability for a child at this stage, a residential placement may be required. To encourage the development of desirable behaviours, consequences must remain clear, immediate, and predictable. Evaluations and measures of adaptive behaviour are particularly important to allow for appropriate educational programming (Streissguth, 1997; LaDue, 1989). Many of the skill requirements of daily living, which are taken for granted for most students, become areas of difficulty for these special needs children. To help offset difficulties with the ability to generalize information, a functional or adaptive living approach to education is recommended (e.g., taking a bus, making change, asking for directions, making friends). A behavioural approach has utility when attempting to shape challenging behaviours to within the limits of social acceptability (Burgess, 1994; Burgess & Streissguth, 1992). Given the high incidence of mental health issues for affected individuals as they mature, careful monitoring for signs in this area also is important (Steinhausen & Spohr, 1998).

Most children understand how to make friends and structure their leisure time with minimal guidance when given the opportunity to do so. Although the enrichment of leisure time experiences can be considered beneficial for all children,

given the problems that alcohol-affected children have with foresight, planning, and reading social cues, caregivers must be proactively engaged in this area (Streissguth, 1997; LaDue, 1989).

In adolescence and during the transition to adulthood, planning for adult competencies becomes the main emphasis of intervention. Continuance of respite and support-group membership for caregivers is recommended. As the affected individual enters areas of vocational training, alternative residential placement, and possibly the judicial system, the case manager's role is further expanded to encompass these services (Streissguth, 1997). The requirement for a safe, stable, and structured living environment remains. There is, however, a need for increased focus on personal responsibility and guidance and practice toward making healthy life style choices. Education regarding sex and birth control and protecting one's self from sexually transmitted diseases form an important part of this process (Streissguth, 1997).

Adolescence is the time to initiate planning for future living arrangements, vocational training, and related financial requirements. The importance of the acquisition of functional living skills throughout the childhood and adolescent years cannot be understated, as success in this area allows for a wider scope of choice in the planning process (Streissguth, 1997). Close supervision by caregivers using a behavioural approach and featuring high structure with concrete rules and consequences is recommended at this critical stage of development for the affected individual (Carmichael Olson, Burgess, & Streissguth, 1992). Continued monitoring

and, if required, referral regarding issues of mental health remain essential (Steinhausen & Spohr, 1998).

The arrival of chronological adulthood does not signal an end to the need for support and systems intervention for the alcohol-affected person (Streissguth, 1997). The damage incurred through prenatal exposure to alcohol lasts a lifetime—the help required to approach normalcy must last a lifetime as well. Effective support and intervention and the modelling of prosocial values increase the probability for successful outcomes and may help to avoid the consequences of secondary disabilities.

For the alcohol-affected individual as an adult, the case manager remains essential to obtain successful outcomes (Streissguth, 1997; LaDue, 1989). He/she provides a necessary continuity as, frequently, the involvement of the primary caregiver gives way to institutionalized systems of support. Depending on living arrangements, financial aid for a primary caregiver or a residential subsidy may be required. For those who are able to live independently, support services should be available, most notably in the areas of financial concern (e.g., financial guardianship or assistance in paying rent, utilities, etc.). The ability to take on the responsibilities of gainful employment is a marker of adulthood and can bring meaning, satisfaction, and independence to an individual. Completion of the vocational training planned for in adolescence should help provide the individual with the skills necessary to find employment. Specialized job counselling and placement services, which can direct the person to effective utilization of their particular strengths and abilities, should be available. With adulthood comes a reappraisal

and acceptance of the skills and abilities that the alcohol-affected person possesses and a reframing of expectations that are realistic for each individual circumstance.

Overall, transitions—passages from one life experience to another that all individuals must face—present particular difficulty for alcohol-affected individuals. Transition times from an educational perspective can include: pre-school into school, between schools and levels, between activities and settings, from a treatment centre or special program into a regular school, and from secondary school into adult life (METY, 2001). Steps recommended to facilitate successful transitions for alcohol-affected individuals involve transition meetings, sharing of information, touring new settings, developing plans (including input from affected individuals), developing key contacts, and controlling the pace of entry into new environments.

Prevention

Fetal alcohol syndrome is an entirely preventable phenomenon. The most obvious but simplistic solution to the entire matter would be to ensure abstinence from alcohol consumption during pregnancy. However, human behaviour is influenced by numerous biological, cultural, and situational variables, and knowledge of the risks and knowledge of pregnancy form only a part of the preventive equation.

Streissguth (1997) proposes what she refers to as “the five P’s of prevention”: public education, professional training, public policy, programs and services, and parent and citizen activism. She considers the creation of an

informed public through comprehensive education as the corner stone of any preventive effort. Getting the message out regarding the syndrome includes slogans and messages in public places (e.g., liquor outlets, doctors offices, supermarkets), warning labels on alcoholic beverages, governmental advisories regarding the dangers posed to the fetus through maternal alcohol consumption, media attention, and inclusion in the school curriculum. Professional training regarding FAS/FAE should be directed toward those in a position to act on information and make a difference, including health care providers, educators, and social service workers. Public policy includes legislation surrounding labelling and warnings to alert the public to the consequences of maternal alcohol consumption to the unborn. Programs and services might include direct interventions with high risk women with the overall objectives being to reduce or suspend alcohol intake during pregnancy, increase the use of family planning methods, and provide advocacy for mothers and safety for their children. Finally, Streissguth sees an actively engaged parent/citizenry as instrumental in the "institution and initiation and implementation of enlightened policy for the public good" (Streissguth, 1997, p. 251).

A variety of points of entry have been employed in an attempt to reach women at risk. For example, surveys were given to women admitted to a Denver detoxification centre to determine prevalence of pregnancy and contraceptive use (Shah, Hoffman, Shinault, & LaPoint, 1998). The researchers found a high (7%) pregnancy rate among their sample (N = 373). Of significance was the fact that many (56%) did not use contraception consistently. Because many high-risk

women receive no prenatal care, the researchers believed that the focus on pregnancy prevention was an effective method to reduce adverse outcomes of pregnancy.

Another point of entry for intervention is with women who have already given birth to an alcohol-affected child. Identifying affected offspring utilizing caregiver responses to a questionnaire, Clarren and Astley (1998) attempted to reach women at particular risk of producing further alcohol-affected children. Educational and social concerns were cited as the rationale for the caregiver's interest in responding to the questionnaire. Of 811 children selected for diagnostic evaluation, 238 were confirmed to have had in utero exposure to alcohol and signs of organic brain damage, and 39 presented the triad of diagnostic criteria. Once identified, the mothers of affected children were receptive to intervention (Astley, Bailey, Talbot, & Clarren, 1998).

Yet another point of intervention is with new mothers. The hospital experience of giving birth provides at least one contact with the health care system for marginalized women. This served as the point of intervention for what became known as the Birth to 3 Project in the state of Washington (Grant, Ernst, Streissguth, & Porter, 1997). As alcohol was only one of a variety of chemicals abused by the women recruited, the scope of the project by necessity went beyond intervention into issues of alcohol addiction. Postpartum women were selected based on the following criteria: they disclosed heavy use of alcohol or illicit drugs during pregnancy, they were unconnected with health care systems, and they had received minimal or no prenatal care. These women were encouraged to

participate in a three-year project designed primarily to promote entry into treatment and recovery programs to address problems relating to personal circumstances, and to implement family planning methods. A paraprofessional was assigned as an advocate to each participant in the program. Results from this intervention were encouraging, with 92% of those approached accepting entry into the program. Of the 65 women who chose the Birth to 3 option, 80% entered drug, alcohol, and abuse treatment, with 60% eventually abstaining from drug use. Sixty-two percent of the women chose long-term family planning methods, and 76% of the target children remained with their birth mothers. The overall improvement to the quality of life for these women attests to the efficacy of this type of intervention. In addition, when matters of economics are considered, the costs of advocacy-based intervention are minimal compared with other options such as incarceration and the fostering of children.

Social Impact

The study of fetal alcohol syndrome is one of overlapping disciplines, descriptions, and perspectives, sometimes contradictory but adhering to an overall theme. Exposure to alcohol in utero may result in teratogenic consequence—a constellation of physical and cognitive disabilities that reach across the life span. These disabilities are dose dependent; their severity increases with the amounts consumed. Normalization does not occur. Beyond dysmorphology, it is the cognitive deficits, the response inhibition deficits, and the arrested development of adaptive behaviour that are the truly disabling aspects of the syndrome. These factors may render affected individuals incapable of effectively managing life's

complexities independently. Disabilities arise at each stage of life: the irritable and difficult to care for infant, the child presenting hyperactive and inattentive behaviour problems, the adolescent unable to develop decision-making skills and social competency, and the adult struggling to obtain employment and functional independence.

It was the medical/scientific community who initially discovered and defined the syndrome, and a concerned public viewed those affected as victims. However, the public perception of the problem has changed over time. As a social historian, Golden (1999) contends that fetal alcohol syndrome has undergone a reframing—from that of a medical problem to that of a social problem. According to Golden, the medical/scientific community may have lost its cultural authority to frame the meaning of the syndrome for society. Within the social context of this reframing, the diagnosis of FAS is accepted, but the consequences of the syndrome are not. This “demedicalization” of the syndrome, as Golden describes it, has taken place as awareness of the syndrome has entered the public realm, such that its perception is now shaped within the arenas of political, legal, and public health debate.

Golden (1999) contends that the reframing away from the historic definition of the syndrome as a medical problem has been dependent on the flow of this debate. With the discovery of the affected children of alcoholic mothers came discussion in public policy regarding the risk presented to the unborn through the consumption of alcohol—and the crusade to warn. When it was realized that not all expectant mothers were able to heed the warnings, attention turned to the mothers’ drinking behaviours and away from the teratogenic effects of alcohol to the unborn.

Moral judgments were made about alcoholic mothers and the debate shifted to the political and legal issues of individual, fetal, and community rights. Further, Golden argues, through the perception that morally unfit alcoholic mothers were primarily the underprivileged residents of the city centre and reservation, fetal alcohol syndrome became an issue of race and class, and the offspring of alcoholic mothers became feared as the next generation of criminals. As crack cocaine addicts and their “crack babies” became identified with urban blacks, alcoholism and FAS became identified as a problem of the reservation and people of First Nations descent. The very nature of the cognitive disabilities produced by prenatal exposure to alcohol is made to order for moral evaluation and social condemnation.

As Golden (1999, p. 271) says:

Under the leadership of government officials and legal professionals, and in response to growing public mistrust of the medicalization of deviance, FAS came to be understood not as a cluster of precisely delineated symptoms, but as a social deformity that expressed the moral failings of mothers and marked their children as politically marginal and potentially dangerous.

A final reframing of the syndrome’s meaning took place within the legal arena (Golden, 1999). The assertion—derived from the results of medical research—that prenatal exposure to alcohol diminished capacity for understanding the consequences of one’s actions was rejected. The syndrome was reduced to a courtroom strategy as lawyers used a diagnosis of FAS a legal defence. Along with the public mistrust of the medicalization of deviance in general, this argument was seen as just another courtroom ploy.

Robert Harris was executed in California in 1992 (Golden, 1999). This event, significant to the social history of fetal alcohol syndrome, swayed public perceptions toward viewing the syndrome as a social problem and not as a medical problem. Harris, a convicted double murderer, had been diagnosed as FAS. A plea for clemency was made founded on the expert testimony of Jones and Streissguth. They maintained that Harris was unable to comprehend the consequences of his actions due to his prenatal exposure to alcohol. The plea that Harris was less than fully responsible for his actions failed to convince then Governor Wilson of the State of California. Wilson concluded, "As great as is my compassion for Robert Harris the child, I cannot excuse or forgive the choice made by Robert Harris the man" (cf. Golden, 1999, p. 270). Regarding the overall transformation of FAS from medical to social problem, Golden (1999, p. 286) writes:

Central to the reframing of FAS from a medical problem to social problem was the fact that FAS became public currency traded by politicians, lawyers, and public health advocates for various ends. And as it passed from hand to hand, the imprint of the medical community that had first engraved it into the public record began to fade.

As researchers tell us about the specifics of fetal alcohol syndrome, the work of writers such as Golden tell us of its context—its place in society.

Early in the study of the syndrome, Streissguth (1997) had felt that answers could be found through science and education. However, from the perspective of a quarter century of research of the syndrome, Streissguth (1997, p. 279) summarizes:

As I view the dramatic consequences that FAS/FAE has on individual children, as I realize how poorly our society is equipped for helping

them, and as I see each generation repeating the cycle, I realize that science and education alone are not enough to solve this tragic problem.

After approximately thirty years of research and education, where are we today? Incidence of the syndrome remains high and a solution to the problem has yet to be found. The bulk of the literature speaks primarily to the developmental struggles of children; yet, as children age chronologically, the syndrome obviously affects adults as well. Prevention, diagnosis, and interventions continue as areas of primary concern. The obvious objective is the complete elimination altogether of the teratogenesis caused by exposure to alcohol. Diagnosis of the condition for those affected remains essential for understanding and acceptance. Without diagnosis, there can be no development of an orderly life plan. Regarding ameliorative intervention, Streissguth (1997, p 280) suggests that further research is required, but toward a "type of help children and adults affected by fetal alcohol exposure need to lead productive lives and to control costly and painful secondary disabilities".

Given our current understanding of fetal alcohol syndrome as a life-long and irreversible condition, the acquisition of self-regulation behaviour as it applies to facilitating more positive social outcomes is of prime importance. The struggles that alcohol-affected individuals have with self-regulation are well documented. However, investigations into interventions such as the acquisition of self-regulation behaviour receive little mention in the literature. There is a need to address this issue.

Self-Regulation

The ability to meet societal expectations when immediate constraints are absent is considered an essential attribute for members of society. As Kanfer (1971, p.40) maintains, "The mark of a socialized person is his ability to maintain behaviour, originally shaped by the socio-cultural environment, when this environment is temporarily not an effective controlling influence." Kanfer (1977) postulates that ours is a society in which external control is both morally and philosophically discouraged and individuals are viewed as having personal responsibility for their actions. Group interests are frequently at odds with the interests of the individual. The satisfactions of the individual must be balanced against societal gain and individuals are expected to consider the impact of their actions on the welfare of other group members.

Since immediate satisfaction may have long-term negative consequences, both to the individual and to society in general, our value system encourages development of delay of gratification, resistance to temptation, and tolerance of aversive circumstances (Kanfer, 1977). Independent action, transcending apparent environmentally controlling contingencies, is viewed as praiseworthy conduct. Skinner (1971) felt that those who display the ability to forego immediate gains and/or endure adversity are to be held in high regard. Commenting on the ability to delay immediate gratification, Mischel (1974, p. 250) asserts:

It is difficult to conceive of socialization (or indeed, of civilization) without such self-imposed delays. Learning to wait for desired outcomes and to act in the light of anticipated future consequences is fundamental for planning and for the foresight and future orientation in which complex goal-directed behavior depends.

Kanfer (1977, p. 4) states, "a person is the product of their environment. His behaviour in turn, shapes the environment and thus, the individual is able to modify the conditions under which he lives." Daily living revolves around problem solving and decision-making. An important task in life is learning to direct problem solving and decision-making efforts toward worthy long-range objectives. Daily choices to endure and to defer responses and rewards may ultimately bring one under the control of long-term life fulfilling behaviours, playing out the reciprocity of effect between individual action and one's environment.

The paradigm of self-control presented by Thoresen and Mahoney (1974) has been adapted for this study as a means of understanding and operationalizing concepts of self-control and self-regulation. Self-control is conceived as the alteration of internal and external environments to promote meaningful change. Degree of self-control may range from the dominance of control of one's action by the external environment as arranged by others and natural events to a predominance of individual control of action through self-managed cues and consequences. Overt and covert events are understood to be subject to common underlying behavioural principles.

Self-control is said to have occurred when, "in the relative absence of immediate external constraint, it [the organism] engages in behaviour whose previous probability has been less than that of alternatively available behaviour (involving either less or delayed reward, greater exertion, or aversive properties, etc.)" (Thoresen & Mahoney, 1974, p. 131). The behaviour that is to be increased

(the less likely behaviour) will involve consequences that are immediately less positive than the behaviour to be decreased (the more likely behaviour).

Self-control may be further defined by the following criteria: two or more response options, response options with inherently conflicting consequences, and long term external consequences which promote or maintain a self-controlling action (Thoresen & Mahoney, 1974). An example is given of the individual who initiates and self-administers a program that leads to the cessation of smoking behaviour, but the decision to quit smoking may ultimately be under the control of long-term considerations of health. Conflicting response options are illustrated by this example. The behaviour to be increased (to stop smoking) will involve consequences that are immediately less rewarding (withdrawal symptoms) than the consequences of the behaviour to be decreased (smoking pleasure). It is the long-range external consequences of health that maintain the less immediately rewarding consequences of not smoking.

Self-control is very much a matter of social context and the perspective of the evaluator as well as the apparent degree of external influence. The perceived social desirability of a behaviour heavily influences whether or not a particular behaviour receives a self-control designation. Overall, as Levine notes, a degree of what is felt to be conscious effort is required before a behaviour is given a self-control label (cf. Thoresen & Mahoney, 1974). Specifically, effort must be directed toward the response option which features delay of beneficial consequences with the immediate effects being unpleasant (e.g., physical exercise, study, work, etc.), rather than an alternative option with delayed aversive consequences but pleasant

immediate effects (smoking, overeating, drinking, etc.). It is generally the former that are targeted for increase in frequency (acceleration) and the latter in which effort is directed toward reduction in frequency (deceleration). Given sufficient motivation, people will engage in activities that do not initially appear to have any reinforcing consequences (Thorsen & Mahoney, 1974).

Thorsen and Mahoney (1974) describe a dynamic system where the processes are elemental to all instances of behavioural self-control. Antecedent or initiating stimuli (AIS) precede a controlling response (CR) that may be either a behaviour beneficial to the individual (CR+), with acceleration in frequency as the objective, or a behaviour that is detrimental (CR-), with deceleration in frequency as the goal. CRs are assumed to be maintained by external environmental influences. Self-initiated strategies that are employed to modify or change existing CRs are called self-controlling responses (SCRs). Two types of self-controlling responses (SCRs) are described: environmental planning and behavioural programming.

Environmental planning or stimulus control describes those behaviours which occur "before the fact" in anticipation of an undesirable response to a particular CR, with the objective to decelerate CR- and to accelerate a CR+ (Thorsen & Mahoney, 1974). Three categories of environmental planning are identified: self-instruction and the preprogramming of consequences, overt stimulus control, and covert stimulus control.

Self-instructions can be broadly defined as "verbal statements and images to oneself that prompt, direct, or maintain behavior" (Meichenbaum, 1985, p. 409) and could also include the prearrangement of behavioural consequences. By

having prearranged consequences contingent on the performance of specified behaviours, a person's environment comes to include additional cues for the elicitation of desirable behaviours in the future. For example, if the environment were pre-arranged by an individual to be conducive to getting up on time (e.g., setting out clothing, setting alarm clock) he/she could self-reward by stopping at a favourite fast food restaurant before going to work or school.

Self-instruction may initiate and guide an overt, or public, stimulus control strategy where the objective is to reduce the occurrence of unwanted responses (CR-) and replace them with new and more beneficial responses (CR+) through changing the patterns of eliciting cues and reinforcers that customarily maintain a particular behaviour (Thoresen & Mahoney, 1974). For example, one may self-instruct to select a place conducive to good study habits using stimulus cues that reinforce learning behaviour—desk, chair, lighting, and a location away from unwanted and distracting stimuli such as television, snacks, and opportunities to socialize. When the objective is to avoid consumption of alcoholic beverage, one may self-prompt to stay away from establishments where alcoholic beverages are sold, thus avoiding the stimulus cues associated with drinking behaviour.

Self-instructions are also initiators to covert, or private, stimulus control strategies. Covert cues that are reinforcing to negative outcomes may be replaced with a more positive internal dialogue. This notion has found popular acceptance through authors of self-help books such as Dale Carnegie (1948) and Norman Vincent Peale (1960). However, reduction in the frequency of self-criticism does not necessarily lead to an increase of self-praise (Bandura, 1969). Meichenbaum

and colleagues (Meichenbaum & Cameron, 1974; Meichenbaum & Goodman, 1971) have found success using a progression of internalized instructional cues to supplant maladaptive ones. The classic test preparation exercise in which the negative self-statement "I'm going to fail" is replaced with the more positive and affirmative "Having studied, I'm going to do well" provides an example of this approach.

A self-administered desensitization procedure is also an example of a self-regulated covert stimulus control strategy (Wolpe, 1958). An individual may have a fear of enclosed places. To overcome a fear of riding in an elevator, he/she may self-instruct to ride to an additional floor daily, thereby using a self-regulated desensitizing technique. In this case, the covert response of the fear of enclosed places serves as a stimulus to avoid riding in elevators. By self-instructing to ride to an additional floor in order to stay within the limits of a fear response, the cues of the covert environment are altered and the enclosed space of the elevator no longer elicits a fear and avoidance response.

Ideation patterns, serving as covert cues, also may be altered to elicit more favourable responses. It was shown that children were able to extend their ability to delay gratification when they were taught self-instruction in ideation methods (Michel & Baker, 1975). Practice in ideation methods in which rewards were symbolically represented (marshmallows as clouds, pretzels as logs, etc.) significantly extended their delay of gratification time when compared to controls.

The second type of self-controlling response (SCR) is behavioural programming (Thoresen & Mahoney, 1974). This describes behaviours which occur

“after the fact” in response to a CR+ or a CR-. The activities of behavioural programming are further divided into three categories: self-observation, self-reward, and self-punishment.

Historically, self-awareness has always been considered a desirable attribute; however, self-observation from a behavioural perspective is quite specific, with an emphasis on the relationships between antecedents and their consequences. An accurate assessment must be obtained in order to know what it is that is to be changed. Self-impressions, when compared to a specific collection of observable data, do not necessarily provide the most accurate portrayal of events (Thoreson & Mahoney, 1974). Therefore, the skill of self-recording is basic to the self-administration of an effective program of self-change.

A response to an initiating cue (AIS), either overt or covert, must first be identified in order for self-observation of a behaviour take place. Following the identification of a response, recording of the event takes place through appropriate charting or graphing of the frequency and/or duration observed. Recording of behaviours of interest early in a chain of behaviour has proven more effective than recording done more distant from the initiating event (Thoresen & Mahoney, 1974).

An important outcome to self-observation of a behaviour is the reactive effect, in which the acts of self-observation become discriminatory cues for more favourable controlling responses (Kazdin, 1974). Overall, self-recording as a self-controlling behaviour functions both as a measurement and initial self-change strategy and represents a first step toward the development and implementation of a program of self-change (Thoresen & Mahoney, 1974). The reactive effects by

themselves are of short duration and will not contribute to the long-term maintenance of behaviour unless accompanied by changes in the external environment (e.g., social praise) or the application of additional self-controlling techniques.

The second category of behavioural programming is self-reward or reinforcement. Reinforcement is said to have occurred where the frequency of a behaviour increases following a specific consequence (Alberto & Troutman, 1999). This category may be further divided into the areas of positive self-reward and negative self-reward. Positive self-reward is defined as “the self-administration or consumption of a freely available reinforcer only after the performance of a specific positive response” (Thoresen & Mahoney, 1974, p. 23). Treating one’s self to a special event for having reached a particular plateau in a weight loss program would be an example of a positive self-reward. The reward is contingent upon the completion of some specified performance.

Negative self-reward concerns “the avoidance or escape from a freely avoidable aversive stimulus only after performance of a specific positive response” (Thoresen & Mahoney, 1974, p. 23). An example given is the removal of an uncomplimentary poster for having met the requirements of a diet for a day. Thoresen and Mahoney indicate a lack of controlled research in the area of the self-administration of negative self-reward. They note, however, clinical practice has shown the utility of the concept—when used in combination with positive self-reward—in the treatment of established negative behavioural patterns (e.g., smoking, overeating, etc.).

Overall, the self-administration of contingent reward has been shown to be comparably effective to the external administration of reinforcement, and this skill may be learned through direct training or through social modelling of responses. It is important to note that, since people will tend to impose excessively high standards on themselves, the modelling of "realistic" self-evaluations (including covert modelling) may prove useful toward offsetting "unrealistic" self-expectation (Thoresen & Mahoney, 1974).

When transfer is made from externally administered reinforcement to a self-administered schedule, the rate of self-reward will tend to parallel rates previously administered externally. Discrepancy will occur, however, if the standard of performance is increased and/or tasks become ambiguous (Thoresen & Mahoney, 1974).

Self-reward may require the inclusion of an aversive component. For example, in the case of negative self-reward, an aversive must first be presented; then, contingent upon some desired performance, it can be removed. In the case of positive self-reward, where instead of using a potential reward (e.g., long awaited special activity or purchase), a current activity may be employed which the individual finds enjoyable (e.g., watching TV, eating ice-cream). A state of deprivation must first be created in order that the activity acquires response status as a contingent reinforcer (Thoresen & Mahoney, 1974).

The Premack principle regarding reinforcement may be of some guidance when choosing contingencies and their reinforcements (Premack, 1971). Premack hypothesized that behaviours of high frequency probability may be utilized as

potential reinforcers to behaviours of low frequency probability. Indeed, a reinforcer may become a punishment to a given behaviour should the relative frequency between the two response options become reversed. An example is given in which spinach eating behaviour is a low probability behaviour (LPB) and television viewing a high probability behaviour (HPB). The viewing of television is then suitable as a contingent reinforcer to the eating of spinach. However, according to Premack, should the momentum shift between the probabilities of the two behaviours (that is, should the eating of spinach attain a greater probability than that of television viewing), the contingent viewing of television becomes a punishment to the eating of spinach (Thoresen & Mahoney, 1974).

Thoresen and Mahoney (1974) point out that high probability behaviours (HPBs) that have potential value as reinforcers are not to be confused with high frequency behaviours of little or no reinforcement potential. Frequent behaviours such as watching television or consuming a favourite soft drink may be of utility as contingent reinforcers; other frequent behaviours such as flushing a toilet or opening a door may not.

The final category of behavioural programming is the area of self-punishment. Thoresen and Mahoney (1974) further divide self-punishment into two areas: positive self-punishment and negative self-punishment. Punishment is said to have occurred when a behaviour decreases following a specific consequence (Alberto & Troutman, 1999). Positive self-punishment is described as "the removal of a freely available reinforcer after the performance of a specific, negative response (Thoresen & Mahoney, 1974, p. 23). Example is given of tearing up a

dollar bill after breaking one's diet. Negative self-punishment is described as "the presentation of a freely available aversive stimulus after the performance of a specific, negative response". The presentation of a noxious odour when indulging in prohibited snacking is the example given for this procedure. Note that, in contrast to self-reward where the objective is to accelerate or increase the frequency of a behaviour, the objective of a self-punishment procedure is to decelerate or decrease.

Thoresen and Mahoney (1974) report mixed results concerning the use of negative self-punishment; however, the results from studies regarding positive self-punishment are more promising. The case is presented in which an individual was instructed to tear up a dollar bill for having exceeded smoking a daily allotment of cigarettes. The number of cigarettes allowable was decreased according to a schedule, eventually bringing the number of smokes allowable to zero. The subject's consumption of cigarettes dropped to zero according to the schedule and the contingency never had to be invoked (Axelrod, Hall, Weis and Rohrer, 1974).

Because they are difficult to distinguish from behaviours of self-abuse, there are some problems associated with the procedures of negative self-punishment or the voluntary self-administration of aversives. Self-abusive or masochistic behaviours are correctly considered as the positive reinforcement of reoccurring patterns of behaviour and are not to be confused with punishment procedures where the objective is deceleration of behaviour (Bandura, 1971). That is, self-administration of aversives is risky. When a self-punishment procedure is chosen as a self-management strategy, positive self-punishment—perhaps more aptly

named the voluntary self-withdrawal of opportunity for reinforcement—has been found to be more effective than negative self-punishment. In addition, its value as a treatment option is enhanced when used in combination with a program of self-reward (Mahoney, Moura, & Wade, 1973).

The controlling responses affecting our lives form an important foundation for what appears to be self-control. Depending upon what controlling responses an individual is operating under, one may appear to act with direction, dedication, and purpose or to behave in a seemingly out of control manner. Of particular interest to the study of self-control is the area of aversive self-regulation. Aversive self-regulation describes the qualities of endurance and restraint that are properly considered as controlling responses (CRs) not the self-controlling responses (SCRs) of environmental planning and behavioural programming. Endurance is described as the behaviour “in which an organism optionally tolerates or intensifies some form of aversive stimulation in the absence of any *immediate* external contingencies” (Thoresen & Mahoney, 1974, p. 94). Restraint is “displayed when a person optionally delays, reduces, or foregoes some positive consequences”.

As with all controlling responses, it is felt that endurance and restraint patterns are maintained through a combination of self-controlling actions and long-range environmental influences (Thoresen & Mahoney, 1974). Social praise and respect are frequently given to those who display the behaviours of endurance and restraint. For example, accolades are given to the athlete who overcomes pain and discomfort in pursuit of excellence.

Behaviours of endurance are correctly considered as controlling responses (CRs not SCRs). In support of the notion of endurance as a controlling response, it was found that the ability to withstand an aversive stimulus (hand immersed in cold water) was enhanced by self-controlling responses such as distraction, contracting, and anticipated benefits (Kanfer & Seidner, 1973).

Popular notions of self-control often centre on the concept of restraint. An individual who has the ability to delay, forego, or reduce a positive consequence in some fashion is viewed as one who possesses a high degree of self-control. "Resistance to temptation" (Thoresen & Mahoney, 1974, p. 96), is seen as an essential ingredient to one's successful self-management. Indeed, Goleman (1997, p 81) asserts, "there is perhaps no psychological skill more fundamental than resisting impulse. It is the root of all emotional self-control. Since all emotions, by their very nature, lead to one or another impulse to act". In a now classic study, Shoda, Mischel and Peake (1990) illustrated the importance of the ability to resist temptation as it related to overall life success. Four-year-old children were given the option to receive a single marshmallow in the immediate present or, by waiting for an experimenter to return from running an errand, could receive two marshmallows. For those who did not immediately consume the marshmallow, it was left within easy reach for the duration of the wait. In a follow up study of the same children as adolescents, the ability to delay gratification as a four-year-old appeared to be strongly related to life success as an adolescent quite apart from IQ. Those who were able to wait for the second marshmallow as four-year-olds

demonstrated higher levels overall of social and academic competence as adolescents.

The phenomenon of counter-control also receives mention by Thoresen and Mahoney (1974). Counter-control describes those seemingly self-sacrificing behaviours that have as an apparent objective the control or influence of the behaviour of others. Recalling that aversive self-control behaviours are properly considered as controlling responses (CRs), the determination of contingents for such circumstances becomes problematic. Individuals will respond at great self-expense and, although it may be difficult to understand what controlling response is driving the behaviour, a significant degree of "self-control" may have been displayed. Thoresen and Mahoney cite as examples, parental experience with oppositional children and experimenters whose subjects performed contrary to the directives of the experimenter.

Thoresen and Mahoney (1974) discourage the use of conceptualizations of self-control that are centred on philosophic concepts of *will* or dichotomy of internal and external control. From their perspective, the self-controlling individual is a person who has gained knowledge of their controlling responses. Through self-controlling actions of environmental planning and behavioural programming, such a person is able to develop more effective controlling responses and to discourage or discard those that are unwanted. It would appear that for effective functioning to occur, the aversive self-regulating qualities of endurance and restraint must be present in some capacity and, indeed, it is the display of these very behaviours that serves to confer upon an individual a measure of dignity and respect.

To know one's controlling variables and, through self-directed management, manipulate them for personal growth as one works toward personal objectives, represents a measure of personal freedom and empowerment. As Thoresen and Mahoney (1974, p. 142) explain:

The key to self-mastery is not to found in appeals to willpower and other presumed inner resources, but rather in awareness, *the knowledge of how to use various stimuli to increase and decrease certain responses*. In effect, the person who learns how to manipulate his own sources of stimuli by arranging his internal as well as external environments is one who exhibits self-mastery".

Individuals affected by a prenatal exposure to alcohol characteristically exhibit difficulty with development of effective patterns of self-management (Streissguth, 1997; Streissguth, Barr, Kogan, & Bookstein, 1997). As mentioned earlier, the attainment of independence and employment often proves difficult for these individuals. The purpose of this research is to demonstrate that it is possible to improve self-regulatory behaviours of those affected through engagement in a structured program of self-management enhancement. The purpose of this study is to test a curriculum of instruction designed to improve the self-regulatory behaviour of adolescents affected by prenatal exposure to alcohol. It is proposed that long-term controlling behaviours necessary for independence and employment can be developed using a structured curriculum of skill building in which delay of gratification and tolerance of adversity are employed to attain specified goals.

Method

Participant

One participant, from a special education classroom, was selected for this study. There was medical confirmation of prenatal exposure to alcohol and a diagnosis of Alcohol Related Neurodevelopmental Disorder (ARND). This research was approved by the Research Ethics Board of the University of Manitoba. Appropriate permission/consent to take part in the study was obtained from the parent/guardian, participant, and classroom teacher, and protocols of informed consent were followed in accordance with the guidelines of this institution (see Appendix B). The selection process involved both the classroom teacher and the researcher. Factors of interest, school attendance, and potential for taking part over the time span of the study were considered. Prior to commencement of the investigation, school personnel carefully explained the purpose of the study and its procedures to the parent/guardian and participant.

The participant was a 12 year 5 month old male of First Nations decent. English was the primary language spoken by this individual. The effects of a prenatal exposure to alcohol had not been confirmed until the age of 8 years 7 months when the diagnosis of Alcohol Related Neurodevelopmental Disorder (ARND) was made. His mother had disclosed consuming six to seven beer approximately three times a month during her pregnancy with him. Although both academically and socially delayed, it was felt that he was physically within norms and not dysmorphic. He had a history of seizures of unknown origin. However, currently these do not appear to be a presenting issue. It was the researcher's

initial impression that, in spite of his history of severe acting out behaviour, this individual seemed to have a genuine interest in having friends and pleasing teachers and caregivers.

Results of IQ testing at the age of 10 years 7 months indicated a Verbal Score of 60 and a Performance Score of 72. The evaluating psychologist at the time felt the Verbal IQ placed the subject in the "educably challenged" range and that his short-term auditory memory was consistent with the verbal score. The Performance IQ Score, however, was felt to be an underestimation of his ability to reason with things he could see. Picture Completion and Picture Arrangement subtest scores were within the average range, but Block Design and Object Assembly results were much lower. The subject was observed by the testing psychologist to be quite impulsive and distractible and not able to delay responding or see consequences, particularly on verbal tasks. It was felt that sub-test scores were confounded due to inattention. School placement in a modified program was recommended, planning was to take into account his impulsivity and distractibility.

The life history of this individual is not unlike the recorded life experiences of so many others affected by a prenatal exposure to alcohol. Born in a rural setting and apprehended at eight months from his then 19-year-old birth mother due to a chaotic and unstable home environment, this student has had a life-long experience of impermanent living arrangements, eventually leading to his current group home placement in an urban context. The oldest of four siblings, he has experienced multiple foster placements, which alternated with attempts to reintegrate with his

birth mother or with his father who had separated from the birth mother and subsequently remarried.

Although first impressions described him as fitting in well and adapting to routines in nursery school, social and academic difficulties were recorded early in the subject's school career. He was retained in kindergarten but attended selected activities in a grade one classroom. By the age of six, described as a student with significant speech and language delays, he was receiving speech therapy services on a daily basis. In addition, he had become assaultive toward teachers and classmates with two to five episodes occurring daily. These episodes involved defending possessions, manipulating the behaviour of others, expressing anger, and attempts to terminate academic activity.

When assessed at age of six years eight months, the subject's speech and language development—as tested on the Peabody Picture Vocabulary Test (PPVT) (Dunn & Dunn, 1981)—was at the three-year-five-month level. His articulation of words was unclear and he communicated in three to four word utterances. He could print his first name but did not know the alphabet. Fine motor skills were described as delayed. Educational objectives included developing a concept of numbers, language skills and an awareness of print, and fine motor skills through cutting and pasting articles. Behavioural objectives included developing a tolerance to current activity through a reduction of sources of volatility, and reducing outbursts and aggressive episodes.

At approximately eight years of age, the subject was placed in a grade-three modified program. There he was described as being socially immature with a

history of violent and defiant behaviours both at home and at school, acting without thinking and creating danger, and presenting language delays and difficulty with on task behaviours. The possibility of fetal alcohol syndrome was raised at this time.

Subsequent to confirmation of ARND, evaluations of the subject's academic progress indicated a four-year delay. He was described as a non-reader. He was functioning at a grade-one level in concepts, operations, and applications on the Key Math Diagnostic Arithmetic Test, Revised (Connolly, 1991). Behavioural descriptions remained similar to previous ones: unsafe behaviours, threatening peers, stealing from peers and teachers, and presenting aggressive behaviour toward younger siblings. Although it is difficult to determine from the school records it would appear that this individual had experienced at least five changes in his living arrangements in his lifetime, alternating between attempts to reunite with his birth mother or father, and various foster placements. School changes would appear to have occurred five times as well.

Although his behaviour in his current group home remains somewhat problematic (but unspecified), the subject's extreme behaviours noted in earlier reports have diminished dramatically. He attends school regularly and is an enthusiastic participant in gym activities at lunchtime. Day-to-day school behaviour, however, would seem directly related to current environmental conditions of his group home.

The participant's present school placement appears to have produced beneficial results. Although he demonstrates some good general knowledge, it is often difficult to understand what he is trying to express. Sessions with a speech

therapist have been arranged to help increase his articulation skills. Oral reading has shown some improvement. He volunteers to read aloud (i.e., when the teacher reads a phrase, he then reads it back). He understands basic arithmetic operations and is able to use a table for multiplication and division questions that are difficult for him, but he needs assistance with reading word problems. Reading and spelling are difficult for him, but he does attempt independent writing with support from the teacher or teacher's aide. Behaviours that result in being sent to a resource room for a time-out include out of seat behaviour and negative peer interactions.

Materials

The perspective of self-control/self-regulation presented by Thoresen and Mahoney (1974) has been adapted for this study to provide understanding of behavioural self-control principles and to integrate theory with practice. To summarize: it was asserted that our controlling responses (CRs+, CRs-) could be modified or maintained through our self-controlling responses (SCRs) of environmental planning and behavioural programming. Seven strategies of self-controlling action have been identified for this study: self-instruction and preprogramming of consequences, covert stimulus control, overt stimulus control, self-observation, positive self-reward, negative self-reward, and the self-withdrawal of opportunity for reinforcement. As socially defined, negative controlling responses (CR-s) are those behaviours which feature short-term pleasure and/or benefit in the present, in exchange for long-term aversive consequences in the future. Positive controlling responses (CR+s) are alternately viewed as behaviours of temporary aversive consequence in the present in exchange for future consequences of long-

term pleasure and/or benefit. Endurance and restraint have been described as potentially powerful controlling responses (CRs) that grant a tolerance for adversity and delay of gratification to an individual that allow for a functional efficacy conducive to the development of beneficial long-range life goals and objectives (CR+s). Counter-control describes behaviours of a confounding nature in which the individual may go to great lengths and personal cost to control the behaviour of others. It is suggested that these counter-control behaviours are influenced by unknown and difficult to determine negative controlling responses (CR-s).

The following is an example of a procedure that might be used to facilitate the attainment of the goal of being on time for school (CR+). It illustrates the principles reviewed: planning evening activities which help prepare for morning routines (self-instruction), setting the alarm clock, setting out clothes (overt stimulus control), reviewing agreed upon contingencies regarding being on time for school (preprogramming of consequences), responding to the alarm clock and not sleeping in (self-instructed covert stimulus control), taking note that changes to morning routine result in being on time for school (self-observation), choosing the response of meeting friends at the mall (positive self-reward), and not having to stay in and watch TV for the evening (self-withdrawal of opportunity for reinforcement). In order to avoid the long-term consequences of inconsistent school performance (CR-) and to achieve the social and academic rewards consistent with getting to school on time (CR+), an individual would presumably now have to forego the immediate gratification of sleeping in, in favour of the immediately aversive experience of getting up with sufficient time to get to school. It is felt that issues of counter-

control, although difficult to manage from a helping point of view, would suffer the fate of extinction (to a degree) when new and possibly more rewarding and attractive behaviours are adopted.

The technique of Goal Attainment Scaling (GAS) (Kiresuk, Smith, & Cardillo, 1994) was chosen for this study as a means to measure the changes to participant behaviour that presumably result from intervention/treatment. The scaling of goals provides for the measurement of intervention effectiveness and can address a broad range of treatment issues (see Appendix C, Appendix D). The emphasis is on achievement and away from the deficiencies of an individual—an affirmation of accomplishment. The technique is deliberately tailored to the needs of the individual, encouraging the active engagement of the client in their treatment process through mutual formulation of goals and expected outcomes. GAS is loosely organized around a three-phase schema (Cardillo, 1994b): goal setting, intervention/treatment, and goal attainment assessment using a five-point scale with a minimum of three scaled goals.

To help understand the principles of GAS, a brief review of small-group and single-subject approaches may be useful. Designs for small group and single subject research customarily emphasize the importance of establishing baseline measures of target behaviours—the differences noted between baseline and post-intervention/treatment measurements are presumed to be the consequence of the intervention/treatment experience (Hersen & Barlow, 1976; Kratochwill & Levin, 1992). Attention must be paid to maintaining experimental conditions so that outcomes may be attributed only to the intervention and not to some alternative

explanation. This is particularly crucial when attempt is made to evaluate the comparative effects of two or more treatments. Problems, or threats to validity, include those of multi-treatment interference, the non-reversibility of behaviour, and the need to separate the effects of individual treatments (Holcombe & Wolery, 1994).

In contrast, GAS would appear to side-step the whole issue of pre- and post-intervention/treatment differences as target measures and related concerns of validity through its use of a summary score measuring the amount of change relative to a predicted or expected outcome (Cardillo & Smith, 1994). GAS is an intra-individual approach, where the objective of measurement is defined as "the perceived ability to change" (Cardillo & Smith, 1994, p. 181) within a particular domain of behaviour, not the specific scale content. By providing for the possibility of both positive and negative outcomes, the GAS technique is felt to be free of floor and ceiling effects (Cardillo, 1994b) and it is assumed that each increment on the five point scale will have the same meaning regardless of client or scale content (Cardillo & Smith, 1994). Summed data may be converted into individual *T*-scores allowing for meaningful interpretation of individual performances or comparison across subjects and scale content areas. The use of the *T*-score is based on the concept of the GAS scale as a continuous measure and an assumption of a normal distribution of scores.

Creative Problem Solving (CPS) (Treffinger, Isaksen, & Dorval, 2000), a system for solving problems and meeting objectives, was chosen for goal selection and as a structure for the intervention process. There are three primary

components to the CPS process: understanding the challenge, generating ideas, and preparing for action (see Appendix E). Divergent and convergent modes of thinking are introduced and are intended to stimulate creative thought as part of problem resolution. A Desired Future State Interview, as part of understanding the challenge, initiates the goal selection process and identifies expected outcomes (see Appendix E).

It was anticipated that direct instruction of social skills could be necessary where a participant's lack of social skill was a hindrance to goal attainment. *Teaching Social Skills to Youth: A Curriculum for Child Care Providers* was chosen to guide this process (Dowd & Tierney, 1995). This comprehensive text uses behavioural principles—antecedent event, behavioural response, and consequent event (Alberto & Troutman, 1999)—with skills arranged in order of ascending complexity and abstraction.

The Scope and Sequence of progressive life skill development found in the *Syracuse Community-Referenced Curriculum Guide for Students with Moderate to Severe Disabilities* (Ford et al., 1989) provides a reference for the development of realistic, attainable, and age-appropriate goals. Skill sets are sequenced chronologically and in progression of developmental complexity. Attainment of proficiency across skill areas helps prepare one for eventual independence and employment. Age appropriate Repertoire Charts were chosen to provide a guide for assessment for this study (see Appendix G).

Procedures

The study was conducted over a six-week period with two one-hour sessions per week. The first two sessions were spent engaging the participant with the study and securing informed consent to take part. A final session involved the participant in goal attainment assessment procedures. One session was missed due to the participant's suspension from school. Preplanning and monitoring of environmental contingencies were practiced throughout the study in order to elicit responses favourable to goal development and to produce an environment where overall self-control could be maintained. For the intervention/treatment sessions, an attempt was made to follow the basic Creative Problem Solving format—understanding the challenge, generating ideas, and preparing for action (Treffinger, Isaksen, & Dorval, 2000). Each session was conducted around a theme with additional recreational activities (a pencil-and-paper game called SOS, and ping-pong) included as necessary as an aid to providing an environment conducive to maintaining self-control. Sessions were held in the office of the classroom teacher and away from distracting influences in order to increase the probability of the participant self-rewarding in response to the procedures of the study. The ping-pong activity took place in a resource room across the hall. A coaching/mentoring approach was utilized in an attempt to keep the meetings interesting and enjoyable and to maintain motivation. Sessions were structured to guide the participant toward a utilization of self-controlling response strategies (SCRs) that would lead to successful goal attainments. In the session descriptions, attempt has been made to

highlight, within the context of use, the principal SCR(s) required to successfully complete a task.⁴

Session one: Introduction to the study.

The participant was asked by the classroom teacher if he would like to take part in a program designed to help him meet his individual needs of growing up and to help prepare him for eventual independence and employment. It was explained that his participation was voluntary and that program activities were to take place during regular school hours over a six-week time frame with two one-hour sessions each week. The study was presented in terms of an opportunity of potentially greater self-reward than the activities he might otherwise engage in during the school day. Also, it was clarified that the participant understood that he had been diagnosed as being affected by a prenatal exposure to alcohol. He agreed to meet with the researcher for further discussion regarding his participation in the study.

Session two: Introduction to the study.

The participant met with the researcher and the classroom teacher, and the purpose and procedures of the study were explained once again. Consent to take part in the study was obtained from the participant in accordance with the guidelines of this institution.

Session three: Goal setting.

The process of becoming a part of this study was reviewed with the participant. He was asked to relate what he had been told about the study and his

⁴ Identifying a behaviour as a particular SCR is a qualitative exercise. What is actually happening in a particular circumstance can be open to interpretation.

commitment to taking part in the study was reaffirmed: "This is about you and for you." His participation in the assessment process was also discussed.

The Desired Future State Interview was conducted (covert stimulus control—anticipation of future opportunities for self-reward) and was framed with "There are things that you can do today that can help with what you want in the future, but first we need to talk a little about what you want for your future," and, "Now let's take a look at the kinds of things you need to have and the things you need to do to get what you want." The researcher suggested potential life objectives to help facilitate discussion:

- Have your own place to live
- Have a job
- Get a drivers license
- Own a car
- Have some money in the bank.

We discussed that things could be done in the present that could help him achieve his future goals (covert stimulus control). Three intervention/treatment issues were mutually arrived at and agreed upon by the participant and the researcher—"write last name", "greet adults appropriately", "clean hands, no ink." The participant was given verbal reinforcement for his efforts and was told that the researcher would then review the selected goals with the classroom teacher to make sure that the issues selected were "O.K". The game of ping-pong was used as a part of providing an environment conducive to maintaining self-control while at the same time paying attention to the participant's attention span and need for

physical activity (maintain environment conducive to self-control). The session was concluded with a handshake to provide positive reinforcement for his time and to model prosocial behaviour, and agreement was made to meet next session. After the session, the researcher completed a tentative Goal Attainment Follow Up Guide and reviewed the intervention/treatment issues, goals, and expected outcomes with the classroom teacher to ensure that goals selected were appropriate, realistic, and attainable (see Appendix H).

Session four: Intervention/treatment.

Issues, goals, and expected outcomes were reviewed and discussed with the participant to ensure agreement and continued commitment to taking part in the study (covert stimulus control). A completed copy of the Goal Attainment Follow Up Guide was provided to him (self-instruction, self-observation).

The participant practiced the writing of his full name using a pre-written example as a template (self-observation, self-reward). Proper greeting etiquette was taught and practiced using the greeting sequence from *Teaching Social Skills To Youth* (Dowd & Tierney, 1995)—look at the person, use a pleasant voice, say “hi” or “hello” (self-instruction, covert stimulus control, overt stimulus control). The use of a handshake was discussed and practiced. A rationale for having clean hands without any writing on them was presented and discussed—“Adults will view you as being grown-up” and, “Someday when you want to find a job it will be important to look good to those who might give you a job” (self-instruction, covert stimulus control—anticipation of future opportunities for self-reward). The remainder of the time was spent playing the SOS game (maintain environment

conducive to self-control). The session was concluded with a review of the purpose of our meetings and his goals (covert stimulus control—anticipation of future opportunities for self-reward). Progress made toward goal attainment was verbally reinforced.

Session five: Intervention/treatment

The session was initiated with a handshake and “hello” by the researcher as a modelling of a prosocial greeting and to assess the participant’s progress in the skill of greeting others (self-instruction, covert stimulus control). This also afforded the opportunity to check his hands for ink. The purpose of our meeting and participant’s goals were reviewed at this time (covert stimulus control—anticipation of future opportunities for self-reward). The participant completed a Name Writing Puzzle (self-observation, self-reward) (see Appendix I), and greeting etiquette was explored using a Greeting Etiquette Discussion Guide, in which figures were provided both for emphasizing key points (covert stimulus control) and passing time colouring (see Appendix J). Ping-pong and the SOS game were used again to attend to the participant’s need for physical activity and to accommodate his attention span limitations (maintain environment conducive to self-control). The session concluded with a review of the reasons for meeting (covert stimulus control—anticipation of future opportunities for self-reward). The activity for the next meeting was introduced (covert stimulus control)—a walk to a local convenience store to practice social skills. A handshake and “see you next time” modelled prosocial behaviour and provided practice of the skill.

Session six: Intervention/treatment.

The researcher and the classroom teacher accompanied the participant on a walk to a local convenience store. This provided an opportunity to observe the participant's behaviour in the community. The plan was for the participant to initiate a proper greeting with the store clerk and to successfully negotiate a small purchase (self-instruction, covert stimulus control, overt stimulus control, self-observation, self-reward). The researcher initiated the session with a handshake greeting (self-instruction, covert stimulus control) and the purpose of the walk was explained prior to departure—appropriate greeting and dialogue with the store clerk while making a purchase. Review and discussion of in-store performance took place on the return walk. Verbal reinforcement was given for successful instances of prosocial behaviour.

Session seven: Intervention/treatment.

This session did not occur. The participant had been suspended from school on this particular day.

Session eight: Intervention/treatment.

The plan for this session was for the researcher, participant, and classroom teacher to walk to a nearby restaurant and have lunch. This was to provide a context where social skills could be taught, used, monitored, and reinforced. The participant's task would be to greet restaurant personnel in an appropriate manner and to order off the menu (self-instruction, covert stimulus control, overt stimulus control, self-observation, self-reward). The researcher initiated this session with a greeting handshake (self-instruction, covert stimulus control), and the plan for the

day was explained. The trip to the restaurant took place as planned. Verbal reinforcement was given to the participant for his efforts and successes throughout the event. The session was concluded with a handshake and the participant was reminded of the date and time of the next session.

Session nine: Intervention/treatment.

A Word Search Task had been devised that engaged the participant with the task of finding his name hidden within the background of distracting letters (self-observation, self-reward) (see Appendix K). A greeting handshake initiated the session (self-instruction, covert stimulus control) and the reasons for the meeting and the participant's goals were reviewed (covert stimulus control—anticipation of future opportunities for self-reward). The participant completed the Word Search Task, and then the remainder of the time was spent playing a game of SOS and engaging in informal conversation (maintain environment conducive to self-control). The session was concluded with a handshake and a review of the purpose of the session and the participant's goals.

Session ten: Intervention/treatment.

The researcher greeted the participant with the now familiar handshake greeting, and he was reminded that this would be our last session. Two activities were planned: a Sample Job Application form to provide an example of why it might be important to write your full name (covert stimulus control—anticipation of opportunities for future self-reward, self-observation, self-reward) (see Appendix L) and a Pictorial Review of Goals (covert stimulus control—anticipation of future opportunities for self-reward) (see Appendix M). Both were completed with

assistance from the researcher. The remainder of the time was spent with the participant talking about his home community. The session was concluded with modelling of prosocial behaviour—a handshake and with the researcher thanking the participant for having taken part in this study (self-instruction, covert stimulus control).

Session eleven: Goal Attainment Assessment.

To avoid scoring bias, it is recommended that assessment of outcome procedures are performed independently from goal setters and service providers (Cardillo, 1994b). Assessments in this study were at some variance to this standard. The classroom teacher, in addition to being involved in goal setting, was chosen to rate the degree of outcome success for the participant. The researcher felt that someone familiar to the participant should complete the assessment process, since familiarity with the rater could yield a higher quality of participant input. Each goal was reviewed and rated, and mutual agreement was reached between the classroom teacher and the participant (see Appendix N). The participant was also asked what he had learned from his experience and what was helpful or worthwhile. His satisfaction and enjoyment from participation was explored. He was thanked by the classroom teacher for having taken part, which concluded both the session and the data-gathering portion of the study.

Results and Discussion

Evaluation of the participant's rated performance followed the guidelines for the summary and conversion of goal attainment scores (Cardillo, 1994a). The rated performance of the participant came close to expected levels of outcome. The summation of the scores was -1. "Write last name" was rated at a -1 (somewhat less than expected outcome); "greet adults appropriately" was rated at 0 (expected level of outcome); and "clean hands, no ink" was rated at 0 as well (expected level of outcome). Table 1 provides a summary of the results.

Table 1

Participant Goal Attainment Conversion Scores

Goal	Rating	Av. Scale Score	T-Score
Write last name	-1	--	--
Greet adults appropriately	0	--	--
Clean hands, no ink	0	--	--
Sum	-1	-.33	45.44

Goal Attainment Scaling is felt to be an assessment tool sensitive to the measurement of treatment-induced change (Smith & Cardillo, 1994) and it would

appear that a valid measure of change had taken place for the participant during the course of this particular study. Goals for this study were designed to be sensitive to a brief period of specific and intensive intervention/treatment. This makes changes noted in participant behaviour attributable to treatment/intervention effects, rather than to some alternative explanation. Treatment-induced change, however, is not to be taken as an indicator of overall adjustment but to be considered only in relation to the selected goals.

As the derivation of *T*-scores for GAS is based on the assumption of a normal frequency distribution (Cardillo & Smith, 1994), an important objective of the goal setting stage is to achieve congruence between the order of difficulty for the attainment of a goal and its particular level of outcome⁵. Therefore, goal attainments that greatly exceed, either above or below, expected levels of outcome, may have been assigned inaccurately. That the participant in this study was at or near expected levels of outcome for the goals selected would appear to indicate that the expected level of performance had been accurately assessed in the goal setting stage of implementing the GAS technique.

Attainment of expected outcomes—and the experience of their benefits—was intended to be contingent on a capacity to tolerate a measure of temporary adversity and delay of gratification. Long-term controlling behaviours, as represented by the goals selected, required the participant to employ the constructs of endurance or restraint in the attainment of each of his three goals. The goal of

⁵ A correspondence is intended between the 0-point of the five-point GAS scale (the most expected level of outcome) and a *T*-score of 50.0 (the mean/median of a normal frequency distribution).

“write last name” was rated at below expected level of outcome with a score of -1. The participant’s writing of his first name posed no particular problem for him, but it was the writing of his last name (comprised of nine letters) that was problematic. Prior to his volunteering to take part in this project, the participant would identify himself on school items by printing only his first name. The manner in which he signed the informed consent document for his participation in the study was an example of this. When the topic of name writing was broached in the context of goal setting, the participant enthusiastically self-rewarded by printing his full name on whatever paper was within his reach—including paperwork belonging to the classroom teacher—until appropriate practice paper was supplied. Some prompting was required to produce a correct last name spelling (reinforcement of effort to write full name, maintain environment conducive to self-control). In the course of the study, the participant began to write his full name on his schoolwork where only his first name had been written before. He then went through a period when he wrote no name at all on his schoolwork before establishing a modest pattern of both names on his work. It would seem that the adversity of the cognitive burden of focusing his attention and taking the time to write his full name overtook the self-reinforcement potential that the novelty and attention of writing his full name for the researcher had initially brought to him.

The goal of “greet adults appropriately” (which was rated at 0, the expected level of outcome) was easier to reward and easier practice. His initial presentation of himself seemed to indicate that he had no concept of greeting others appropriately. The necessity of learning how to greet adults was clearly

demonstrated by an event that had taken place prior to participant selection for this study. The participant introduced himself to the researcher in the school cafeteria with the unorthodox style of coming from behind the unsuspecting researcher and slapping him forcefully on the back. He then self-rewarded by proudly standing back with a big grin on his face and looking at the researcher. Also, when formally introduced to the researcher in the initial session of the study, the participant's rather reluctant handshake was accompanied by a look toward the classroom teacher and the comment, "Oh, him!" Over the course of the study his greeting style developed a form and content more appropriate to that of a young adult. In order to meet the expected level of outcome on this goal, the overall rewards of knowing that he was now behaving in a more mature manner (covert stimulus control) would surmount the potential adversities associated with the greeting sequence. It was necessary to overcome feelings of awkwardness or shyness in speaking to someone unfamiliar or making eye contact. The "real world" practice and opportunity for reinforcement provided by the convenience store and restaurant outings probably contributed to his success in this area.

In contrast to the other two goals, the goal of "clean hands, no ink" (which was rated at 0, the expected level of outcome) required the resistance to temptation or delay of gratification, rather than a tolerance of adversity. The participant acknowledged that he had to tell himself (self-instruction) not to write on his hands. Initially this must have felt like a self-withdrawal of opportunity for reinforcement until the rewards of presenting clean hands were realized. The participant's long-standing habit of writing on his hands was quite evident in the goal-setting

interview. Both hands were covered with inked names, initials, words, and designs that extended from the palms across the backs, including the knuckles and fingers. At first, he seemed unaware of the immaturity of the behaviour and he was quite proud (self-reward) to provide explanations to the researcher regarding the meaning of his "work". The researcher helped him to think about his "future state" and he was quite adamant that he was going to go to work someday. He recognized the incongruence of looking for work with his hands in their present condition and agreed with the researcher that learning to keep his hands clean was important for his future objective of someday finding a job. The skill development technique employed in the attainment of this particular goal was primarily discussion and review of the importance of clean hands (the look of a grown-up person). Verbal reinforcement on clean appearance was offered where appropriate. His hands, although sometimes written upon, never again presented the same degree of clutter as they had in the initial goal setting session.

In terms of the paradigm of Thoresen and Mahoney (1974), it could be said that the participant had replaced less adaptive CR-s with more effective CR+s in respect to all three of his goals. On the matter of counter-control, the participant did not seem to act at deliberate self-expense in an effort to confound study outcomes although his commitment to the attainment of his goals was, at times, greatly influenced by his fluctuation in mood.

The difficulties that alcohol-affected individuals can have with self-regulation (Streissguth, Barr, Kogan, & Bookstein, 1997) were quite evident for the participant. What may start out as progress can suffer abrupt and unexplained turnaround and

regression, only to pick up again at a later date (Lutke, 1997) (e.g., the participant's early success in writing his full name, to writing no name, back to sporadic instances of writing his full name). Also, the participant appeared to function primarily in the moment, and from moment to moment in a "stream of consciousness" manner with frequent shifts of mood and interest. That made it difficult for him to conceptualize or act on information in a logical or sequential manner. It was difficult to guide him in any kind of thematic discussion at all.

Confounding events are going to be a part of any study that uses a "real world" context for its data source, but these only mirror what might occur in an actual teaching or training session. The participant's day-to-day performance was very much influenced by his group home milieu and by one peer in particular. He presented a spectrum of mood, interest, and motivation during the sessions that required management—the games of ping-pong and SOS were instrumental in keeping the participant engaged over the time span of the study.

Behavioural self-management is not something that is acquired overnight or from a single series of lessons; it is best thought of as a work in progress. This study has shown that it is possible, in a small way, to make positive and measurable changes to the self-regulatory patterns of a member of a target group that characteristically has difficulty with issues of self-management. At first look, the goals selected for development in the study may appear somewhat trivial when held in comparison to some of the broader issues of emotional and behavioural self-control the participant has yet to face. However, imbedded in a larger context as markers of a mature person, the ability to write one's full name, greet others

appropriately, and present one's self in a well kept manner are essential factors contributing to the overall success of an individual. The curriculum approach, centred on the technique of GAS (Kiresuk, Smith, & Cardillo, 1994), provided a means through which the behavioural changes took place. As has been discussed, GAS is a measure sensitive to treatment-induced change, but, in addition, its use allowed for a rapid start-up of a program of treatment/intervention. Once the participant selection process was completed, goals were easily and quickly formulated and formatted and the treatment/intervention process begun. Closure was an equally economic process with its single session rating interview and feedback to the participant.

In contrast, the Creative Problem Solving model (Treffinger, Isaksen, & Dorval, 2000) (understanding the challenge, generating ideas, preparing for action) was difficult to implement with this particular participant—as it would be with others like him. It did serve, however, as a useful guide to help keep the researcher on track while conducting sessions.

Although an overall structure and plan was in place prior to goal setting, the actual instructional materials and aids used to develop understanding and skill in the selected target areas were, by necessity, created after the goal selection. To maintain interest, commitment, and motivation during the life of the study, factors of aptitude, attention span, educational attainment, and the occurrence of confounding events had to be considered. As participation was voluntary, sessions needed to be seen by the participant as more attractive than competing activities.

The life experiences and physical and emotional manifestations of the syndrome for this participant—who was essentially chosen at random—typifies the life of many others born with the effects of a prenatal exposure to alcohol (Aronson & Hagberg, 1998; Clarren & Astley, 1998; Mattson, Riley, Gramling, Delis, & Jones, 1998; Steinhausen & Spohr, 1998; Streissguth, 1997). Cognitive impairments, motor difficulties, attentional and hyperactivity issues, and even seizures have framed the life experiences of this individual. There were numerous upsets in his living and school environments, beginning with early removal from his birth home (without diagnosis of his condition). In spite of his obvious social and intellectual problems, diagnosis did not occur until later in life.⁶ That he did not show any obvious physical markers of the syndrome perhaps contributed to the delay.

This investigation, obviously, had only one subject; however, much of our knowledge in the area of human behaviour has been generalized from the information gathered from single case research (Hersen & Barlow, 1976; Krishef, 1991). Also, single case research can provide a richness of detail and insight that may not be found using other methods of investigation (Hersen & Barlow, 1976). Although there was material in the proposed curriculum that remained untapped, the model of intervention/treatment performed basically as was anticipated and positive growth was observed for the participant who volunteered to take part. Further testing of this particular approach is required in order to verify its effectiveness in producing change in other members of the target population.

⁶ In the selection process of finding a participant for this study, there were others who appeared to be suitable to take part given their history, behaviour, and intellect. However, in these cases, the medical examination required to confirm or disconfirm the presence of the syndrome had not yet been performed.

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Appendix A

Approval Certificate: Research Ethics Board



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APPROVAL CERTIFICATE

06 February 2002

TO: Andre Lacabanne
Principal Investigator

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2002:007
"Behavioral Self-Management"

Please be advised that your above-referenced protocol has received human ethics approval by the the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

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Appendix B

Informed Consent



Participation Consent Form for Participants

Research Project Title: Behavioral Self-Management: A Curriculum for Those Affected by Fetal Alcohol Syndrome

Researcher: Andre Lacabanne

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Description of Research Procedures

People who have been exposed to alcohol before they were born sometimes have trouble learning how to manage themselves. The purpose of this research is to show that by taking part in a program that will teach you some new ways of managing yourself, you will learn how to control your own behavior so you can accomplish your goals. The project is Andre Lacabanne's master's thesis project and the reporting on the study's procedures and results will be included in a thesis submitted for Masters of Education, University of Manitoba. Your participation is voluntary.

You will be asked to describe what you want for yourself for the future—for example, a job, living on your own, money in the bank. You will be able to choose goals from your present day activities that will help to prepare you for what you want for yourself in the future—for example, getting up and arriving on time for school or choosing recreational activities that are both fun and good for you. Choosing your goals and practicing what you need to learn will take place during regular school hours. There will be two meetings a week for up to an hour per meeting for a six week period; however, you will be responsible for working on the goals on your own outside of class at home, in school, and in the community.

As a part of writing this study, I need to describe those who take part. In order to help me do this, I am requesting access to your cumulative school files. Information that may be used may include age, gender, cultural/ethnic identity, confirmation of FAS/FAE, social/family history, living arrangements (e.g., with birth parents or in foster home), school history including current reading and

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math levels, and results of aptitude testing. All information will be used only for this thesis project and will be kept strictly confidential.

The only information I will have about our meetings will be in the form of handwritten notes and they will be destroyed the end of the thesis project (anticipated date May, 2002). Notes will not include any identifiable information and will only be shared with my supervising professor. No one will be able to tell that you are the person who had taken part in this study. In reporting the results, you will be given a different name and your school will not be identified. In addition, any confidential information contained in school records required by this study will contain no identifiable information linking you to this study.

The risks of harm to you for having taken part in this study are minimal and are not any greater than what you might already experience in your everyday life and in doing activities like those you take part in, in gym class or in school.

Your list of goals will be shared with your teacher who may help keep you on track. At the end of the study, your teacher will do the final rating on how you did in trying to reach your goals. At the end of the study, you will take part in the evaluation of your progress and your successes in learning new skills will be recognized. Also, at the end of the study, if you want a summary of what we learned, it will be sent to you if you fill in your address at the bottom of this form.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Andre Lacabanne, Researcher

Ken McCluskey, Ph.D., Supervising Professor

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature Date

Parent or Guardian's Signature Date

Researcher's Signature Date

Yes, please send me a copy of the summary of the results of this study.

Street Address City Province Postal Code



Participation Consent Form for Parent/guardian

Research Project Title: Behavioral Self-Management: A Curriculum for Those Affected by Fetal Alcohol Syndrome

Researcher: Andre Lacabanne

(Please note, it is important for your child to understand the information contained in this section.) This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Description of Research Procedures

Individuals affected by a prenatal exposure to alcohol frequently have difficulty developing effective patterns of self-management. The purpose of this research is to demonstrate that it is possible to improve their self-regulatory behavior by taking part in a structured program of self-management enhancement. The project is Andre Lacabanne's master's thesis project and the reporting on the study's procedures and results will be included in a thesis submitted for Masters of Education, University of Manitoba. Participation is voluntary.

Your child will be asked to describe what he/she might want as it relates to future life objectives (employment, financial independence, etc.). Goals will be chosen which help facilitate the development of his/her future life objectives from present day activities (for example, getting up and arriving on time for school or choosing healthy recreational activities). Initial development of your child's goals and the practice of related skills will take place during regular school hours in twice weekly meetings of up to an hour in duration over a six week period; however, overall pursuit of a goal's development is to take place by their own initiative where appropriate (e.g., home, school, community).

As part of this thesis study, a detailed description of the participants is required. In order to provide this description, I am requesting access to your child's cumulative school file. Information that may be used for this description may include age, gender, cultural/ethnic identity, confirmation of FAS/FAE, school history, social/family history, living arrangements (e.g., with biological parents or foster home), academic history including current levels of function in reading and

math, and results of aptitude testing. All information will be used only for this thesis project and will be kept strictly confidential.

Data will be collected in the form of handwritten notes and will be destroyed upon completion of the thesis project (anticipated date May, 2002). Notes will not include any identifiable information and will only be shared with my supervising professor. In the final written report, steps will be taken to protect the anonymity and confidentiality of your child. Your child will be assigned a different name for reporting of results and the school will remain unidentified. In addition, any confidential information contained in school records required by this study will contain no identifiable information linking it to a particular person or location.

The risks of harm to your child for having taken part in this study are not greater nor more likely, considering probability and magnitude, than those ordinarily encountered in life, including those encountered during the performance of routine physical or psychological examinations or tests. Your child may gain the benefits of learning more effective patterns of self-management and reducing risky behavior in favor of more personally responsible behavior.

Your child's list of goals will be shared with the classroom teacher who will provide a daily reminder of the process. At the end of the study, the teacher will provide the final rating of your child's progress towards his/her goals. The researcher will review the progress made towards goals with your child and recognition will be given for his/her successes. Also, you can receive a summary of the results of the study by providing your address at the bottom of this form.

(Please note, it is important for your child to understand the information contained in this section.) Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Andre Lacabanne, Researcher

Ken McCluskey, Ph.D., Supervising Professor

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may

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contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature Date

Parent or Guardian's Signature Date

Researcher's Signature Date

Yes, please send me a copy of the summary of the results of this study.

Street Address City Province Postal Code



Participation Consent Form for Classroom Teacher

Research Project Title: Behavioral Self-Management: A Curriculum for
Those Affected by Fetal Alcohol Syndrome

Researcher: Andre Lacabanne

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Description of Research Procedures

Individuals affected by a prenatal exposure to alcohol frequently have difficulty developing effective patterns of self-management. The purpose of this research is to demonstrate that it is possible to improve their self-regulatory behavior by taking part in a structured program of self-management enhancement. The project is Andre Lacabanne's master's thesis project and the reporting on the study's procedures and results will be included in a thesis submitted for Masters of Education, University of Manitoba. Your student(s) will be asked to describe what he/she might want as it relates to future life objectives (employment, financial independence, etc.). Goals will be chosen which help facilitate the development of his/her future life objectives from present day activities (for example, getting up and arriving on time for school or choosing healthy recreational activities). Initial development of your student's goals and the practice of related skills will take place during regular school hours in twice weekly meetings of up to an hour in duration over a six week period; however, overall pursuit of a goal's development is to take place by their own initiative where appropriate (e.g., home, school, community).

Your involvement would include providing a brief daily reminder to the student(s) of the process he/she is working on to attain the chosen goals. At the end of the study it is requested that you provide a final rating of the student's progress. This rating process should take approximately one hour per student. Your participation is voluntary.

Data will be collected in the form of handwritten notes and will be destroyed upon completion of the thesis project (anticipated date May, 2002). Notes will not include any identifiable information and will only be shared with my supervising professor. In

Page 2

the final written report, steps will be taken to protect your anonymity and confidentiality. You will be referred to as the classroom teacher and your school will remain unnamed.

You can receive a summary of the results of the study by providing your address at the bottom of this form.

The risks of harm to you for having taken part in this study are not greater nor more likely, considering probability and magnitude, than those ordinarily encountered in life, including those encountered during the performance of routine school day.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate in the manner described above. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Andre Lacabanne, Researcher

Ken McCluskey, Ph.D., Supervising Professor

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Teacher's Signature Date

Researcher's Signature Date

Yes, please send me a copy of the summary of the results of this study.

Street Address City Province Postal Code

Appendix C

Summary of Goal Scaling

1. Define the issues that will become the treatment/intervention focus. Focus only on those issues that are expected to change during the course of intervention/treatment.
2. Select at least three goals from items identified as treatment issues. Treatment issues are selected from any behavioral, affective, or cognitive concern.
3. Select a title for each goal (e.g., Save money, control anger, attend school). Place the goal title in the title box of the Goal Attainment Follow-Up Guide.
4. Choose an indicator for each goal that represents the goal and can illustrate progress. The indicator can be any behavior, affective state, skill, or process that exemplifies the goal (e.g., Depression—frequency of depression episodes, school attendance—percentage of time spent in school, or self-esteem—positive or negative thoughts of attribution).
5. Determine an expected level of outcome for the goal. This may be done quantitatively by specifying a particular frequency, percentage, or level of intensity. Judgment may also be made qualitatively (e.g., Degree of hallucinatory control of an individual). Avoid stating exact figures; express as a range of possibility (e.g., 7.5 to 8.5 hours of sleep, 2 to 4 depression episodes).
6. Critique the expected level of outcome. Indicator and expected level of outcome should be consistent with the stated goal. Language should be specific and concise, clear of vague references, jargon free, and have only one variable per scale. Ensure that evaluative materials and sources of information are specified (e.g., observations, self-reports, records).

7. Determine the *somewhat more* and *somewhat less* than expected levels of outcome using criteria established for setting the expected level of outcome
8. Determine the *much more* and *much less* than expected levels of outcome.

These levels represent the extent of what may be feasibly achieved.

Repeat steps 4-8 for each of the goals selected (adapted from Kiresuk, Smith & Cardillo, 1994).

Guidelines for Goal Scaling

1. Use one variable per scale.
2. Consider all possibilities for each scale.
3. Leave no cells blank.
4. Information contained in one cell should not overlap to another.
5. The levels from one cell to another should be continuous (no gaps).
6. Avoid abbreviations, special terms, or ambiguous terms

Scoring and Conversion of Scaled Goals

1. Rate each scale from its range of possibilities, -2 to +2.
2. Sum all scores for total raw score.
3. Consult appropriate conversion table that corresponds with the number of scored scales (see Kiresuk, Smith, & Cardillo; 1994)
4. Find matching scale score sum and corresponding average score and T score.
5. T scores may be used to make comparison between two or more sets of scaled goals that may differ in goal content and/or goal number.

GOAL ATTAINMENT FOLLOW-UP GUIDE

LEVEL OF ATTAINMENT	Scale 1	Scale 2	Scale 3	Scale 4	Scale 5
Much less -2 than expected					
Somewhat less -1 than expected					
Expected level 0 of outcome					
Somewhat more +1 than expected					
Much more +2 than expected					
COMMENTS					

(Adapted from Cardillo & Choate, 1994)

Appendix E

Creative Problem Solving

- Understanding the Challenge
 - Identify and select a broad goal or starting point.
 - Determine direction of effort through exploration of tasks.
 - Create problem statements from which to choose a specific problem for consideration.
- Generating Ideas
 - Respond to problem statement through articulation of new, unusual, or varied ideas.
 - Identify those ideas that have the greatest solution potential.
- Preparing for Action
 - Develop potential solutions.
 - Find ways to support potential solutions and overcome obstacles.
 - Formulate action plan to implement those solutions chosen as answer to understanding the challenge (adapted from Treffinger, Isaksen & Dorval, 2000).

Appendix F

Desired Future State Interview

- What are you doing now?
 - Education/vocational training
 - Employment experience
 - Current living arrangements
 - Independent
 - Dependent
 - Family
 - Foster placement
 - Group home
 - Institutional
 - Other
 - Current financial status
 - Independent (name sources of income)
 - Dependent (name sources of income)
 - Partial dependence (describe)
- What do you want for yourself?
 - Education/vocational training
 - Employment
 - Financial
 - Living arrangements
 - Leisure time

- What is getting in the way of your getting what you want?
- What do you think you need to do to get what you want?
 - What areas of your life require your attention
 - What type of educational/vocational training do you require
 - What personal skills do you need to learn (adapted from Treffinger, Isaksen, & Dorval, 1994)

Appendix G

Blank Repertoire Charts

FORM C.13

Repertoire chart for: Middle School (ages 12-14) Student: _____

Domain: Self-Management/Home Living Age: _____ Date: _____

Goal area	Present activities	Performance level				Critical features			Note priority goal areas
		Check one				Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent	Has related social skills?	Initiates as needed?	Makes choices?	Uses safety measures?	
Eating and food preparation	Eat balanced meals with appropriate manners								
	Choose nutritious foods: breakfast, lunch, snacks								
	Plan and prepare snacks for self								
	Prepare simple meals: breakfast, lunch (some cooking)								
	Serve food items to others								
	Clear table and do dishes after food preparation								
	Store food and leftovers								

(continued)

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

FORM C.13
(continued)

Goal area	Present activities	Performance level				Has related social skills?	Critical features			Note priority goal areas
		Check one					Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent			Initiates as needed?	Makes choices?	Uses safety measures?	
Grooming and dressing	Brush/comb and style hair (also choose hairstyle)									
	Use skin care products (cosmetics if desired)									
	Care for eyeglasses/contact lenses									
	Get dressed/undressed (physical education, outer clothes)									
	Maintain neat appearance throughout school day									
	Use private and public toilets									
	Wash hands and face: routine times and for specific activities (food preparation)									
	Follow acceptable hygiene practices									
Manage menstrual care										

(continued)

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

Form C.13
(continued)

Goal area	Present activities	Performance level				Critical features			Note priority goal areas
		Check one				Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent	Has related social skills?	Initiates as needed?	Makes choices?	Uses safety measures?	
Safety and health	Follow safety rules								
	Exit building for emergency/alarm								
	Take care with utensils								
	Inform adult when sick/injured								
	Take medicine with supervision								
	Avoid/report sexual abuse								
	Report emergencies								
	Use caution with strangers								
	Use phone to obtain emergency help								
	Avoid alcohol and other drugs								
	Use appropriate first-aid procedures: minor injuries (cuts, burns)								
	Maintain good personal health habits (diet, exercise) with supervision								

(continued)

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

FORM C.13
(continued)

Goal area	Present activities	Performance level				Critical features			Note priority goal areas
		Check one				Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent	Has related social skills?	Initiates as needed?	Makes choices?	Uses safety measures?	
Assisting and taking care of others (examples)									
Budgeting and planning/scheduling	Plan and gather belongings for outings/activities								
	Take care of personal belongings								
	Manage allowance and other personal purchases and money for personal gifts								
	Manage weekly/monthly schedule								
	Arrange activities with friends and family								
	Participate in fundraising activities								

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. *The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities* (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

FORM C.14

Repertoire chart for: Middle School (ages 12-14) Student: _____

Domain: Vocational Age: _____ Date: _____

Goal areas and experiences	Performance level			Has related social skills?	Critical features				Note priority goal areas
	Assistance on most steps	Assistance on some steps	Independent		Broadens repertoire	Challenging	Student preference	Provides interactions with nonhandicapped co-workers	
Kindergarten and elementary school classroom/school jobs									
Middle school vocational training experiences									
High school vocational training sites									
Transition to community employment									

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

Form C.15

Repertoire chart for: Middle School (ages 12-14) Student: _____

Domain: Recreation/Leisure Age: _____ Date: _____

Goal area	Present activities	Performance level			Critical features	Note priority goal areas	
		Check one					Check all that apply
		Assistance on most steps	Assistance on some steps	Independent			
School and extra-curricular (examples)							
Activities to do alone: at home and in the neighborhood (examples)							
Activities to do with family and friends: at home and in the neighborhood (examples)							
Physical fitness (examples)							
Activities to do alone: in the community (examples)							
Activities with family and friends: in the community (examples)							

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. *The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities* (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

FORM C.16

Repertoire chart for: Middle School (ages 12-14) Student: _____

Domain: General Community Functioning Age: _____ Date: _____

Goal area	Present activities	Performance level				Critical features			Note priority goal areas
		Check one			Has related social skills?	Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent		Initiates as needed?	Makes choices?	Uses safety measures?	
Travel	Walk, ride bus, ride bike to and from school								
	Walk to various destinations								
	Cross streets safely								
	Use public bus/subway for general transportation								
Community safety	Problem solve if lost in new places								
	Use caution with strangers								
Grocery shopping	Buy items needed for specific planned menu, with help								

(continued)

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. *The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities* (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

FORM C.16
(continued)

Goal area	Present activities	Performance level				Critical features			Note priority goal areas
		Check one				Check all that apply			
		Assistance on most steps	Assistance on some steps	Independent	Has related social skills?	Initiates as needed?	Makes choices?	Uses safety measures?	
General shopping	Buy few items in store with limited money amount								
	Purchase personal care items								
	Eating out								
	Eat in school cafeteria								
	Order and eat in fast-food restaurant								
	Buy food/drinks from vending machines								
	Budget/carry money for lunch/snacks								
Using services	Use post office								
	Use pay phone								
	Ask for assistance in stores								

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey (1989). Blank repertoire charts. In Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey. The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities (pp. 360-367). Baltimore: Paul H. Brookes Publishing Co., reprinted with permission.

GOAL ATTAINMENT FOLLOW-UP GUIDE

Goals: Write last name
Greet adults appropriately
Clean hands, no ink

LEVEL OF ATTAINMENT	Scale 1	Scale 2	Scale 3	Scale 4	Scale 5
Much less  -2 than expected	Needs prompt to write last name	No proper use of greeting opportunity time	Clean hands, no ink 1 of 5 school days		
Somewhat less -1 than expected	Writes last name ¼ of time without prompt	Uses proper greeting ¼ of greeting opportunity time	Clean hands, no ink 2 of 5 school days		
Expected level 0 of outcome	Writes last name ½ of time without prompt	Uses proper greeting ½ of greeting opportunity time	Clean hands, no ink 3 of 5 school days		
Somewhat more +1 than expected	Writes last name ¾ of time without prompt	Uses proper greeting ¾ of greeting opportunity time	Clean hands, no ink 4 of 5 school days		
Much more  +2 than expected	Writes last name all the time without prompt	Uses proper greeting all of greeting opportunity time	Clean hands, no ink 5 of 5 school days		
COMMENTS					

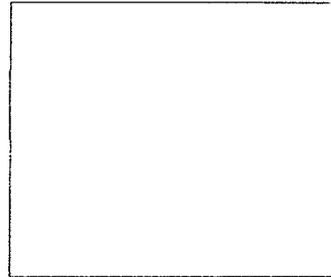
Appendix I

Name Writing Puzzle

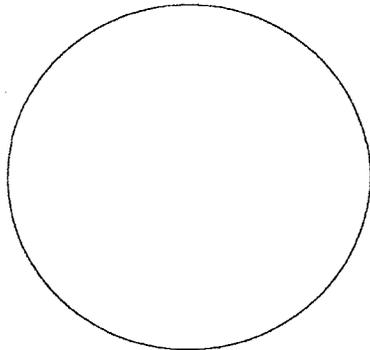
Write your first name in the circle.

Write your last name in the square.

Write your whole name on the line.

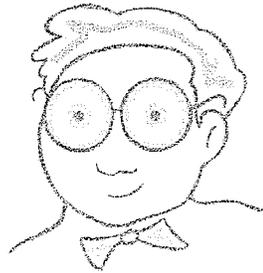


My Name

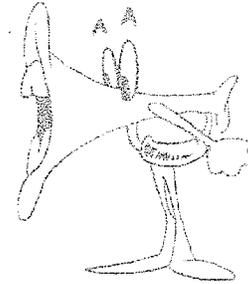


Greeting Etiquette Discussion Guide

Greeting Others



1 Look at the person



2 Use a pleasant voice



3 Say "Hi" or "Hello."

IN SEARCH OF ANDRE'S NAME!

A	O	L	A	C	A	B	A	N	N	E	M	I	O	A	W	S	D	V	W	N	M
B	S	T	Y	E	U	T	Y	T	Y	N	Q	U	T	S	Q	D	G	C	A	W	E
C	E	R	R	Y	U	R	U	R	U	N	W	Y	R	E	M	F	H	X	S	R	Q
D	N	D	I	T	I	E	I	E	I	A	E	T	E	R	N	G	J	Z	D	V	W
E	N	E	O	Q	A	S	X	E	O	B	A	C	A	A	T	N	Q	N	F	A	E
F	A	N	D	R	E	☺	L	A	C	A	B	A	N	N	E	H	A	K	G	N	R
G	B	Q	P	I	U	V	W	V	P	C	R	R	D	W	B	J	Q	J	H	D	T
H	A	E	A	R	O	W	U	W	A	A	T	E	R	E	V	K	A	H	R	R	Y
I	C	C	P	N	P	Q	I	Q	S	L	Y	W	E	R	C	L	N	G	J	E	U
J	A	V	Q	W	D	N	E	Q	E	☺	L	T	☺	A	Q	A	D	N	O	☺	I
K	L	B	A	E	T	R	O	M	D	E	U	Q	L	T	X	P	R	F	Y	L	O
L	☺	R	S	Q	L	M	E	M	F	R	I	M	A	Y	Z	O	E	D	J	A	P
M	E	G	S	M	K	N	P	N	G	D	O	N	C	Y	L	I	☺	S	K	C	A
N	R	E	D	N	J	B	A	E	H	N	P	B	A	U	K	U	L	A	Z	A	S
K	D	C	F	B	E	V	N	B	J	A	A	V	B	I	Y	Y	A	L	L	B	D
F	N	V	G	R	H	N	S	V	K	N	S	C	A	O	J	T	C	K	H	A	F
T	A	B	D	V	A	C	D	A	L	B	D	X	N	P	H	R	A	J	K	N	G
U	J	N	H	B	G	X	N	C	Z	A	F	Z	N	P	G	E	B	H	J	N	H
O	A	N	A	C	F	D	F	X	A	N	D	R	E	Z	F	W	A	G	K	E	J
P	H	C	J	X	R	Z	G	Z	X	D	G	L	R	X	D	Q	N	F	L	C	K
Q	A	D	K	E	F	A	H	L	C	R	H	K	D	C	S	A	N	D	Z	X	L
L	R	J	L	Z	D	S	J	K	V	E	J	J	V	R	A	S	E	S	X	Z	T

EITHER YOUR FIRST NAME OR YOUR LAST NAME IS HIDDEN 20 TIMES IN THE LETTERS ABOVE. HOW MANY CAN YOU FIND?

(Using researcher's name as example).

Word (Name) Search

Appendix K

Appendix M

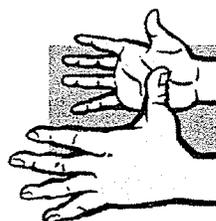
Pictorial Review of Goals

IMPORTANT THINGS TO REMEMBER

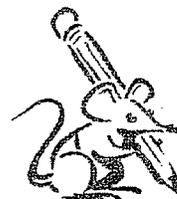
To get a job you have to look and feel good.



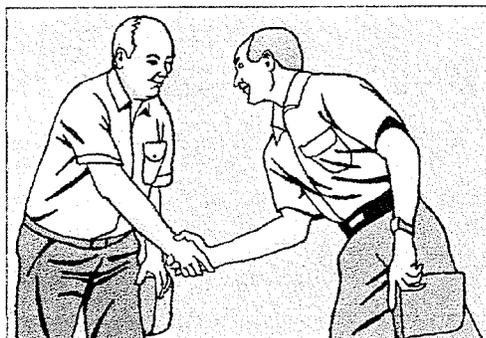
To look good, it helps to keep your hands neat and clean.



When you apply for a job, you will need to sign your name.



And, when you apply for a job and are working . . .



. . . you will need to greet people in a pleasant manner.

GOAL ATTAINMENT FOLLOW-UP GUIDE

Goals: Write last name
Greet adults appropriately
Clean hands, no ink

LEVEL OF ATTAINMENT	Scale 1	Scale 2	Scale 3	Scale 4	Scale 5
Much less ☹️ -2 than expected	Needs prompt to write last name	No proper use of greeting opportunity time	Clean hands, no ink 1 of 5 school days		
Somewhat less -1 than expected	Writes last name 1/2 of time without prompt ✓	Uses proper greeting 1/2 of greeting opportunity time	Clean hands, no ink 2 of 5 school days		
Expected level 0 of outcome	Writes last name 1/2 of time without prompt	Uses proper greeting 1/2 of greeting opportunity time ✓	Clean hands, no ink 3 of 5 school days ✓		
Somewhat more +1 than expected	Writes last name 1/2 of time without prompt	Uses proper greeting 1/2 of greeting opportunity time	Clean hands, no ink 4 of 5 school days		
Much more 😊 +2 than expected	Writes last name all the time without prompt	Uses proper greeting all of greeting opportunity time	Clean hands, no ink 5 of 5 school days		
COMMENTS		<i>This seems to be influenced by the current peer group</i>			