

**Family Therapy with Families with
A Member who was Prenatally Exposed to Alcohol**

By

Susan C. Opie

**A Practicum Report
Submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements for the Degree of**

MASTER OF SOCIAL WORK

**Faculty of Social Work
University of Manitoba
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ABSTRACT

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes a continuum of diagnoses related to prenatal exposure to alcohol. Individuals affected by FASD may exhibit a variety of symptoms in a number of areas including but not limited to behaviour, learning, memory, social interaction, language, and daily living skills. A variety of issues for individuals with FASD and their families may arise as a result of this disability.

This practicum was exploratory in nature, and used an eclectic model of family therapy that included psychoeducational, structural-strategic, psychodynamic, and multisystemic models of therapy. A variety of different families participated in this practicum including biological, foster, adoptive, and grandparent-headed families.

A number of adaptations were made to a more traditional office-based version of family therapy. Services were provided mostly in families' homes, and many services were also provided to other systems in which children with FASD were involved, e.g. schools, or child welfare. Services were adapted to accommodate the neurological differences of individuals with FASD.

A number of recommendations for service providers and policy makers arose from this practicum for providing sensitive services to families dealing with issues related to FASD.

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CHAPTER 1

Objectives and Rationale

Introduction

This practicum was designed to develop family therapy skills in a context of families with a member who has difficulties arising from prenatal alcohol exposure. The families seen in this practicum were raising at least one child who had been prenatally exposed to alcohol. A number of the children had a diagnosis on the Fetal Alcohol Spectrum Disorders (FASD) continuum. Some of these children had received a diagnosis a number of years before, and several had received a diagnosis in the months preceding involvement with this practicum. One child went through the diagnostic process at the Clinic for Alcohol and Drug Exposed Children during the course of the practicum, and another child's family was referred immediately following receiving a diagnosis. One family had a number of adults who identified they had also been exposed prenatally to alcohol. Although they were not the referred client, some of their symptoms related to this had to be taken into account in the provision of services.

With the exception of a family raising a 5 year old with FASD, all the children with FASD in the families seen during this practicum were aged 7-10 or 13-16. Services specific to FASD are not available in Manitoba for families with alcohol-affected children aged 7-18. This practicum allowed for the exploration of providing services to families with an alcohol-affected child who would not otherwise be eligible for FASD services. There was no difficulty in recruiting such families. Specific learning goals and intervention goals are described. A rationale for the relevance of this topic to social work practice is outlined.

Practicum learning goals.

The learning goals were intended to build on the professional knowledge and skills that I had previously developed. I brought three and a half years of experience providing support, parenting education, counselling, and generalist social work interventions to a variety of families raising an alcohol-affected child aged 0-6 years. I had also worked with a number of adults with alcohol-related disabilities who are the parents of the children I work with. I have attended a number of training sessions and have read widely on the literature in the area of Fetal Alcohol Spectrum Disorders (FASD). I further explored the literature on FASD in a variety of contexts as I worked on the course work in the MSW program.

I also brought to this practicum some family therapy experience gained during a concentrated, undergraduate practicum placement at Elizabeth Hill Counselling Centre. I studied family systems theory and a variety of family therapy models at University of Winnipeg in marriage and family conflict courses with Richard Grunfeld, a family therapist with an MSW and a Masters in Marriage and Family Therapy. I further studied systems theory, and family therapy models in coursework in both the BSW and MSW programs, and through reading literature on family therapy. I have experience working with families in their homes through my work at Interagency FAS Program, and as a family support worker with Winnipeg Child and Family Services.

The learning goals for this practicum were:

1. To conduct an exploratory family therapy practicum looking at appropriate models of family therapy for families who include an alcohol-disabled member.

2. To develop family therapy skills using structural-strategic approaches, including skills such as joining with families, mapping family structure, unbalancing, or circular questioning (Gladding, 1998).
3. To explore the use of other approaches to family therapy including multisystemic approaches, psychodynamic approaches and psychoeducational approaches depending on the need of individual families.
4. To deepen self-awareness in working with families.
5. To modify as necessary the family therapy process to accommodate an individual family member with a neurocognitive impairment such as FASD.
6. To broaden my experience in working with families with an alcohol-disabled individual, in particular families with school-aged, adolescent or adult members with FASD.
7. To integrate knowledge of FASD and/or other neurocognitive difficulties with systemic social work practice, specifically family therapy and/or counselling.

Goals for the proposed family therapy intervention.

1. To provide a systems-based, family therapy intervention to families with a member who was prenatally exposed to alcohol, or who has another neurocognitive impairment, e.g. ADHD, or learning disabilities.
2. To provide families with appropriate and accurate information about the disability experienced by the affected family member (i.e. psychoeducational intervention).
3. To help families restructure to accommodate to the needs of the affected family member (i.e. structural-strategic intervention).

4. To help families to work through issues of grief, guilt, etc. as required by each individual family (i.e. psychodynamic interventions).
5. To help families develop internal resources and link to external resources to manage stress in the family system.

Relevance of topic to social work practice.

Social work practice involves helping people improve their social and psychological functioning, and effecting social change to improve the health and welfare of people (Barker, 1995). Individuals with disabilities related to prenatal exposure to alcohol may present with a variety of difficulties that impact on their individual functioning, as well as the functioning of their families, schools, communities, and society as a whole (Streissguth, 1997). These individuals although often unidentified (Malbin, 1993a), may come into contact with social workers in a variety of practice areas including, but not limited to child welfare, schools, mental health, addictions, family therapy, probation and justice. Longitudinal, prospective research on individuals who have been prenatally exposed to alcohol (Streissguth, 1997, Streissguth, Barr, Kogan, & Bookstein, 1997) suggests that these individuals are at high risk for a variety of secondary disabilities, including mental health issues, interrupted school experience, difficulty with legal issues, inappropriate sexual behaviour, employment difficulties, and difficulty parenting children. Any of these issues may bring an alcohol-affected individual and her or his family into contact with the social work profession.

Lack of understanding on the part of caregivers increases the frustration experienced by affected individuals, which in turn leads to increased behavioural

problems (Malbin, 2000, 1993a). Professionals uninformed about issues related to FASD can greatly increase a negative downhill pattern that may occur in some children with FASD and their families (Streissguth, Barr et al., 1997). A professional prescription to parent or discipline a child based on underlying assumptions that the child is neurologically intact and is wilfully misbehaving can have serious consequences for the child who is neurologically compromised and incapable of meeting the expectations the parents then impose (Malbin, 2000).

Preventing iatrogenic damage to a population of individuals disabled with FASD requires that social work professionals recognize the possibility of the presence of this disorder in certain individuals, and requires that social workers modify their practice methods and theories to accommodate the realities with which this population lives. Integration of the research literature related to FASD with social work practice, and exploring appropriate family therapy models to be used with this population are therefore suggested as useful social work endeavours.

CHAPTER 2

Literature Review

This literature review examines fetal alcohol spectrum disorders (FASD), their impact on individuals with FASD, and the family systems in which they live. It begins by defining FASD and the various diagnostic categories included under this umbrella term. The impact of FASD on family systems is discussed, followed by a discussion of family configurations that frequently occur in families raising children with FASD, and some of the issues specific to each of these types of families. Various family systems issues are then explored including the impact of FASD on the family life cycle, family stress, parent's experiences of grief and guilt, and issues of addictions and social stigmatization related to FASD. The review concludes with scientific explanations of the etiology of FASD, including research from the fields of teratology and neuropsychology.

Fetal alcohol spectrum disorder.

FASD refers to a continuum of birth defects, including fetal alcohol syndrome (FAS), caused by prenatal exposure to alcohol (Streissguth, 1997). People suffering from FASD show a wide continuum of effects that can vary from mild behavioural problems to profound difficulties with daily living skills. Birth defects related to prenatal alcohol exposure primarily affect the brain. Effects last for the entire life span of the affected individual, although the actual manifestation of the disability may change at different points of development (Connor & Streissguth, 1996; Malbin, 1993a; McCreight, 1997; Streissguth, 1994; Streissguth 1997). The behaviour difficulties exhibited by children and adolescents who suffer the effects of prenatal exposure to

alcohol may be exacerbated by a poor home environment, but a good home environment cannot 'cure' the effects of prenatal alcohol exposure, although it may be helpful in preventing the development of secondary disabilities (Streissguth, 1997; Streissguth, Barr et al., 1997).

Fetal alcohol syndrome (FAS) was named and described in 1973 by Jones and Smith in Seattle, Washington (Jones & Smith, 1973; Jones, Smith, Ulleland, & Streissguth, 1973). In 1973, FAS was described as a medical syndrome in which patients show symptoms in three categories: (1) evidence of growth retardation of prenatal origin; (2) a characteristic cluster of facial dysmorphology or abnormalities; and (3) evidence of damage to the central nervous system which may manifest as small head size (microcephaly), behavioural difficulties, learning disabilities, hyperactivity and attention difficulties, developmental delays, poor fine or gross motor control, poor balance, central auditory dysfunction, delayed or perseverative language, poor impulse control, memory impairment, difficulties with judgment or abstract reasoning, and poor adaptive functioning (Streissguth, 1997).

The term fetal alcohol effects (FAE) refers to an individual with significant prenatal exposure alcohol but who does not have all the characteristics warranting a diagnosis of FAS (Streissguth, 1997). This term has been used descriptively, but has never been clearly defined as a diagnostic term (Streissguth, 1997). In 1996, the Institute of Medicine introduced the terms Partial FAS (PFAS) and Alcohol Related Neurodevelopmental Disorder (ARND) (Stratton, Howe, & Battaglia, 1996). PFAS refers to an individual with confirmed prenatal alcohol exposure who shows some evidence of growth retardation and/or facial abnormalities as well as evidence of central

nervous system damage. Alcohol Related Neurodevelopmental Disorder refers to an individual with a history of prenatal exposure to alcohol who shows no growth difficulties or facial abnormalities but shows evidence of central nervous system damage (Stratton et al., 1996). The presence of a history of prenatal exposure to alcohol is a critical component of a PFAS or ARND diagnosis because diagnosticians focus on characteristics of the central nervous system that can and do originate from causal factors other than prenatal alcohol exposure (Stratton et al., 1996; Streissguth, 1997).

PFAS, ARND or FAE are not less severe forms of FAS, and may be as debilitating as FAS (Streissguth, 1997). Behavioural and learning difficulties that result from central nervous system damage underlie the primary difficulties affected individuals and their caregivers experience, not the growth deficiencies or the facial dysmorphology (Streissguth, 1994). As FAS has additional biological markers of growth difficulties and facial dysmorphology, it is easier to detect and diagnose. The long-term secondary disability study (n = 415, 37% diagnosed FAS, 63% FAE or possible FAE) found that individuals with FAE are at higher risk for secondary disabilities than those with a diagnosis of FAS (Streissguth, Barr et al., 1997).

Giunta & Streissguth (1988) report individuals with prenatal exposure to alcohol are at higher risk than average for physical abuse, sexual abuse and neglect. Mothers raising children with FASD may continue to struggle with addictions, and have few resources or supports to assist them, which may make it difficult for this group of mothers to provide the supportive nurturing home that research suggests children with FASD require (Giunta & Streissguth, 1988). The long-term secondary disability study

(Streissguth, Barr et al., 1997) found living in stable, nurturing homes for most of life to be a key protective factor that helped prevent the development of secondary disabilities.

Adolescents and adults with FASD suffer lifelong consequences, and outcomes are considerably more complicated than would be suggested by the fact that many people with FASD are mentally retarded (Streissguth, 1994). Adults with FASD are at risk for social isolation because their disability makes it difficult for them to participate in the work force or connect with a peer group (Giunta & Streissguth, 1988; Streissguth, Barr, et al., 1997). Individuals with FASD may be too high functioning to be eligible for special services, but do not have the skills to live independently (Giunta & Streissguth, 1988). Vulnerable, disabled individuals may be unable to obtain services to meet their needs, which may leave their families attempting to fill in service gaps.

Streissguth, Barr et al. (1997) conducted a prospective, longitudinal study of 415 individuals with FAS/FAE (39%, aged 6-11 years, 39%, 12-20, and 22%, 21-51) studying the prevalence of secondary disabilities. Secondary disabilities develop later in life separately from primary disabilities with which a child is born. The researchers looked at six secondary disabilities. They found that mental health problems occurred in over 90% of the full sample 6 years and older; disrupted school experience was experienced by 60% of individuals 12 and over; trouble with the law occurred in 60% of those 12 and over; confinement was experienced by approximately 50% of those 12 and over; inappropriate sexual behaviour was found in 50% of individuals 12 and over; and alcohol and drug problems occurred in about 30% of individuals 12 and over. In addition, 80% of the 90 subjects over the age of 21 years in the study were unable to live independently or to maintain employment (Streissguth, Barr, et al., 1997).

Streissguth, Barr et al. (1997) make a number of recommendations, two of which pertain to the needs of families raising children with FASD: (1) the provision of education and training on FAS/FAE and appropriate support services to all parents raising children with disabilities related to prenatal alcohol exposure; and (2) a full disclosure of the medical and mental health histories of children being placed with foster or adoptive parents. These emphasize the need for parents to be well informed regarding the needs of the children in their care (Streissguth, Barr et al., 1997).

Fetal alcohol spectrum disorder and the family system.

Families and caregivers of children with FASD assume a level of responsibility that is considerably over and above that ordinarily associated with parenting (Giunta & Streissguth, 1988). Prenatal exposure to alcohol may cause physical, intellectual and behavioural difficulties in children, creating a highly demanding parenting context. Consequently, caregivers of children with FASD may require high levels of supportive services to help prevent caregiver burnout. Caregivers require information about fetal alcohol syndrome and parenting strategies (Giunta & Streissguth, 1988; Weiner & Morse, 1994). It is helpful for families to feel empowered to take on the difficult role they have undertaken, and to recognize the 'crucial role they play in these children's lives' (Giunta & Streissguth, 1988, p. 459). Supportive services such as respite, financial support, and parent peer support may be helpful (Giunta & Streissguth, 1988; Weiner & Morse, 1994).

Individuals with FASD require a supportive nurturing home environment (Giunta & Streissguth, 1988; Streissguth, 1997; Streissguth, Barr et al., 1997). Low-key, calm parenting is recommended. Families have been found to be more satisfied

with their role raising an alcohol affected child when they treat the child with FASD as close to normal as possible, and combine 'loving acceptance with firm limit setting' (Giunta & Streissguth, 1988 p. 457). Families who have high expectations for performance in their child are comparatively less satisfied (Giunta & Streissguth, 1988).

Family configurations.

Children prenatally exposed to alcohol are raised in a variety of families including their biological family (Giunta & Streissguth, 1988; Malbin, 1993a; Weiner & Morse, 1994), foster families (Giunta & Streissguth, 1988; Weiner & Morse, 1994), adoptive families (Dubovsky, 2001; Weiner & Morse, 1994), and extended family caregiver families (Jendrek, 1994). Each of these families must confront the difficulties of the child with FASD and the high stress parenting environment that may result from the child's difficulties. Each also struggles with their own, unique issues. This section highlights some of these specific difficulties. In addition, any of the four family configurations listed above may be a single parent family (e.g. Minuchin et al., 1998), a stepfamily (e.g. Visher & Visher, 1993), or a gay or lesbian family (e.g. Laird, 1993), which may affect the structure and functioning of the child's family.

Biological families.

Birth mothers of children with FASD are a special category of caregivers (Giunta & Streissguth, 1988). Their struggle to maintain sobriety coincides with the highly stressful work of raising a child with FASD. This high level of parenting stress may make maintaining sobriety particularly difficult. This group of parents may require parenting classes, one-on-one supports for parenting education, and practical day-to-day

help with parenting. Various needs related to the mother's recovery from addictions may also need to be supported (Giunta & Streissguth, 1988; Gray, 1993; Pape, 1993).

Birth mothers may need to work through feelings of guilt and grief and may require counselling to do this (Giunta & Streissguth, 1988; Hornby, 1993; Malbin, 1993a). The stigmatization associated with alcoholism for women (Malbin, 1993a; Pape, 1993) and with FASD (Malbin, 1993a) may interfere with women and their families seeking help with issues related to FASD and substance abuse (Malbin, 1993a). Issues of grief and shame may further complicate intervention with families (Hornby, 1993; Malbin, 1993a).

Foster and adoptive families.

Children with FASD who are raised in foster care do best when foster parents are 'calm and low-key individuals, secure and comfortable with themselves, and who live stable and predictable lives' (Giunta & Streissguth, 1988, p. 457). Busy professionals who live hyper stimulating lives may become quite frustrated with the apparent lack of progress in children with fetal alcohol syndrome (Giunta & Streissguth, 1988). Dubovsky (2001) states that adoption breakdowns occur more frequently when at least one parent is a professional, particularly in a mental health field. These families may believe they can do it all, and not ask for help until it is too late (Dubovsky, 2001). Adoptive families have issues and characteristics that have been reviewed elsewhere (Anderson, Piantanida, & Anderson, 1993; Smith & Howard, 1999) that may impact on issues related to a family member with FASD. Smith & Howard (1999) report that parents who chose to adopt a child with a disability were found to be more committed to

the adoption and more satisfied with the adoption than parents who believed they had adopted a 'normal' child and later discovered this child was seriously impaired.

Morrisette (2001) conducted in-depth interviews with six parents in a study that explores the experiences of foster and adoptive parents who were raising children diagnosed with FASD. His analysis revealed seven themes: constant vigilance by parents, effects on marriages, management of children, issues with parenting, interactions with professionals, concerns regarding children's emancipation from their home, and medical implications (Morrisette, 2001).

Constant vigilance by parents due to children's unpredictable behaviour and inability to keep themselves from being exploited by others resulted in physical and emotional exhaustion for parents (Morrisette, 2001). Vigilance remained high as children became older, with parents noting increasing concerns about the potential for the child to become involved in sexual activities or drinking, smoking, and drug use (Morrisette, 2001).

Study respondents (Morrisette, 2001) reported exhaustion from the multiple stresses of raising children with FASD affected marriages and sometimes ended in divorce. Particularly for foster families, divorce usually resulted in the placement breaking down, and the child's potentially re-entering a cycle of being bounced from one home to another. Couples with strong marriages reported the need to maintain a high level of communication and to remain mutually supportive (Morrisette, 2001).

Issues related to child management included behaviour parents viewed to be manipulative, and underlined the need for parents to collaborate to ensure consistent parenting (Morrisette, 2001). Unmanageable behaviour, particularly physical outbursts

and violence were noted as problematic, with these behaviours becoming more concerning as children grew older, and became physically stronger. Parents noted that their children appeared to be ashamed of their disability, spent a lot of energy hiding it, and pretending to know answers or following what everyone else was doing rather than asking for help. This in turn frequently resulted in children becoming socially isolated or not being noticed in classrooms to be in need of help and direction (Morrissette, 2001).

Parents noted that children relied heavily on routines and the sequences of routines (Morrissette, 2001). Slight changes in routines (e.g. taking a different route home) sometimes caused children with FASD to have severe reactions and become extremely upset or panicked. (Morrissette, 2001).

All of the parents interviewed had previously parented their own biological children successfully (Morrissette, 2001). Parents reported feeling inadequate as parents because their previously learned skills did not produce positive outcomes with children with FASD. Parents identified that had they known about FASD, things would have been much easier, and reported a sense of relief when they received correct information (Morrissette, 2001). Streissguth (1997) quotes an adoptive mother:

We raised Pierre just like our other children, but he responded totally differently—we couldn't figure it out. It was as though all the typical ways of teaching our other children about how to behave had no effect on Pierre. It wasn't until we read about FAS, went back and got more information from the adoption agency, and found out that his mother was an alcoholic that we finally figured out what the problem was (Streissguth, 1997, p. 67).

Parents found their ability to adequately parent their child with FAS and to accommodate to the child's disability grew with time, often through a process of trial

and error (Morrissette, 2001). Parents reported the need for a high energy level, while remaining low key enough to let things go easily, and to acknowledge that the parent needed to make changes rather than expecting the child to change. Consistency was important, as was the need for unique approaches to each incident (Morrissette, 2001).

Mostly, parents reported that teachers, physicians and social workers were perceived as helpful; some were not (Morrissette, 2001). Parents were concerned that their children would remain vulnerable and unable to care for themselves when they grew up, due to a lack of life skills and job skills (Morrissette, 2001). Fears were expressed that services to help children become functional members of society did not exist. Parents reported concerns about their children's entering puberty, and how to appropriately deal with issues of sexuality. Parents had fears that children would be sexually victimized, and that children would not retain education about sexuality. Parents stated they did not know where to seek help about such issues (Morrissette, 2001). Some children with FASD had medical complications and required a high level of care (Morrissette, 2001).

Extended family caregivers.

Jendrek (1994) conducted in-depth interviews with 114 grandparents who responded to advertisements to participate in her study. Thirty-six of these grandparents had legal custody of at least one grandchild. Five primary reasons were cited grandparents for their custodial relationship with their grandchild: 72.7% of the birth mothers were having emotional problems; 53.1% of the grandparents did not want the grandchild in a foster home; 52.8% of the birth mothers were having a drug problem; 48.3% of the birth mothers were having a mental health problem; and 44.1%

of the birth mothers were having an alcohol problem (Jendrek, 1994). Any of these factors may be present in families in which a grandchild has been exposed to alcohol prenatally.

Grandparents and other extended family caregivers caring for a child with FASD may present with issues of grief and loss (Goldberg-Glen, Sands, Cole, & Cristogalo, 1998; Minkler, Driver, Roe & Bedeian, 1993; Pinson-Millburn, Fabian, Schlossberg & Pyle, 1996). These families are formed on a foundation of loss similar to stepfamilies (Visher & Visher, 1993) or infertile adoptive families (Anderson et al., 1993). For example, the death or incapacitation due to addictions or HIV, or incarceration of a birth parent may have resulted in the grandparent taking custody of the grandchild.

Custodial grandparents are subject to all of the stressors that affect any parent raising children with FASD. Grandparents may experience further stressors such as a mismatch of the life-cycle stage of the grandparent with the care giving role of raising a grandchild (Goldberg-Glen et al., 1998), grandparents' health concerns (Goldberg-Glen et al., 1998; Joslin & Brouard, 1995; Minkler et al., 1993; Pinson-Millburn et al., 1996) which may put children at risk of losing another caregiver (Goldberg-Glen et al., 1998), or economic stressors (Goldberg-Glen et al., 1998; Pinson-Millburn et al., 1996). Grandparents may be reluctant to raise their grandchildren and give their grandchildren rejecting messages, or model cross-generational patterns related to issues such as substance abuse that may impact negatively on the grandchildren potentially causing a repetition of unhealthy patterns in another generation (Goldberg-Glen et al., 1998).

Goldberg-Glen et al. (1998) suggest using long-range planning with grandparent-headed families to ensure supports and back-up arrangements for these caregivers.

Family system issues.

This section explores a number of issues that can impact family systems with a member with FASD. Issues such as stage of the family life cycle, experiences of stress, guilt, grief, addictions, and stigmatization of alcoholism or FASD will be reviewed briefly.

The family life cycle.

McGoldrick, Heiman, & Carter (1993) discuss a family life cycle model in which the individual life cycle is embedded. The persistence of symptoms of FASD for the entire lifespan of individuals with FASD leads families to have varying difficulties as their child passes through different developmental stages (Malbin, 1993a; McCreight, 1997; Streissguth, 1994; Streissguth, 1997). Certain stages of the family life cycle may be more stressful for families (McGoldrick et al., 1993). These stages may intersect with issues presented by a child with FASD to become considerably more stressful (McCreight, 1997). For example, many families find adolescence to be a stressful stage (Wolf, 1991), and it may be exceptionally stressful if the child has FASD (McCreight, 1997).

McCreight (1997), a family counsellor and adoptive parent of a son with FAS looks at the needs of children with FASD at different developmental stages. She cites adolescence as a stage during which parents must learn to let go. This is particularly difficult for parents of children with FASD because of the intensive parenting style that has frequently been used up to this time. Parents of adolescents with FASD find it

particularly difficult to distinguish between normative adolescent behaviour and behaviours resulting from prenatal alcohol exposure. Parents respond differently to ordinary teen-parent conflict than to a child who is lost in her or his anger as a manifestation of FASD (McCreight, 1997).

Adolescence is frequently the stage in which the child becomes aware of the extent of her or his learning disabilities, and the realization that some of these difficulties are intractable and will not improve with time (McCreight, 1997).

Normative activities for teenagers, e.g. obtaining a driver's licence, may not be possible for some children with FASD. Adolescents coming to terms with the extent of their difficulties go through a grief process similar to their parents' grief for the loss of potential for their child at an earlier stage of development (McCreight, 1997).

Many difficulties may complicate the period of launching for young adults with FASD, e.g. learning disabilities, lack of work skills, or inability to continue on to higher education or training (McCreight, 1997). Independent living, which requires the ability to budget for expenses such as food, rent, or hydro, may be quite difficult for those unable to manage money. Streissguth, Barr et al., (1997) noted high rates of difficulties with work and independent living for adults with FASD. Adult relationships may be difficult for those with FASD, and this may lead to loneliness. Poor boundaries and poor judgement may lead to involvement in relationships, without the affected individual first assessing the appropriateness of these relationships (McCreight, 1997).

Despite their disabilities, young adults with FASD still desire to become independent adults with an independent life (McCreight, 1997; Miranda & Levine, 2000). Young adults may not be ready emotionally or educationally to move out on

their own, but they want and need to move out, and parents may be exhausted from the incessant care giving demands and ready for the child to leave home (McCreight, 1997).

Stress.

High levels of potential stress for caregivers of children with FASD are reported (Giunta & Streissguth, 1988; McCreight, 1997; Morrisette, 2001). Not all families' experiences concur with the literature reports of stress. Diane Malbin, MSW, who works with families affected by FASD, and is herself a birth parent of two alcohol-affected daughters, reports that it is not stressful raising children with FASD once families have developed structures and routines that work for the child and have come to accept a lifestyle that supports the children's functioning (Malbin, 2001).

The ABC-X Model of Family Stress and Coping (Hill, 1958; Vosler, 1996) was developed by Hill to describe family stress from sources such as unexpected impoverishment or acquisition of wealth, unemployment, natural disasters, refugee migrations, and deprivations and violence associated with war. In this model A represents the stressful event, B the resources the family has for coping with the event, C the family's perceptions of the event, and X the level of stress experienced by the family. This model has been widely used or modified for use in discussions of families experiencing various stressors, for example the changing economy and job market (e.g. McKenry & Price, 2000; Vosler, 1996), or divorce (e.g. Buehler, Hogan, Robinson & Levy, 1985).

McCubbin & Patterson (1983) looked at the concept of stress pileup in which a number of stressors accumulate to cause a crisis, and modified the ABC-X Model to develop the Double ABC-X Model (McKenry & Price, 2000; Vosler, 1996). This

model consists of the ABC-X Model followed by the Double ABC-X section which looks at factors following the initial crisis and at how satisfactory the family's adaptation is to the crisis or stress. In the Double ABC-X Model, the double A refers to the pileup of stress experienced by the family including ongoing effects of the initial stressor event, normative developmental changes of the family that would have occurred with or without the stressor, and the resulting effects of the family's coping with the situation. The double B refers to two sets of family resources, one which was pre-existing and helped to minimize the impact of the stressor, and the other which are new resources that were strengthened or developed as a result of the crisis. The double C refers to the family's perceptions of the initial stressor and to the continuing pileup of stressful events. The double X involves both the initial response of the family to the crisis or stress and their subsequent adaptation, positive or negative (McKenry & Price, 2000).

This model has been further developed into the T-Double ABCX Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1987). It includes factors such as family hardiness that mediate how families respond to stressful events. In addition, this model builds upon family strengths and capacities such as resources and coping and looks at how these help lessen negative effects of stressful events, and encourages positive adaptation to crises (McCubbin, 1995). Reddon, McDonald, & Kysela (1992) explored the use of the T-Double ABCX Model of Family Adaptation with 16 families raising preschool children with developmental disabilities and found it provided a useful framework for describing the adaptive functioning of these families.

Understanding families' responses to stressors would ideally consider the multiple demands on the family at any point in time (Patterson, 1988). These demands change over time, with some disappearing, and other new demands challenging the family. For example, a major illness in a family member may move a family into crisis as normal family routines and roles become disrupted. Family recovery from this crisis may be facilitated by accurate information about the medical condition given to family members, and linking families to resources such as support groups (Patterson, 1988). A requirement for accurate information and linkage to appropriate resources is similarly noted in literature describing families of children with FASD (Giunta & Streissguth, 1988; Malbin, 1993a; Morrisette, 2001; Streissguth, 1994; Streissguth, 1997).

Chronic illness or disabling conditions may be more stressful because the family carries the primary responsibility to provide care to the disabled or ill family member (Patterson, 1988). When the quantity or type of demands placed on a family exceed the abilities and resources a family has to deal with a crisis, a state of instability may occur (Patterson, 1988). FASD is life-long and chronic (Malbin, 1993a; McCreight, 1997; Streissguth, 1994; Streissguth, 1997), and entails a high number of demands being placed on families (Giunta & Streissguth, 1988; Hornby, 1993; Morrisette, 2001).

Floyd & Gallagher (1997), in a study on stress levels in families with a child with a disability or a chronic illness, suggest that the special care required by children with disabilities can cause considerable stress for parents as well as significant disruption in the relationships in a family. They found the occurrence of problematic behaviour in children with disabilities was predictive of poor adjustment of the family. The presence of behavioural problems in children with mental retardation or chronic

illness was found to be more important than the type of disability in creating parental stress (Floyd & Gallagher, 1997). Peterson & Mathieson (2000) note that while parental stress is a universal phenomena, parents of children with autism or attention deficit disorders frequently display high levels of stress as they attempt to deal with ongoing, difficult behaviours in their children. Severe behavioural issues are a frequent component of FASD and are frequently cited to be stressful for parents (Giunta & Streissguth, 1988; Streissguth, 1994; Streissguth, 1997; Weiner & Morse, 1994).

Peterson & Mathieson (2000) suggest families move from the potentially crisis-evoking shock of an initial diagnosis in their child to the reality of the long-term responsibilities that parents have for children with disabilities. Children with chronic illnesses, birth defects, or physical disabilities frequently 'confront parents with substantial demands for investments of time, energy, and emotion' (Peterson & Mathieson, 2000, p. 76). Children with identified social or emotional problems such as conduct disorders, attention deficit disorders, autism, or schizophrenia, particularly when they live with their parents, may exert stressors such as high supervision needs, constant care giving demands, treatment costs, and 'feelings of anger, embarrassment, guilt and despair' (Peterson & Mathieson, 2000, p. 77). Many children with such difficulties do not move out on their own and take on adult responsibilities as they mature, but continue to provide an ongoing source of stress to their parents even when they reach adulthood (Peterson & Mathieson, 2000). Similar issues are reported for families with children with FASD (McCreight, 1997; Morrisette, 2001; Streissguth, 1997).

Peterson & Mathieson (2000) state that parental stress has important consequences for children. Stressed parents are more likely to be emotionally reactive, and more focussed on adult goals than child-focussed goals. Parents may then be less responsive, and more punitive towards their children, which may cause children to become more aggressive, and less willing to meet their parents' expectations (Peterson & Mathieson, 2000). Children with FASD need a low-key responsive parenting style (Giunta & Streissguth, 1988), but frustrated parents of children with FASD, with no supports or inadequate information may fall into an emotionally-reactive, punitive style of parenting (Malbin, 1993a; Peterson & Mathieson, 2000).

Positive parental resources (the B factor in the ABC-X Model) may help lessen the effects of demanding stressors resulting from a child's disability (Peterson & Mathieson, 2000). Parental competence, defined as psychological maturity, empathy, warmth, self-efficacy, and an ability to provide firm control for a child, a strong marital relationship, and social support from family or friends are potential resources. Personal resources may sometimes be compromised in families raising children with FASD (Giunta & Streissguth, 1988; Morrissette, 2001).

The family's perception of an event (the C factor in the ABC-X Model) affects whether a stressor is positive, negative, or neutral (Peterson & Mathieson, 2000). Each parent in a marital dyad may have a different perspective, which may have implications for family functioning and communication. The way parents interpret their child's moods, behaviours, or intentions helps determine both the parent's emotional responses to their child as well as how they approach parenting their child. When a parent perceives their child's behaviour as wilful and deliberate, they are more likely to be

upset and to use punitive measures in response to their child's behaviour. In contrast, parents who interpret that their child is not completely competent and did not deliberately act in a particular way are more likely to be nurturing and moderate in their attempts to control their child's behaviour (Peterson & Mathieson, 2000). Malbin (1993a, 1993b, 2000) speaks about the need for families to change their perceptions of their child with FASD. She calls this a paradigm shift.

Patterson (1988) suggests that families attempting to re-establish equilibrium following a stressful event or crisis may do so in one of three ways: seeking new resources or coping mechanisms, reducing the number of demands families must deal with, or reframing their perceptions of the situation. Peterson & Mathieson (2000) define coping by parents as taking action to access resources, learn new skills, request help, reframe interpretation of events, and manage emotional reactions to stressors. For families dealing with FASD, accessing accurate information, accessing appropriate resources, and shifting perceptions may be helpful (Giunta & Streissguth, 1988; Malbin, 1993a; Streissguth, 1994; Streissguth, 1997; Weiner & Morse, 1994).

Guilt.

Children with major social-emotional problems, such as those with conduct disorders or autism may have parents who experience strong feelings of guilt (Peterson & Mathieson, 2000). One adoptive mother in Morrisette's study (2001) reported feeling guilty because she wanted to do so much more than she was doing. She questioned her ability to do the right things or make the right decisions for her child. Hornby (1993) suggests guilt, particularly in birth families, may manifest in parental behaviours such as overprotecting the child, being unable to discuss the child's

difficulties, distancing themselves from the child, minimizing the child's difficulties, becoming punitive or highly critical of the child, or giving up on the child. Parents may become hostile or blaming towards the other parent, or towards professionals (Hornby, 1993).

Parents' experiences of guilt, which may be difficult to identify as such because of its manifestation in confusing symptoms, may prevent parents' attending to their child's special needs (Hornby, 1993). Minimizing or denying the child has a problem, or seeing the problem as much less severe than others see it should be gently but consistently and firmly addressed, so that parents come to see themselves as responsible for ensuring that their child receives what he or she needs in terms of education, stimulation at home, and consistency and support from the family (Hornby, 1993). Projections of blame onto doctors, spouses, or cultural groups may also indicate issues of guilt. These need to be addressed in a non-defensive way, allowing a parent to come to an acceptance of the current reality, and how to help the family member with FASD (Hornby, 1993).

Grief.

Daniel Dubovsky, MSW has thirty years experience working with people with developmental disabilities, and was the adoptive father of a son with FAS until his son's untimely death in fall 2002. Bill was hit by a car, an event his father said was a direct result of Bill not having adequate services. Streissguth, Aase, Clarren, Randels, LaDue, and Smith (1991) report that adolescents and adults with FAS have an average level of adaptive functioning (which includes factors such as daily living skills and socialization skills) equivalent to that of a seven year old. Difficulties with executive functioning

including remembering important information particularly in distracting situations (e.g. crossing a busy street) or remembering which rule to apply in which situation (Connor, Sampson, Bookstein, Barr & Streissguth, 2000) put individuals with FASD at risk in a variety of situations. Dubovsky (2001) suggests that had appropriate adult services, such as one-on-one support personnel, been available, Bill would not have been attempting to cross a road alone.

Dubovsky (2001) identifies a large number of losses that families of individuals with FASD experience. These include the loss of hopes and dreams, and the loss of a balanced family system, because life with a member with FASD is not what families have imagined for themselves. Chronic acting out behaviour of the child, despite parents' best efforts, erodes parents' self-esteem and leaves parents feeling incompetent (Adams, 2002; Dubovsky, 2001; Morrisette, 2001).

There may be losses of support from family, friends, and community when, for example, others ask the family not to bring the alcohol-exposed individual to events (Dubovsky, 2001). Dubovsky points out this type of reaction by others outside the family is completely opposite from the type of community support a family may experience if a child has a serious illness. Families may experience loss of companionship or loss of a family member if the family breaks up or the individual with FASD is placed outside the home. They may lose faith in their own ability or the ability of other systems to respond appropriately to difficult crises involving FASD. The family may lose faith in their spiritual beliefs. Financial security, privacy because of the involvement of outside systems, freedom because of ties to care giving roles with the affected individual, and a sense of security about the future because of fears for the

child if the parent becomes incapacitated are further losses that may occur. Families may lose a sense of control over what the affected family member is doing, what systems may be providing or not providing, and an ability to plan for the future (Adams, 2002; Dubovsky, 2001). Loss of a sense of control may lead family members to blame other family members, professionals, systems, health care providers, or birth mothers possibly exacerbating the family's difficulties (Dubovsky, 2001).

Adams (2002) describes the painful experiences of adoption breakdown in six families, and the serious loss of self the parents suffered. Adams also recounts a loss of support, when extended family and community members fail to ask about the absentee adopted child. Some of Adam's (2002) extended family refused to attend funeral services when her own adopted son died on the streets.

All of the losses immediate members of families experience are frequently experienced by extended family members and the siblings of the alcohol-affected individual (Dubovsky, 2001). Affected individuals experience an equally long list of losses similar to the family, including a loss of hope and dreams, self-esteem and a sense of competence, peer and intimate relationships, support from others, their family due to separations, vocational and educational opportunities, joy and pleasure, potential, ability to be like everyone else, freedom to come and go as they please, a sense of security about the future, and a sense of control.

Many individuals with FASD have a limited sense of control in their own lives. A 23 year old man with FAS told Dubovsky the 'only control [he] has is to not do something [he] is told to do' (Dubovsky, 2001). Individuals with FASD lose many relationships with peers and caregivers as they are moved in and out of short-term

hospitalizations, from foster home to foster home, or group home to group home. In time, these individuals become very difficult for anyone to connect with, as they protect themselves from further losses by refusing to open up and connect with caregivers or professionals. They are then viewed as non-compliant, uncooperative, resistant, manipulative, and unmotivated, or what Dubovsky (2001) has termed NURMU.

Birth parents of children with FASD experience the losses all families may experience, in addition to feeling blamed for the child's disabilities, despite the fact that many birth parents were unaware of the harm that alcohol use during pregnancy could cause (Dubovsky, 2001). Women may experience profound grief when they learn the effect their alcohol use has had on their child (Malbin, 1993a). Professionals should be non-judgemental and sensitive in speaking with birth mothers. Women need support to go through the process of addressing their grief, but there are few safe places for the grief related to FASD to be dealt with by birth mothers. According to Malbin, 'this is a grief unlike any other,' but 'the energy born of this grief is powerful; it may be rechannelled to positive and constructive areas . . . ' (Malbin, 1993a, p. 264).

Malbin cites a case study of a woman in recovery and attending graduate school who comes to realize her own six year old daughter might have FAS:

I couldn't breathe as I began reading about FAS. The pain of recognition was unutterable. The nature of the grief that came with the realization of what happened to my daughter when I drank during pregnancy is unparalleled. It is profound, all-encompassing, mind-numbing, excruciating, ongoing, and unlike any other. The process of resolution of this particular kind of grief was prolonged: I looked at my children, checked for signs, denied, acknowledged, avoided, and confronted my perceptions. As I went through the grief process, I replayed, wept, became ill, raged, blamed, and feared. I turned yet again on myself, denigrating

my own recovery and raging at a perverse deity. How hideous that I could recover and she would have possibly life-long struggles! (Malbin, 1993a, p. 259).

Another birth mother, Mercedes Alejandro (2002), writes about coming to terms with her son's alcohol-related disability:

As his mother, I had to make a conscious decision to either wallow in guilt and despair or face it head on and deal with it. I had caused in my child a preventable disability! Of course the first step, hard as it was, was to forgive myself. I had made a very serious life-altering mistake. One my child and I both had to live with. But there was no going back in a time machine to undo the damage and there was no point in punishing myself (Alejandro, 2002, p. 12).

Addictions.

Awareness of the stigmatized nature of alcoholism, particularly women's alcoholism, the necessity for different treatment approaches for women as opposed to men, and issues women may experience because of previous involvement with addictive substances may all impact on working with families with a member with FASD. Hornby (1993) states the need for professionals counselling birth families of children with FASD to have an understanding of issues related to alcohol abuse for women and men in helping address issues such as guilt.

There are important differences between female and male alcoholics (Pape, 1993). For example, a stressful event is more likely to precipitate problem drinking in women than men, and women are more likely than men to follow spells of excessive drinking with depressive reactions (Turnbull, 1988). Women are more likely to experience a relapse and return to drinking while experiencing a negative affect, e.g. guilt, anger, sadness (Rubin, Stout & Longabaugh, 1996). Men may also relapse following negative affect, but are more likely to do so following problems in the environment or in the

company of other people (Rubin et al., 1996). Women are more likely to drink alone, or in relation to a partner who is a heavy drinker (Rubin et al., 1996). Loneliness was a common aspect of relapse for many subjects (Gray, 1993; Rubin et al., 1996).

Research on alcoholism has focused almost exclusively on male subjects, often white and middle-classed, up until very recently. This has led to what Wilke (1994) has described as a male-as-norm bias in which male alcoholic behaviour developed as a norm or standard against which women's alcoholic behaviour is judged, which has led to a bias that women alcoholics are sicker than male alcoholics and harder to treat. While women's alcoholism is viewed as abnormal when compared to men's, research about women is conducted as if their addiction were the same as men's (Wilke, 1994).

Malbin (1993a) suggests that women and men in recovery from alcoholism go through a long process coming to terms with the harm they have caused while drinking. This is further complicated in cases where a child has been prenatally exposed to alcohol (Hornby, 1993; Malbin, 1993a). Malbin (1993a) discusses the need for people in recovery to understand the loss of choice as alcohol use came to determine the course of their lives more and more. Hornby (1993) suggests the need for parents to come to an abstract understanding of how their alcohol use came to affect their child.

Stigmatization.

Social stigmatization is an important concept when working with women who are alcoholic or birth mothers of children prenatally exposed to alcohol. Feminist literature and analyses (Bates et al., 1995; Mandell, 1995) suggest women are discriminated against on the basis of sex. Double and triple discriminations occur for women who are non-white, or disabled (Bates et al., 1995; Mandell, 1995).

An additional triple stigma is associated with women who are alcoholic (Pape, 1993). A general stigma assumes moral weakness or lack of willpower is associated with alcoholism (Malbin, 1993a; Pape, 1993). Moral standards are often higher for women than for men, leading to viewpoints of disgust towards a woman who is drunk, while a man who is drunk may be viewed with humour (Pape, 1993). A third stigma (Malbin, 1993a; Pape, 1993) results from a belief that alcohol and drug use are associated with sexual promiscuity. Research actually shows a reduction in sexual desire among female alcoholics and drug addicts, but an increased risk of being sexually victimized, because a drunk or stoned woman is viewed as an acceptable target of male aggression (Pape, 1993). These multiple stigmas suggest an extremely vulnerable client group, which requires careful examination of practice and research ethics.

Fetal alcohol spectrum disorders are highly stigmatized diagnoses. This stigmatization is strongly connected to the stereotypes about alcoholic women. Alcoholic women have been stereotyped as bad mothers, and birth mothers of children with FASD are stereotypically blamed for harming their unborn children (Malbin, 1993a). Women who are seen as neglectful or abusive mothers are also heavily stigmatized in North American society (Swift, 1996).

Over a four year period, the FAS diagnostic clinic in Seattle, Washington gave 160 children a diagnosis of full FAS (Clarren, 1999). The clinic attempted to find the birth mothers of these children with the purpose of developing an understanding of this group of women. Twenty-five per cent of these mothers were dead or missing. The clinic found that for the 80 birth mothers they interviewed: (1) 65% were Caucasian and 35% Black, Aboriginal, or Asian women, proportions that roughly matched the

population of Washington State; (2) women who came from a variety of families: high and low socioeconomic status, some well-educated, some not, and a largely normal IQ range from high to low; (3) 80% had received a mental health diagnosis—most commonly for schizophrenia or bipolar disorder; (4) 100% had been severely, traumatically, and repeatedly sexually abused—75% as children; 25% as adults; (5) 60% had phobias, most commonly agoraphobia; (6) 80% lived with men who didn't want them to go into treatment; (7) health care during pregnancy was the most commonly accessed health or social service; (8) 20% of them had FAS themselves (Clarren, 1999).

A stigma attached to both FASD and to alcoholism in women acts as a powerful barrier to women accessing services for themselves (Malbin, 1993a) and for their children. Clinicians should examine their own biases, and maintain non-judgemental and supportive approaches to intervention (Hornby, 1993, Malbin, 1993a).

Theoretical explanations of the etiology of fetal alcohol spectrum disorders.

Teratological explanations.

Teratology is the study of substances (teratogens) that disrupt normal development in offspring during gestation, and thus cause birth defects (Streissguth, 1997). Various teratogenic agents have been studied including x-rays, heavy metals such as lead, certain drugs, and alcohol. A developing fetus, exposed to a teratogenic substance such as alcohol, may die, develop malformations, exhibit growth deficiency, or develop functional deficits (Streissguth, 1997).

Different doses and timing of doses differentially affect the outcome for a fetus exposed to alcohol. Early in gestation when the embryo is forming major physical

structures, exposure may disrupt this process. During the final trimester of gestation, teratogenic exposure affects the overall size of the offspring. As the brain develops throughout gestation, it is vulnerable throughout a pregnancy (Streissguth, 1997). Genetics and teratogenic substances interact to create disrupted development. The genetic makeup of the mother and the child has a major influence on whether a particular fetus will suffer adverse effects from exposure to alcohol (Streissguth, 1997).

Alcohol may disrupt prenatal development by producing cell death through a direct toxic effect on cells (Streissguth, 1997). This process causes certain areas of the brain to have fewer cells than would normally be present. Animal models have shown the following brain regions affected by prenatal exposure to alcohol: hippocampus, cerebellum, corpus callosum, and cortex. Alcohol interferes with the transport of amino acids, key building blocks for protein, and glucose, the main source of energy for cells. It interferes with the blood flow through the placenta to the fetus causing oxygen deprivation or hypoxia. Hormone and chemical regulatory systems that control the process of maturation and migration of nerve cells in the brain may be disrupted by alcohol (Streissguth, 1997).

Neurobehavioural teratogens, including alcohol, cause damage to the brain and modify behaviour in exposed individuals (Streissguth, 1997). Larger doses of a neurobehavioural teratogen can cause physical malformations, while lower doses can cause neurobehavioural manifestations without producing physical abnormalities. Investigation of alcohol as a behavioural teratogen found a variety of behaviours to occur in both animal studies and human studies of FASD (Streissguth, 1997).

According to Streissguth (1997) six key conclusions can be drawn from research on the teratogenic effects of alcohol. (1) Alcohol is a teratogenic drug that can cause damage and disruption to a developing embryo and fetus. (2) Dose, timing, and pattern of exposure modify the prenatal effects of alcohol, and research has shown that moderate and episodic exposure can produce negative effects as well as chronic heavy exposure. (3) There are individual differences in mothers and children that modify the severity and type of effect in offspring exposed prenatally to alcohol. (4) Prenatal alcohol exposure can cause brain damage even without co-occurring physical manifestations and with lower doses and frequency of exposure, which suggests that children without physical markers, e.g. those with ARND, may have brain damage as well as those with FAS. (5) Animal studies have established relationships between brain dysfunction and subsequent deviant behaviour in the offspring, which may include hyperactivity, difficulties with response inhibition or impulsivity, difficulty learning from experience, and perseverative attempts at solving problems. (6) The resulting effects of exposure to alcohol during the prenatal period last into adulthood (Streissguth, 1997, pp 66-67).

Neuropsychological explanations.

Human neuropsychology is the study of how neurological organization in the brain affects cognition, affect, and behaviour (Banich, 1997). Brain damage due to prenatal alcohol exposure can manifest in a variety of neuropsychological deficits depending upon the timing and dose of alcohol exposure interplayed with genetic risk factors for both the biological mother and the fetus (Streissguth, 1997).

Neuropsychological concepts are helpful in understanding specific deficits and

strengths that individuals with FASD have, and inform decisions around appropriate interventions for parents and professionals.

Roebuck, Mattson, & Riley (1998) report human and animal studies clearly demonstrate that alcohol is a physical and behavioural teratogen, with heavy prenatal exposure to alcohol leading to a distinct pattern of birth defects called fetal alcohol syndrome. Autopsy studies of children with FAS who died in the neonatal period have failed to show a specific pattern of anatomical deformity although they have shown a wide range of devastating physical effects (Roebuck et al., 1998). These are extreme cases and most people with FASD likely have less severe abnormalities of the Central Nervous System. Clarren (1981) reports a single case autopsy of a 4 year old with FAS who died of accidental causes in which he found a small brain size (microencephaly), reduction in the white matter of the brain, and neuronal heterotopias (overgrowths), but these were less severe than those found in autopsy studies on neonates (Roebuck et al., 1988).

More recently magnetic resonance imaging (MRI) studies in conjunction with quantitative analysis methods have demonstrated several specific areas of the brain that appear to be more susceptible to the teratogenic effects of alcohol (Roebuck et al., 1998), specifically the basal ganglia (Mattson et al., 1994; Mattson, Riley, Sowell, Jernigan, Sobel, & Jones, 1996), the corpus callosum (Riley, Mattson, Sowell, Jernigan, Sobel, & Jones, 1995; Swayze et al., 1997) and the cerebellar vermis (Sowell, Jernigan, Mattson, Riley, Sobel, & Jones, 1996). The basal ganglia (Banich, 1997) are located subcortically in the brain near the frontal areas of the cortex. The corpus callosum is a large neural tract composed of more than 250 million nerve fibres that connects the two

hemispheres of the brain. The cerebellar vermis is a part of the cerebellum which regulates muscle tone, guides motor activities, and is involved in the learning of motor skills (Banich, 1997).

Mattson & Riley (1998, p. 279) describe FASD as a 'devastating developmental disorder' caused by exposure to large amounts of alcohol in the prenatal period. There is a broad continuum of the effects of prenatal alcohol exposure with perinatal death and FAS at one end of the continuum, and relatively normal functioning at the other, with a variety of alcohol-related birth defects manifesting as behavioural or physical factors in between. Mattson & Riley (1998) reviewed research looking at the behavioural and cognitive effects of prenatal alcohol exposure including IQ, activity levels, attention, learning, memory, language, motor and visuospatial abilities in children.

Intellectual functioning may be quite compromised in children with FAS, with the average IQ score falling close to 70, but ranging widely from 20 to 100 (Mattson & Riley, 1998). Cognitive deficits, including mental retardation, may be present in individuals without the physical features that would give them an FAS diagnosis. Studies looking at intellectual functioning in children exposed prenatally to alcohol have found children with FAS or ARND/FAE have significant deficits in overall IQ as well as most scores on subtests compared to normal controls (Mattson & Riley, 1998). Twin studies (e.g. Streissguth & Dehaene, 1993, $n = 16$ pairs of twins) have shown identical twins (monozygotic) receive the same alcohol-related diagnosis, although IQ scores may show small variations. Fraternal (dizygotic) twins show more variation in the diagnosis and IQ scores (Streissguth & Dehaene, 1993).

Hyperactivity and attentional deficits are strongly associated with fetal alcohol syndrome and with prenatal alcohol exposure (Mattson & Riley, 1998). Children with FASD have been found to have difficulties in organizing and maintaining attention and to have a higher number of impulsive responses. Adolescents and adults with FASD have shown deficits in focusing, encoding information, and shifting attention (Mattson & Riley, 1998). These attentional difficulties may be similar to those found in children with Attention Deficit Disorder (Nanson & Hiscock, 1990). Nanson & Hiscock (1990) reported that 20 children with FAS/E were more intellectually impaired and showed slower performance and more practice effects than did 20 children with Attention Deficit Disorder or 20 normal control children. Nanson & Hiscock (1990) concluded, attentional deficits were similar in the FASD and ADD groups and treatments known to facilitate learning in children with ADD may also be helpful for children with FAS.

In contrast, Coles, Platzman, Raskind-Hood, Brown, Falek & Smith (1997) reported differences in attention between 149 low-income children who were prenatally exposed to alcohol, and 27 low-income children with an ADHD diagnosis whose mothers reported no alcohol intake during pregnancy. Children with an ADHD diagnosis had difficulties with focusing and maintaining attention on a stimulus, but were all responsive to stimulant medication (Ritalin). When these children were able to focus their attention appropriately, they were found to perform relatively well on encoding activities, which relate to learning and to working memory. Children with FASD could focus and maintain attention very well, but had difficulties encoding the information they were attending to, or making use of this information to solve a problem which has implications for intervention with children with FASD (Coles et al.,

1997). Stimulant medications which can help to improve focus may not be helpful with difficulties with encoding and problem solving. Therefore, educational interventions that provide strategies for encoding and problem solving may be more useful for children with FASD (Coles et al., 1997).

Research on learning and memory in children and adults with FASD has shown a variety of difficulties. Children and adults show impaired learning but relatively unimpaired retention of material that has been learned (Mattson & Riley, 1998). Deficits have been found in auditory memory, memory for stories and designs, spatial memory, and working memory in a study involving 10 subjects with FAS/FAE (mean age = 13 yrs) and 10 control subjects (mean age = 12 years). Subjects with FAS/FAE were relatively high functioning with receptive language (understanding) that did not differ significantly from the control group (Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995). Studies looking at language in children with FASD and prospectively identified alcohol-exposed children have found some deficits in speech and language (Mattson & Riley, 1998). In one study, 15 children with FAS and 10 with prenatal alcohol exposure showed impairment on tests of language, verbal learning and memory, academic skills, fine motor speed, and visual motor integration compared to 25 normal control children (Mattson, Riley, Granby, Delis & Jones, 1998).

Prenatal alcohol exposure has been found to have an affect on motor abilities (Mattson & Riley, 1998). Studies have shown delayed motor development as well as difficulties with both fine and gross motor abilities. Fewer studies have been done on visuospatial abilities in children with FASD (Mattson & Riley, 1998). However, there have been reports of difficulties with simple drawing tasks, as well as deficits in clock

drawing which is considered a classic test of visuospatial abilities. Uecker & Nadel (1996) found deficits in memory of where objects were located, but ability to recall the objects themselves in 15 children with FAS (mean age = 10.03) compared to 15 control children (mean age = 10.02).

People with FASD frequently show poor social judgment, poorly developed living skills, and intellectual impairments (Giunta & Streissguth, 1988). Thomas, Kelly, Mattson & Riley (1998) compared 15 children diagnosed with FAS with two comparison groups, 15 children matched with the children with FAS for verbal IQ scores, and 15 normal control children with average to above-average IQ scores. Children with FAS were most impaired on the interpersonal relationship skills subscale of the Vineland Adaptive Behaviour Scale (VABS). Older children in the FAS group showed an increasing discrepancy between their chronological age and their age-equivalent scores as they grew older, a phenomenon was not seen in either control groups. Thomas et al. (1998) conclude social deficits in children go beyond what could be explained by low IQ scores. They suggest this indicates arrested versus delayed development of social abilities in children with FASD (Thomas et al., 1998).

Kelly, Day & Streissguth (2000) review a number of studies that report social behavioural difficulties in both human and animal populations with prenatally exposed to alcohol. Some of these changes are noted early in life. Streissguth, Aase et al. (1991) tested 61 adolescents and adults with FAS (a few with FAE). The sample averaged a chronological age of 17 years, but showed an average adaptive functioning level of 7 years on the VABS. On subscales of the VABS, the highest subscale was daily living skills which averaged a 9 year level, and the lowest was socialization skills

at an average 6 year level. One or two subjects in this sample had age appropriate living skills, but none had age appropriate socialization or communication skills (Streissguth, Aase et al., 1991).

Executive functioning abilities, largely controlled by the frontal cortex of the brain, include the ability to plan actions toward a goal, to use information flexibly, to realize the consequences of behaviour, and to make reasonable inferences based on limited information (Banich, 1997). Deficits in executive functioning are seen in four major areas: (1) deficits in initiation, cessation, and environmental control of behaviour; (2) impairments in abstract and conceptual thinking, and in cognitive estimation; (3) lack of cognitive flexibility, and deficits in response to novel situations, and (4) deficits in goal-directed behaviours (Banich, 1997). Other deficits related to frontal lobe damage include specific difficulties with motor functions such as manual dexterity, impaired social and sexual behaviour, deficits in olfactory discrimination, and deficits in working memory (Jakobson, 2001).

Executive functioning deficits may result in poor daily living skills, making it difficult for people to live independently, and have been found to occur in people with FASD. Kodituwakku et al., (1995) found 10 children with FAS or FAE (mean age = 13 yr) had difficulties with some facets of working memory, which refers to the use of memory in short term storage, compared to 10 control subjects (mean age = 12 yr). Kopera-Frye, Dehaene, & Streissguth (1996) found that 29 alcohol-affected subjects (aged 12 – 44 yr) could read and write numbers but had deficits in a variety of number processing tasks including calculations with numbers and cognitive estimation tasks compared to a comparison group (N = 29) matched for age, gender and education levels

and with no history of prior learning disabilities. Mattson, Goodman, Caine, Delis, & Riley (1999) tested children (aged 8-15) who had been exposed to large amounts of alcohol prenatally with a battery of tests designed to measure executive functioning skills. They found that alcohol-exposed children (FAS, $n = 10$; PEA, $n = 8$) showed difficulties on planning tasks, cognitive flexibility tasks, selective inhibition of stimuli, and concept formation and reasoning tasks compared to nonexposed controls ($n = 10$) (Mattson et al., 1999).

Connor et al. (2000) found that their sample of 30 men (FAS, $n = 15$; FAE, $n = 15$) performed more poorly in nearly all cases on a number of executive functioning scores when compared to young adults, whose mothers had reported drinking alcohol during pregnancy, participating in a longitudinal prospective study ($n = 419$) and 15 control participants who made up a comparison group. They found difficulties in the ability of subjects to shift from one task to another, to maintain complex attention, to perform visuospatially mediated tasks, and to maintain and manipulate information in working memory, particularly when distractions were present (Connor et al., 2000).

Connor et al. (2000) suggest that research findings of executive functioning deficits have important ramifications for daily living and employment settings for individuals with FASD. The authors recommend to keep instructions concrete and unambiguous, to repeat information a number of times, and to use multiple modalities (visual, auditory, tactile) in presenting information to people with FASD. Difficulties with abstraction, planning and problem solving in individuals with FASD require helpers to 'plan out contingencies for many possible problems' that could arise during daily living (Connor et al., 2000, p. 351). Similar guidelines have been suggested for

parenting children with FASD (Hornby, 1993; Streissguth, 1997; Weiner & Morse, 1994).

Summary

FASD describes a continuum of serious disabilities that result from prenatal exposure to alcohol. These manifest in a number of neuropsychological difficulties in the areas of behaviour and learning. Individuals with FASD may live in a variety of families, including biological, foster, adoptive, or extended family. Each of these families may experience stresses related to raising children with FASD, and stresses from other issues confronting their families such as grief, health difficulties, or addictions. Clinical intervention with families raising individuals with FASD requires an understanding of the wide variety of issues that face these families.

CHAPTER 3

Intervention

Practicum setting.

This practicum was completed at the Family Program of the Elizabeth Hill Counselling Centre, located in the inner city area of Winnipeg. The Centre is a training facility for the Faculty of Social Work at the University of Manitoba. Therapists are mostly undergraduate or graduate social work students supervised by trained, experienced therapists. The Family Program provides family therapy training to social work students, and family therapy interventions to client families. Services are provided free of charge to clients.

The original intention of the practicum was to provide most services to clients at the offices of the Elizabeth Hill Counselling Centre, with perhaps some sessions provided in clients' homes to accommodate the needs of children with FASD or to assess the children's functioning in their own environment. Three families were seen for initial intake sessions at Elizabeth Hill Counselling Centre. Several attempts were made to schedule two other families for intake at Elizabeth Hill Counselling Centre offices, but due to unexpected crises, these appointments did not occur. Of the three families that were seen in the office, there were two no show appointments. One birth mother made several office appointments but was unable to attend any, possibly because she had relapsed after a number of years of sobriety and was drinking heavily.

After these initial difficulties, appointments to meet families in their homes were scheduled. Three of the seven families had young infants or toddlers and sessions at home allowed families to be engaged in therapy, while meeting the needs of their young

children. One of these younger children had also been exposed prenatally to alcohol, and was difficult to settle and care for even at home. The family did not have a suitable babysitter to care for this child, and would not have been able to attend therapy easily at the office. One family lived outside of Winnipeg; the parent did not like winter driving, and had children coming home on school buses, making it difficult to schedule appointments in the office. One foster family was seen at home when the foster mother was off work over the Christmas Break, and the Elizabeth Hill office was closed. The final family was offered services at home, because all of the other families were by that point receiving services at home.

Clients.

Clients were all families seeking therapy related to issues of a family member with prenatal alcohol exposure. A summary of family type, referral source, the number of alcohol-affected individuals in the family, gender, and range of diagnoses is reported in Table 3.1. Alcohol-affected family members were mostly children, mostly latency aged 8-10 or adolescent. Two other latency aged children related to a child in a foster home were seen for school consultation. In all, four school consultations were done as part of the practicum.

As predicted, families were seen both with children already diagnosed with FASD, children who had recently been diagnosed, and children with known prenatal alcohol exposure who were supported through the diagnostic process as part of therapy. Families sought services to manage difficult behaviours in their child, because they were relinquishing or considering relinquishing the child to another home, and to help them manage other related issues such as processing grief related to the child's

exposure to alcohol. Some families received therapy for other family issues peripheral to their child's FASD, or issues that arose during the course of therapy, e.g. relationship difficulties, issues related to sexual abuse in the parent's family of origin, issues related to stepfamily formation, or current family crises.

Table 3.1
Summary of Families

Family	Referral Source	Family Type	No. of Individuals With FASD	Gender	Diagnoses
1	FAFA*/ Self	Birth	6+	Male/ Female	ARND
2	CFS/ EHCC Wait List	Foster	3	Male/ Female	FAE
3	CADEC**	Foster	1	Male	FAE
4	FAFA/ Self	Extended	2	Male	PFAS/ undiagnosed
5	CFS/ EHCC Parent Child Program	Foster Birth	2	Female	ARND/ FAS
6	Self	Extended	2	Male	PFAS
7	CADEC	Adoptive	1	Female	ARND

* Fetal Alcohol Family Association of Manitoba

** Clinic for Alcohol and Drug Exposed Children

No instances of contraindications to therapy arose during the practicum. One adult believed to have been prenatally exposed to alcohol chose to receive services through another agency because of conflicts of interest with personnel at the Elizabeth

Counselling Centre. One birth mother was reported to be actively drinking by peripheral family members, but she did not attend scheduled sessions. One parent had major mental health issues, but these did not directly interfere with or preclude therapy services, and the parent was already dealing with these issues with appropriate services.

Personnel.

Personnel included the faculty advisor, Dr. Harvy Frankel, who was also the supervisor for this practicum. Dr. Frankel is certified with the American Association of Marital and Family Therapy as a therapist and supervisor. The second committee member was Marlene Richert, MSW, a family therapist with and Program Manager of the Families Affected by Sexual Assault program at New Directions for Children, Youth and Families. Ms. Richert is an adjunct professor of the Faculty of Social Work, University of Manitoba, and the clinical supervisor for and a Steering Committee member of the Interagency FAS Program in Winnipeg. The third committee member was Dave Schwab, MSW, who works for Child Guidance Clinic. He served as the external committee member.

Procedures

Assessment.

Assessment focused on the presenting issues and problems families brought to therapy, and at family functioning. The family's description of their needs and the therapist's assessment of the family's needs were combined to develop an assessment of what issues could reasonably be dealt with in the context of therapy.

Paquin & Bushorn (1991) describe an assessment model based on Weltner's Level One to Level Four Families, with level one families showing underorganization

and neglectful behaviour and with level four families having basic needs met and being reasonably healthy on a structural level. Treatment is determined by the needs and organization of the family and the presenting problem. In the context of families raising children with FASD, assessment also looked at which of the different proposed treatment models fit with the therapy needs of each family. Attempts at organizing these models suggested that there was no clear pattern of progression in using these models.

The literature (e.g. Streissguth, 1997) suggests that all families require information about FASD, but not all families can make use of this information initially. For example, Weltner's Level One family (Paquin & Bushorn, 1991) may be struggling with basic needs and organizational issues around housing, poverty, or neglectful parenting. In this case, structural approaches may be needed (Minuchin et al., 1998; Paquin & Bushorn, 1991) before the family can effectively integrate new information about FASD. Issues such as guilt (Hornby, 1993) or grief (Malbin, 1993a) may need to be addressed before families can integrate information about FASD and mobilize to meet the needs of the alcohol-affected individual.

Haley's (1987) exploratory problem-solving model was explored for initial assessment. His general assessment entails a number of stages: (1) a social stage of connecting with each family member to commence the process of joining with the family; (2) the problem stage, in which each family member comments on their perception of the problem; (3) the interaction stage, in which family members are coached to talk to one another so therapist can observe family interactions; (4) goal setting stage based on what changes the family identifies they would like to see. The

goals may then be used as a baseline for intervention and define the purpose of therapy. (5) the final stage, setting the next appointment, and usually an agreement for an initial direction of treatment. Assessment may involve more than one interview (Haley, 1987).

Haley (1987) varies this approach when families are in crisis. The above approach may weaken the parental authority and thus exacerbate a crisis, particularly if it involves a serious behaviour problem in a family member. Therefore, in this situation the therapist joins with the parental subsystem to help form a more solid hierarchy that can assume appropriate power to deal with the crisis (Haley, 1987).

Haley's (1987) general model was followed, in part, for initial assessment. However, given the nature of the difficulties all of the children in the practicum were having it was often modified to the more crisis oriented approach, with joining usually occurring initially with parents. Children were involved in sessions as much as possible, and when it made sense. Having therapy sessions in families' homes allowed children to come and go out of sessions. Ordinarily this might not be desirable in family therapy, but given that many children with FASD are easily overwhelmed by too many questions, too much verbal information, or everyone 'talking too much,' it was quite appropriate. An overwhelmed child could go and play or watch a video in another room.

The one family referred to this practicum from a more traditional family therapy practicum had not been able to keep the children in the therapy room for an hour session. Children running loose in the Centre had been a major problem, leading to the referral to this therapist. These same children were able to quietly play with their toys,

watch a video, and go outside and play, during a two hour session in their foster home. Therapy provided in family homes needs to be flexible to allow for minor interruptions to accommodate children's needs. However, it also gives a rich, real-life view of family functioning.

One family was seen in a more traditional family therapy assessment in the family home, with the parents and the alcohol-affected teenager meeting together in one room for the length of the appointment. It was clear to the therapist that the teenager was struggling with a number of difficulties. For example, she was unable to access memories of incidents, and had difficulty processing questions. Joining with her in this context was very difficult. Given the extreme processing difficulties many individuals with FASD have, it is not appropriate to expect that they will easily follow the interactions in a family session. This leads to the affected individual either shutting down and getting little out of the session, or could possibly lead to disruptive behaviour due to boredom or frustration. Joining with adolescents occurred better in other families where the therapist had opportunities to connect one-on-one (i.e. less sensory overload). Where possible, longer periods of time (what Malbin (2001) has called 'the gift of time') spent doing something such as transporting a child to an appointment allowed for a better sense of an adolescent's functioning, and a more helpful joining process.

Treatment Plans.

Treatment plans were developed by the therapist in conjunction with the supervisor and the families following initial assessment. Goals for change identified by families were an integral part of these plans. Contracting was done with the families

to gain their agreement to implement the treatment plan. Some families were contracted with for a specified number of sessions to work on specific issues. Other families were seen every one to two weeks for the period of the practicum. Termination occurred when the presenting issues (e.g. relinquishing a child) had resolved or ended, or the family was referred to other services.

Treatment plans included a variety of family therapy interventions, including psychoeducational intervention to increase family's understandings of FASD and appropriate parenting of a child with FASD, structural and strategic intervention to help families with issues of family structure and organization, and psychodynamic interventions to assist families with grief and guilt. A multisystemic approach was taken to therapy, usually in addition to one of the preceding interventions when families identified issues with other systems, e.g. schools or child welfare. A summary of possible indications for use of these models is provided in Table 3.2.

Table 3.2
Summary of Treatment Interventions

Model	Examples of indications for use of model
Psychoeducational	<p>Child symptoms:</p> <ul style="list-style-type: none"> • Behavioural or learning problems • 'Strange behaviour,' e.g. confabulation (makes up stories to fit expectations), does not understand ownership (eats off other's plates, 'takes things'), perseveration (gets stuck thinking or acting) • Forgets what to do (memory problems) • Misunderstandings (language and information processing problems) • Hyperactivity/'out of control' behaviour (e.g. overwhelmed by environment).

	<p>Parent symptoms:</p> <ul style="list-style-type: none"> • Feeling inadequate as a parent (has 'incorrect road map' (Malbin, 1993a). • Frustration or anger with child's behaviour. • Insists the child 'has to learn sometime' what the child is not capable of doing consistently. • Wanting to relinquish care of the child.
Structural-strategic	<ul style="list-style-type: none"> • Disorganized or chaotic family system. • Divided couple/parental subsystem. • Child appears to be 'in charge' of the family. • Sibling subsystem issues related to having a disabled sibling. • Wanting to relinquish care of child. • Family system stress. • Stress in parental subsystem.
Psychodynamic	<ul style="list-style-type: none"> • Grief and loss, e.g. loss of dreams of idealized child or 'happy family', loss of sense of parental competence. • Grief and loss (may present as anger) that parent did not have knowledge of child's disability earlier in child's life. • Grief and guilt related to mother's drinking during her pregnancy by mother, father, or extended family members. • Grief and guilt that situation cannot be righted. • Grief and guilt re: prior apprehensions of child or other children. • Loss of children to child welfare agency. • Loss related to currently relinquishing care of child. • Other related losses: e.g. loss of fertility leading to adoption • Grief and guilt that family regrets adopting child. • Anger at birth mother of child or at adoption professionals.
Multisystemic	<ul style="list-style-type: none"> • Major problems at school. • Conflict between school and parents. • School suspensions or suspensions from school programs, e.g. lunch programs. • Conflict or misunderstandings between families and child welfare agencies. • Problem behaviours in day care or recreational programs. • Conflict of child or adolescent with the justice system.

Supervision.

Supervision was provided by Dr. Harvy Frankel. As planned, initial sessions at Elizabeth Hill Counselling Centre were viewed live, using the one-way mirror.

Sessions at Elizabeth Hill offices were all videotaped as per the policy of the Centre.

The therapist reviewed these tapes after the session. When therapy became more home-based, supervision became a verbal and consultative.

Use of standardized measures.

The original proposal suggested the use of a standardized measure, the Parenting Stress Index (Abidin, 1995). The Parenting Stress Index (PSI) has a clinical cut off point, and a variety of subscores, and has been standardized on a variety of families including those with children with Attention Deficit Disorders, conduct disorders, and developmental delays. A high level of internal consistency has been reported for the PSI (Abidin, 1995). Test-retest reliability studies have shown that scores have remained stable across 3-week periods, 3-month periods, and particularly for the Parent Domain for a 1-year period (Abidin, 1995). Abidin (1995) reports a large number of validity studies that have explored the use of the PSI with a variety of populations, including children with developmental delays, language difficulties, conduct disorders, hyperactivity, attention deficit disorder, autism, Down's syndrome, and prenatal drug exposure. Sample questions from the PSI can be found in Appendix A.

The PSI was completed by three families. The other four did not fill it out. One family found the questions too invasive. One family went in and out of crisis a number of times and therefore did not fill out the forms. Two other families were given the forms, but did not fill them out for unspecified reasons.

For the families that did fill out the forms, the scores confirmed clinical impressions of families raising children with high needs, but who were mostly successfully managing their tasks, i.e. child-domain stress was high and often into the clinical range, while parent domain stress was often in the non-clinical range. This is similar to the pattern of stress reported by Abidin (1995) for families raising children with ADHD. Attachment measures were in a non-clinical range for the three families who completed the measures, with the exception of one relinquishing foster family where attachment was slightly over the clinical cut-off point. Scores for a family with an adolescent who scored in the clinical range on all externalizing behaviours on the Child Behaviour Checklist (Achenbach & Rescorla, 2001), and who was suspended from school for eight months of the school year, showed a non-clinical range of stress on all domains. This case in particular underlined that the Parenting Stress Index (Abidin, 1995) measures parent's perceptions of stress. The life stress subscale was extremely high for this mother, a fact which surprised her when the results were discussed with her. Her perceptions of stressful events were considerably different than most of the other families seen in this practicum. However, Malbin (2000) has also stated that her experience as a birth mother raising two alcohol-affected daughters who are both now adults was that it was not stressful once she had restructured her life to accommodate her children.

The Child Behaviour Checklist (Achenbach & Rescorla, 2001) provides a standardized description of a child's functioning. Ideally multiple informants provide information of their impressions of a child's functioning. It provides a clinical cut-off point. This instrument has been extensively tested over several decades and has been

found to have very high test-retest reliability over 1-week intervals, and very high inter-interviewer reliability. Reliability studies have been conducted on children receiving special education services, as well as children referred for services and for non-referred children. Research over a number of decades, and in different cultures has shown high levels of content validity and criterion-related validity in which items were found to discriminate significantly between demographically matched referred and non-referred children. Construct validity of the scales has shown significant associations with similar scales in other instruments and with DSM criteria (Achenbach & Rescorla, 2001). Sample questions from the Child Behaviour Checklist can be found in Appendix B.

The Child Behaviour Checklist and Teacher's Report Form (Achenbach & Rescorla, 2001) were used with one family and the child's school to gather some additional information about the child to support the diagnostic clinic's efforts to get as broad a perspective as possible of the child's functioning. Very similar reports were provided by both the parent who had resumed parenting six months previously and a teacher who had worked with the child for 2 months. The computer printout of the scores suggested the child's behaviour matched with several DSM-IV diagnoses: Oppositional Defiant Disorder, Conduct Disorder, and ADHD. Such correlations need to be viewed with suspicion in a child with neurological differences (Greene, 2001). Achenbach & Rescorla (2001) state that data from these scales should be carefully integrated with other types of clinical data before particular diagnoses are made.

Use of the PSI and CBC-L was also somewhat problematic for some of the parents with language processing or reading impairments, requiring the therapist to

assist the families in filling out the forms, because of difficulties or fears of difficulties in understanding the questions and/or statements. The PSI (Abidin, 1995) and the CBC-L (Achenbach & Rescorla, 2001) are rated at a Grade 5 reading level, but they were difficult for a parent with a Grade 8 education to complete. Complex questions involving different ways of wording negative statements were particularly problematic and required the therapist to interpret the statements for the parent. No standardized measures of family functioning or child behaviour have currently been normed for use with children or adults with FASD, so interpretation of results needs to be done with caution.

The results of standardized measures such as the PSI and CBC-L had some limited usefulness, particularly for seeking diagnostic services for FASD where there was no previous educational or psychological testing. The scores reflected that the children were struggling with behavioural concerns in ways that were outside normative populations of children, which was helpful information to medical diagnosticians as part of a more comprehensive diagnostic assessment. However, if these results were interpreted without knowledge of prenatal alcohol exposure, diagnoses of family system issues or child domain problems such as Oppositional Defiant Disorder or ADHD could lead professionals to treat families and children in ways that could cause both the child and her or his family increased distress.

Termination considerations.

There are no services in Winnipeg dedicated to FASD-appropriate services to families with alcohol-affected children aged 7-18. Because of this, the therapist was aware of the need for families to be linked to some appropriate supports at the end of

the practicum. Families were frequently quite isolated from community supports with regards to the child's FASD and it would have been unethical to leave families without access to some services should they need them in the future.

Some families were aware of the Fetal Alcohol Family Association of Manitoba. Other families were made aware during the course of therapy of the Family Association's newsletter, ongoing information sessions, and support group. One family was transferred to ongoing services with Interagency FAS Program because a younger child who had also been exposed prenatally to alcohol qualified the family for services. Another family was already linked to Interagency FAS Program services for a younger alcohol-affected child, and therefore had ongoing services following completion of the short-term therapy provided for an older alcohol-affected child. One family had set up comprehensive services with Children's Special Services and the FAS Outreach Team during the course of the practicum and therefore had ongoing supports. The other four families were offered access to short-term consultations from the therapist at Interagency FAS Program for specific purposes, e.g. school consults for the following fall, or more generally should a need arise in the future. Two families may make use of Theraplay services at Elizabeth Hill Counselling Centre in the future.

Overview of family therapy approaches.

No specific model of family therapy has been reviewed in the literature for use with families with members with FASD. This section looks briefly at relevant issues related to the four treatment approaches that together formed the model of therapy that was used with families in this practicum. It also explores a strengths-based approach that was used with all the other approaches throughout the practicum.

Psychoeducational approaches to family therapy.

Caregivers and families of individuals with FASD need accurate information on FASD (Giunta & Streissguth, 1988; Hornby, 1993; Malbin, 1993a; Morrisette, 2001; Streissguth, 1997; Weiner & Morse, 1994), and most families would benefit from linkage to appropriate resources where these exist (Giunta & Streissguth, 1988; Morrisette, 2001; Streissguth, 1997; Weiner & Morse, 1994). This suggests a psychoeducational approach to family therapy may be helpful for families dealing with FASD as has been recommended by family therapists for use with families dealing with other neurocognitive disabilities (Everett & Volgy-Everett, 1999; Greene, 2001, Trimble, 2001). A family therapist's role requires a demonstration of knowledge and expertise about the specific problem the client is experiencing (Patterson, Williams, Grauf-Grounds, & Chamow, 1998).

Parents who are knowledgeable about child development (Peterson & Mathieson, 2000), learning disabilities (Silver, 1998; Trimble, 2001), inflexibility or low tolerance frustration (Greene, 2001) or ADHD (Everett & Volgy-Everett, 1999) have more realistic expectations for their children and more compassion for children's struggles. Recognizing the organic brain damage that is part of FASD prevents inadvertently making problems worse, and helps decrease caregivers' levels of frustration (Malbin, 1993a).

Structural approaches to family therapy.

Family functioning and stability are sometimes disrupted in families with children with disabilities (Dubovsky, 2001; Floyd & Gallagher, 1997; Morrisette, 2001; Peterson & Mathieson, 2000). Structural therapy describes families as alternating

through periods of change, when rules, roles, and ways families accomplish tasks are reworked, and periods of stability (Minuchin et al., 1998). Families need to learn new ways to parent a child with FASD, and to adjust their perceptions to more realistic expectations for their child with FASD (Malbin, 2000), which would suggest a period of change.

Presenting problems may have their origins in inappropriate family structure, e.g. flawed family hierarchy or boundaries (Patterson et al. 1998). A flawed family structure may exacerbate behavioural difficulties in children with FASD, but a well-functioning, nurturing family cannot ameliorate all difficulties associated with FASD (Streissguth, 1997). The difficulties presented by an individual with FASD can cause a great deal of stress and disruption to the structure of a family (Dubovsky, 2001; Morrisette, 2001).

Viewing family structure as the only causal factor in children's behavioural problems may further disempower the parental hierarchy and increase feelings of parental incompetence (Morrisette, 2001). The family structure may be disrupted by the presence of the individual with organic brain damage due to FASD, as has been documented in families with a child with a learning disability (Silver, 1998). Structural family therapy may work to solidify couple subsystems, or redefine boundaries among the various family subsystems (Everett & Volgy-Everett, 1999; Minuchin et al., 1998; Patterson et al., 1998), or otherwise reorganize family structure such as intergenerational patterns in grandparent-headed families (Goldberg-Glen et al., 1998).

Psychodynamic approaches to family therapy.

Psychodynamic approaches to family therapy may help families deal with issues of grief or guilt. Strengths-based approaches and psychoeducational approaches may not be as powerful as acknowledging the pain a family has experienced in learning to cope with a learning disabled child (Trimble, 2001). Issues of grief requiring extensive working through by family members (Malbin, 1993a) and guilt that interferes with families' functioning to meet an alcohol-disabled child's special needs (Hornby, 1993) may require inclusion of psychodynamic approaches to family therapy. Individuals affected by prenatal alcohol exposure may have difficulty with insight-oriented therapy approaches, and other approaches may need to be explored (Novick & Streissguth, 1996).

Families with an alcohol-affected individual may not have known that FASD was an issue perhaps for a number of years (Dubovsky, 2001; Morrisette, 2001; Streissguth, 1997). Families may have been blamed by professionals for the child's difficulties if family functioning or interactions were seen as causal of the behavioural difficulties rather than a reaction to them. Families who have experienced prior professional intervention as unhelpful (Morrisette, 2001) may need to have their feelings understood and validated before they would consider connecting to a new process of family therapy (Trimble, 2001). Unaddressed grief or guilt may interfere with families' integration of psychoeducation intervention (Hornby, 1993; Malbin, 1993a) or follow through with structural/strategic approaches.

Multi-systems approaches to family therapy.

Families with a member with neurocognitive difficulties often experience difficulties beyond their home environments, which leads family therapists to advocate a multi-systems approach to therapy (Boyd & Franklin, 2000; Everett & Volgy-Everett, 1999; Streissguth & O'Malley, 1997). Therapists emphasize the importance of co-coordinating intervention approaches for families with children with neurocognitive differences such as FASD (Everett & Volgy-Everett, 1999; Streissguth, 1997; Weiner & Morse, 1994).

'[I]nflammation at the boundaries between subsystems of learning-disabled child, sibling, parents and school' (Trimble, 2001, p. 274), tensions and conflicts between parents and teachers of children with disabilities (Floyd & Gallagher, 1997), and difficulties in school for children with FASD (Streissguth, 1997; Streissguth, Barr et al., 1997; Weiner & Morse, 1994) often arise. Mediating or soothing such conflicts is often a therapist's first priority in families with school age children (Trimble, 2001). Therapists need to make specialized knowledge of neurobiology or developmental psychology understandable for the learning disabled child, their families, and their teachers. Therapists should acknowledge what families are doing well, and point these things out to schools to help alleviate the blaming of families that may be part of the conflict (Trimble, 2001). Multisystemic intervention can help to lessen the 'destructively poor fit' (Trimble, 2001, p. 480) between a child and his or her environment.

Strengths-based approaches to family therapy.

Strengths-based approaches may reframe learning disabilities as neurobiological variations that become problematic when there is a poor fit between child and family or other systems (Trimble, 2001), help identify strengths and ways to work around weaknesses (Levine, 1993, 2002, 2003), or assist children with FASD and their families to understand how the child's mind works differently and to use this information to inform parenting and other interventions (Malbin, 2000).

A strengths-based approach to providing family therapy was used in this practicum to empower families (e.g. Saleebey, 1996, Weick & Saleebey, 1995). Madsen (1999) advocates for the use of strengths-based, collaborative approaches to family therapy, taking into account a balance between acknowledging and building on strengths, and acknowledging and addressing real difficulties. Families sometimes struggled with difficult behaviours in their children with FASD, and with complicated, frustrating issues with other systems involved with the family.

Madsen (1999, p. 15 ff) suggests that family therapists take 'an appreciative ally' stance with families. The stigmatized nature of FASD (e.g. Malbin, 1993a) leaves families struggling with children with FASD feeling quite isolated, and the families seen in this practicum sometimes felt criticized by extended family, community members, and even professionals at times. These families were in need of an 'ally' who could appreciate their strengths, acknowledge their difficulties, and reassure them that other families with children with FASD sometimes had quite similar struggles.

Duration of Services and Recording

This practicum took place between September 2002 and June 2003. Seven families were seen for therapy. Two families were seen on an intensive basis, one for approximately 15 sessions and the other for 21. In addition, systems meetings with Winnipeg Child and Family Services, schools, the diagnostic clinic, and justice occurred for these families. Other families were seen for three to five sessions, in addition to school consultations or meetings with the Clinic for Alcohol and Drug Exposed Children or Winnipeg Child and Family Services. Therapeutic work with almost all families included numerous phone calls with workers from Child and Family Services, the Clinic for Drug and Alcohol Exposed Children, or personnel at schools or the Child Guidance Clinic. Several families made extensive use of phone consultations in addition to home or office sessions.

All sessions that took place at Elizabeth Hill Counselling Centre were videotaped. An initial assessment summary was produced for each family. Process notes were kept for all sessions and all phone calls. A treatment summary was produced for each family at termination.

CHAPTER 4

Themes Emerging from Therapy with the Families

This practicum was developed to explore issues related to families raising children, especially older children, who had been prenatally exposed to alcohol and to use family therapy interventions to effect change. A total of seven families were included in this practicum. They included birth families, foster families, grandparent-headed families, and adoptive families. All families were raising at least one alcohol-affected child. Several families had more than one alcohol-affected child, and a few families included adults who had also been exposed to alcohol prenatally. Some of the affected children had previously been diagnosed with some form of FASD. One child was directly supported through the diagnostic process, and another child and family were seen in follow up to receiving a diagnosis. Several additional children with FASD connected to families seen in this practicum were also provided with consultation about FASD either in their schools or foster homes.

Thematic reporting versus case studies.

It is usual to report this type of a practicum as a series of case studies. It was decided that this was not appropriate in this practicum because of the highly individualized nature of the families and the issues that they presented with. It would not be possible to adequately disguise the families to protect confidentiality if a case study approach was used, without losing some of the key themes that families struggled with.

In addition, families dealing with issues of FASD have access to a limited number of services in Winnipeg. There is therefore a high level of interconnectedness

between families raising children with prenatal alcohol exposure that increased the possibilities that confidentiality would be lost in a case study report. There were two instances during the course of the practicum in which this issue was salient. The therapist found two families were connected to each other and saw one client in another client's home. In another instance, a foster parent believed she recognized a story about a particular problem with FASD to be about a family she knew. These issues underlined the importance of protecting families' confidentiality, and thus thematic reporting was chosen versus case study reports.

Referrals.

Referrals were made by the families themselves, by the Fetal Alcohol Family Association, by the Clinic for Alcohol and Drug Exposed Children at Health Sciences Centre, or Winnipeg Child and Family Services. A number of referrals on the wait list at the Elizabeth Hill Counselling Centre may have been for children with prenatal alcohol exposure, but this was frequently difficult to confirm. Three of the families seen were from the Elizabeth Hill wait list, having been referred by Winnipeg Child and Family Services or self-referred.

Family therapy and the families with a child affected by FASD.

Family therapy with these families looked somewhat different than traditional family therapy, which is typically described as occurring in an office setting, with various expectations of who in the family will attend sessions, and very specific treatment goals looking at specific problems generated by the family (presenting problem) or by the therapist (assessment). In fact one of the families was referred to the

therapist after attempts to provide traditional, office-based family therapy was deemed to be inappropriate.

The presence of an ill or disabled family member in a family system necessitates adjustment by other family members to allow families to function to meet all family members' needs. When a child has a disability (such as FASD) that includes behavioural difficulties this has been found to contribute a great deal of stress to a family system (Floyd & Gallagher, 1997). In the simplest case, a family might consist of mostly high-functioning individuals plus one or two alcohol-affected children. The individuals with FASD at times stress the family system, but by and large the family accommodates the individual(s) with a disability, ensures that other systems meet the needs of those with FASD, and overall meets the special needs of the individual(s) with FASD. Several such families were seen in this practicum. These families would fit into Weltner's Level Four Families (Paquin & Bushorn, 1991).

In other families, a grandparent has stepped in to raise a grandchild who has FASD because the child's parents cannot parent, often due to ongoing substance abuse. The grandparent(s) may have already successfully raised a number of children who are functioning well with the exception of the birth parent. They struggle a little more, because of their own doubt about how their child could have become involved in substance abuse, and produced a child with FASD, an event they see as stigmatized and are afraid to discuss with many people in their world. If they are strongly focussed on the 'problem' of FASD and unwilling to make changes to accommodate the child with FASD they could fit into Weltner's Level Three Families (Paquin & Bushorn, 1991).

Other grandparents may struggle with issues of poor physical or mental health, poverty, ongoing concerns about their own children's substance abuse, their children's difficulty parenting other grandchildren, and concerns about whether they contributed to their own children's difficulties. Such a family may fit into a Weltner's Level Two Family in regards to setting limits with out of control adult children who are interfering with their parenting the grandchild, and yet function in terms of a Level Three or even Four family in terms of parenting the grandchild (Paquin & Bushorn, 1991). Yet both types of grandparents are deeply committed to being the best parent they can to their alcohol-affected grandchild, and have hopes and dreams that this child will meet their potential. Grandparent families at different levels of Weltner's model were seen in this practicum.

Birth families have usually struggled with addictions or abuse of alcohol or drugs, which resulted in the birth of a child with FASD. These children were welcomed and loved by their parents as children are in all well-functioning families. Their parents were deeply concerned about their children. Birth fathers or mother's male partners often fought with the mother during the pregnancy if she felt the urge to use alcohol. When they lost this fight and the mother used alcohol, the fathers were devastated and could recall that devastation vividly many years later. When they won and the mother was able to overcome the force of addiction in their lives, the fathers felt they had accomplished something, even if the child still ended up alcohol-affected. In some families the birth father was also lost in addiction or alcohol and drug use and was not available to support or help the mother fight the addiction. These fathers' children too ended up alcohol affected, although the meaning for them was less clear in this

practicum because such fathers were still lost in addictions themselves and minimally available to engage in therapy.

Birth parents had lost children to the child welfare system. Birth parents who were sober recognized that apprehensions by the child welfare system had been necessary, but these parents also felt deeply hurt by or frustrated with the child welfare system. Child welfare treatment plans for these parents often required participation in services that had become meaningless for parents who had already made major changes in their lives. One father was told he could not have his children returned until he went for assessment of his alcohol use. Yet probation services had already had him assessed and he was deemed not to have a problem. He recounted to the therapist the huge impact of reading John Bradshaw's book on the family over 10 years ago (Bradshaw, 1988), and his subsequent decision to stop drinking. He was devastated by his treatment at the hands of child welfare workers saying he had never been so badly treated by anyone in his life.

Birth families seen in this practicum were well aware of their children's disability. Although some birth families deny the existence of problems their children have due to FASD, perhaps to protect themselves from grief and guilt (Hornby, 1993), the birth families in this practicum fully recognized the difficulties their children had. These families had sought out services for their children at preschool or early school age. One birth mother had asked and asked for services for her three alcohol-affected children. Such requests dated back over a decade, yet no system had responded. These children had fallen through every 'crack' in school systems, and child welfare systems.

This mother continued to lobby with child welfare until her children were returned to her care, albeit undiagnosed and without adequate services.

Prenatal alcohol exposure was sometimes an issue for family members in addition to the children. Some family systems had such an entrenched problem with alcohol that parents identified multiple cases of women drinking through all their pregnancies. In some cases this meant almost entire families struggled with some level of learning difficulties or cognitive issues related to prenatal alcohol exposure. Despite this the families seen in this practicum managed to function appropriately in running their families and parenting children. Families with parents who themselves were prenatally exposed to alcohol who were functioning well are likely an exception rather than the norm. Streissguth, Barr, et al. (1997) report that only 7 out of 90 adult subjects in the long-term secondary disability study were able to live independently and had no employment problems.

The birth families seen in this practicum demonstrated resilience and a strengths based perspective. One birth mother recounted stories of cutting up towels for diapers and cutting leg holes in vegetable bags when she ran out of disposable diapers. Birth families lived on low incomes, budgeted carefully and met goals and had long-term dreams for their children. These families were much harder to characterize using Weltner's model (Paquin & Bushorn, 1991). Completely out of control teenagers would suggest Level Two functioning. Yet the teenagers had reached this level of dysfunction while in the care of the Child Welfare System. Upon return home, birth mothers were able to restore some level of functioning in the teen at least for periods of time in some cases. Because such families were somewhat resistant to changing their

responses to the adolescents at times, Level 3 functioning may be more accurate (Paquin & Bushorn, 1991).

Last but certainly not least were the foster families that cared long-term for children with FASD. The foster families were all strong, committed, knowledgeable families. They had all made a paradigm shift (Malbin, 2000, 2001) in seeing children with FASD differently, including one family that had many questions about sensory integration. These families received almost no emotional support from the child welfare systems that employed them. The two families who were considering relinquishing children had fostered for six or ten years. They had been creative in meeting the children's needs, with little help or support from the system. Several of the alcohol-affected foster children involved in this practicum had originally been placed for 3 weeks or a few months. Years later these children were still in the homes, and the families identified that little support had been given them. Burnout became a major issue in some of these homes. Burnout of foster homes overtaxed by systemic issues in the foster care system has been discussed elsewhere (Steinhauer, 1991).

When these families started to burn out, they asked for help from the child welfare system. One of these families requested help as this practicum commenced. The home-based therapy services, together with a respite break, and a support worker to take the child to recreational programs, allowed the family to regroup, and the child's behaviour became less problematic. An immediate response by the child welfare system has allowed this placement, at least for now, to remain intact.

The other family had been requesting help for three years, and burn out was deeply entrenched when this practicum started. Therapy services were directed to

supporting the foster home and the child with FASD through a difficult transition year, supporting the school in dealing with difficult behaviours, and collaborating with child welfare and the receiving foster home and its supporting agency in creating a smooth transition for an alcohol-affected ten year old. These families had maintained long-term placements for alcohol-affected children, with little perceived support from the child welfare system, when so many children with FASD are bounced from one home to another because of their difficult behaviours (Streissguth, 1997). These foster families were functioning largely at a Weltner's Level Four (Paquin & Bushorn, 1991).

Home-based Therapy Services.

Although some families were seen initially in the offices of the Elizabeth Hill Counselling Centre, by the end of the practicum all families were being seen in their homes. A variety of difficulties arose in client families' lives that produced a number of missed office sessions. Therapy provided in home produced only two no shows, both because of misunderstandings. Providing services in family's homes proved to be advantageous in a variety of ways.

Firstly, it was much easier for most families. Transportation was an issue for two of the families due to low socio-economic status, but both these families were in fact the most successful in attending office sessions. Several families had young children or infants in the home, and providing therapy in the home avoided issues of finding a babysitter for the child, or keeping a young child safely occupied in an office setting.

Home-based therapy services allowed the therapist to provide services in the environment in which the child with FASD actually lived and functioned, which was a

key consideration for children with a disability that is often impacted in a major way by environmental elements (Schwab, 1999). Families' questions could be answered in a way that fit the context in which the alcohol-affected child lived, and could be fine tuned to make sense for the family's life style. Environmental issues in the neighbourhood of the home were immediately apparent to the therapist and did not require detailed questioning of families, or attempting to comprehend issues from second-hand information.

Many family therapy models require the attendance by all relevant family members at all sessions. The busy nature of many people's lives makes it difficult to actually get a number of family members together in a therapy office on a regular basis. Providing therapy services in families' homes made a number of family members available to engage in therapy services at least some of the time, when these individuals would likely not have been able to attend office sessions due to work or school commitments, or due to disinterest or anxiety about therapy. Ex-partners, parents' siblings, adolescents' girl/boyfriends, close family friends, support workers, young siblings, and so on were all at times available at least briefly during the context of home therapy sessions.

The involvement of these people was helpful to the therapist and the family in several ways. It gave the therapist a more detailed knowledge of the ecology of the family, and at times it allowed minimal interaction or intervention with individuals whose lives intersect and impact the family, but who it would not usually be appropriate to involve in formal therapy sessions. Given the wide-spread impact of FASD on children's and families' lives which can frequently spill widely into the neighbourhood,

community, and extended family, occasional contact with a wide array of people connected to the family makes sense. Providing families with the tools to support their child with a large circle of support (Lutke, 2002; Malbin, 2001) means the family needs to involve a number of systems and community supports.

All of the families who participated in this practicum were dealing with at least one child with FASD. Children and adults with FASD frequently have difficulties in new or strange environments (Schwab, 1999). Therefore, providing services in the home removed the strange and unusual environment of the therapy room that could easily have cued very different behaviour in an affected child than that the family usually experienced. Home-based services allowed alcohol-affected children to respond largely in ordinary day-to-day ways given that the therapist's presence was also a change in the environment. The older children with FASD came after several sessions to see the therapist more as a frequent visitor to the family, and they were quite willing to some degree to talk with and engage with the therapist. Children with FASD who manifest symptoms of hyperactivity were able to come and go in their homes, versus being asked to sit relatively still in a small therapy room for an hour or more at a time. Most of the children were quite happy to spend a few moments to engage with the therapist and a parent regarding a specific issue when invited to do so.

Similar advantages to home-based therapy services have been reported by Boyd-Franklin & Bry (2000) and Minuchin et al. (1998). They reported home-based therapy allowed therapist an *in vivo* view of client's and their families' lives. In addition, they report the opportunity to engage with and join with extended family networks, form therapeutic alliances with boyfriends and fathers who may have a lot of power to effect

change in the family, but who frequently are unavailable for office sessions (Boyd-Franklin & Bry, 2000).

Minuchin et al. (1998) provide some guidelines and warnings about home-based services. The reader is reminded of the need for visiting workers to be respectful of families and their life-style. One of the families seen in this practicum had had a prior conflict with a home-based health care professional who had assumed a decorative bottle meant the family was using alcohol and had reported the family to child welfare workers. This had ended the professional's involvement with the family.

Few disadvantages were found to the home-based service model during this practicum. The major disadvantage identified by the therapist was exposure to second-hand smoke. Time spent travelling between clients could be seen as a disadvantage by some therapists. However, given the relative closeness of most areas of Winnipeg, the relatively short times between locations were useful transition times between clients.

Another potential disadvantage, particularly for student therapists, was that home visits did not allow for videotaping or supervisor observation of sessions. All sessions held at Elizabeth Hill Counselling Centre were videotaped, and almost all were observed by the practicum supervisor through a two-way mirror. Supervision for home-based services was through consultation and discussions of client sessions. In the context of this practicum, this fit with the plan of moving towards a more consultative model of supervision as the practicum progressed. However, it did not allow for exploring a variety of methods of live supervision, as office-based services would have.

All of the families the therapist saw in the course of this practicum appreciated receiving services at home. Several families with infants were particularly appreciative

because bringing a baby to the offices at Elizabeth Hill Counselling Centre was problematic for the family especially as most of the infants were crawling by the onset of services. Foster families with multiple responsibilities to several children also found home-based therapy service helpful. Families highly stressed and considering relinquishing children found home-based services allowed them access to therapy services without the added stress of getting to appointments, finding parking, and so on.

Families who were particularly knowledgeable about FASD were able to identify that home-based services allowed the therapist to truly see the child with FASD in her or his environment, and what issues families actually faced in parenting the child. Particularly the families who had felt violated by negative pronouncements by previous professional interactions felt validated by the therapist who could acknowledge the difficulties the families were dealing with, and the creative ways they had developed to respond to these difficulties. Experts in FASD (e.g. Lutke, 2002; Malbin, 2001, 2000, 1993a, 1993b) all advocate the need to do things quite differently with children with FASD. Families may have intuitively worked out parenting strategies that work for their children, but these strategies that appear strange to others. There is a risk if professionals are not truly knowledgeable about FASD and related issues that they will misconstrue these families to have poor parenting or inadequate family functioning.

Multisystemic intervention.

Multisystemic intervention was used with almost all families. If a child with a disability, in this case one of the various Fetal Alcohol Spectrum Disorders, is viewed as a beginning point, and the family that cares for her or him the next, assessment begins with where the child and the family are at. A family-centred approach to

assessment included meeting with the family and learning from the family what difficulties they could identify, how they perceived these problems, what they were already doing, what things had worked, and what had not in the past. From this initial interview, a treatment plan was developed with the family that made sense to the family. Boyd-Franklin & Bry (2000) identify the use of a multi-systemic model based on ecological assessment and intervention at various system levels within the family.

Some families at initial contact identified a need to understand the child's disability and asked for information about how to help their child grow and learn in healthy ways. Some families came with many questions about their child and the FASD diagnosis. For the most part these were families who had recently received a diagnosis, or who had not had access to specific information about FASD and how to adjust their parenting methods and expectations to accommodate the child. Interestingly some families had been aware that their child was prenatally exposure to alcohol, but did not begin to access information until they had a definite diagnosis. Without a formal diagnosis, families had ignored or denied at least at times that the prenatal alcohol exposure was in fact an issue for their child. They were even more likely to do this if professionals not knowledgeable about FASD had previously blamed the family for the child's difficulties.

Other families who had been parenting the child longer, and had known about the child's diagnosis for longer periods of time were mostly very knowledgeable about FASD. Many had attended workshops, researched FASD on the internet, read widely about FASD, or otherwise learned much about FASD. These families had developed or were using a variety of strategies that were helpful in managing their child's behaviour.

For these families identified difficulties were often either outside the family (e.g. in schools) or were indicative of what David Trimble (2001) has called 'inflammation around the boundaries.' Trimble uses this term to delineate the conflict that he found frequently occurred between families with a child with learning disabilities and school systems. Many of the families seen in this practicum had varying degrees of 'inflammation' around the boundaries between their child or their family and their child's school, the child welfare system, or the justice system. Minuchin et al. (1998, p. 59) discuss the same phenomenon which they call 'problems that beset a family [and] lie at its juncture with larger systems.'

Similar to the huge level of 'inflammation around the boundaries' that Trimble (2001) found with families with children with learning disabilities, some level of conflict between schools and families was found with almost all families. One family had developed a good relationship with the school, and identified that the school continued to bend over backwards to modify and adapt programming for their teenage child. They were the exception. Another adolescent was expelled from school and was not in school for the remaining eight months of the school year during which this practicum was occurring. This latter situation was clearly a systemic issue given that no one, including the child's parent, the child welfare workers involved with the family, the school social worker or the therapist, believed this child would not be better off in an appropriate school setting.

In families with older elementary school aged children, experienced and knowledgeable parents identified much frustration that the schools did not understand their children's difficulties or needs. A number of consultations with schools were done

during the course of the practicum. In most cases, these difficulties had not developed into actual conflict, but manifested more as frustration often by both the family and the school. However, in one family, the parent had refused to respond to the school in the same way she had previously to reduce stress on herself and her family which had reached a high level. In another family, transition plans for a foster child being relinquished had to be moved up because the school could no longer manage the behaviour of the child. This added considerable stress to the relinquishing foster parent, who was committed to seeing the transition through in the way originally planned and presented to the child.

The benefits of seeing a child in the context of their classroom and school, and meeting directly with teachers and other school professionals struggling with the child were enormous. Boyd-Franklin and Bry (2000) note that a well-timed visit to a community agency can allow a therapist to get a better view of a client's world than hearing about such interactions from the client. In the context of this practicum, the therapist found that even frustrating interactions with other systems increased the level of joining with the family and the stance of being an 'appreciative ally' (Madsen, 1999). Families who had felt violated by systems unresponsive to children with FASD felt validated when the therapist met with similar difficulties. The therapist could then work with the family to effect change in the systems where problems were occurring.

'Inflammation around the boundaries' (Trimble, 2001) was also seen between child welfare agencies and families. Some level of difficulties occurred as expected, but again open conflict was rare. The birth families that identified they could not be totally honest with workers because of fear of losing their children, or who were angry

at the adversarial way they were treated by workers, all agreed that it was a good thing the children were apprehended when they were. They acknowledged that their behaviour or that of their partner had led to inadequate care of the children, and that it was good the workers had stepped in to keep the children safe.

Child welfare workers' own lack of knowledge about FASD beyond a very rudimentary level was sometimes problematic for birth families. Workers who were legal guardians of children did not always truly understand the child's difficulties and made decisions or failed to provide adequate supports because of this. Workers made decisions about the family's level of knowledge and parenting capacity with regards to children with FASD without themselves understanding FASD or how to parent a child with FASD. In some cases, workers appeared to be unaware of the benefits families experienced having access to therapy services which did take into account knowledge of FASD.

More surprising was the level of 'inflammation' (Trimble, 2001) between some of the foster families and child welfare workers. In some instances, foster families had been treated very poorly by the child welfare system. Social workers had been rude to some families, and highly critical of parenting skills that were in fact well suited to raising a child with FASD. Again a lack of truly understanding the disability of FASD and the kinds of difficulties faced by those parenting the children were sometimes at the root of this issue. Parents were sometimes openly criticized for parenting strategies that worked with the child, but the worker perceived as 'poor' parenting practices. These misunderstandings left families feeling misunderstood by the workers who families perceived should have been supporting the family. Foster families also strongly

identified lack of supports, particularly for long-term placements, as an issue. One foster family relinquished the children during the course of the practicum, and another seriously considered relinquishing a child because of the lack of supportive services for the child, and the resultant burnout the families experienced.

Families were provided services by the therapist at the various systemic levels they identified a need. Many families received services that helped them process difficult personal or family issues that they identified at intake, and also received services that included consultations with their child's schools, consultations and meetings with social workers in the child welfare system, or with probation officers. In a number of families, issues arose during the course of the practicum, and therapy services were adjusted to accommodate these.

One of the mothers had a still born baby during the course of the practicum, and therapy was adjusted to allow for a break, and then attention to grief issues, and resultant marital relationship issues between the mother and her partner. In another family, the school asked that a child with FASD be removed from school several weeks before the end of the school year and a planned placement move, which required some adjustment to the transition plans, and supporting the parent and the child with FASD to adjust to different plans than they had anticipated. This situation involved changing interventions at a family, school, and child welfare level.

Structural and strategic therapy.

Structural approaches to family therapy and family systems theories (Minuchin et al., 1998) were used to conceptualize family issues and to guide interventions. Issues such as confabulation (story-telling due to brain damage often misunderstood as lying)

were dealt with using reframing techniques to help a variety of family members (residential parent, non-residential parent, alcohol-affected teen, and boyfriend/girlfriend) to reduce high levels of conflict that were occurring because of inaccurate stories being passed by the alcohol-affected child to both the primary residential parent and a non-residential parent. The family was able to see that the child's brain saw the world differently, did not always accurately remember the original incident, and that therefore 'mix-ups' occurred and stories were not always accurate. This allowed previously conflictual divorced parental relationships to become somewhat less conflictual and for both parents to work a little better together to help their child. Parents realized there was a very real need to check out the accuracy of stories they were hearing. They also had an opportunity to realize that this behaviour was not deliberate lying, but confusion of facts and confabulation due to brain damage. Confabulation is a product of brain damage from a variety of origins in addition to FASD (Banich, 1997).

Structural interventions such as those above, occurred because of the access home-based therapy gave to family members who would not likely have been present in an office session (Boyd-Franklin & Bry, 2000). Much like a concept of using teachable moments when parenting children, therapy in a home-based setting needed to make use of therapeutic moments that occurred when a parent's ex-partner and an adolescent's girl or boyfriend happened to drop by during a session. The individuals naturally replayed their ongoing conflict for the therapist. The family level structural intervention was combined with psychoeducational intervention regarding confabulation to the

adolescent's non-resident parent. Hopefully this served to both prevent future conflicts, and to help the non-residential parent to better understand the teenage child.

FASD may result in inappropriate behaviours that the affected individual may not recognize as problematic for other family members. Structural family therapy approaches allowed parents to recognize that behaviours they had previously believed were deliberate attempts to hurt the parent emotionally were in fact the product of a 'game' the child enjoyed and did not understand was causing difficulties for the parent. Such behaviours can be very difficult for parents to differentiate from normal teenage behaviour which may include various, button-pushing behaviours (Elium & Elium, 1999, Steinberg, 1994, Wolf, 1991). Recognizing the child's different perceptions of events allowed parents to reframe previously distressing behaviour as game playing which allowed the parents to recognize they could choose to play the game to entertain the child when they chose, but could also choose not to play when they did not wish to.

Structural intervention was used with a grandparent family in which the grandmother was worrying about all the children in her family system. She worried about her adult daughters and their children. She also worried about her parents who she described as childlike. She also worried about much younger half siblings because of multiple instances of sexual abuse in her family. Structural formulations were used to encourage this grandmother to focus her efforts on raising her grandchild with FASD, allowing other services to take care of her adult children and the children in their care, and to strengthen the boundaries between her home and those of her adult children. The grandmother appeared relieved when given permission to stop worrying about her entire

family system. Humour was used to underline the impossibility of the task she had set herself.

Later a child in her extended family network disclosed further sexual abuse, and the grandmother was devastated because she had extensively talked to various systems years before to prevent such an event. The systems had failed to protect the child. The grandmother was reassured that she had done everything she could, and that she could not be responsible for social systems' failure to act. Again she was encouraged to strengthen the boundaries between herself and the broader social systems.

Strengthening the parental hierarchy in families is a common structural intervention (Minuchin et al., 1998). This was done with almost all the families but in a somewhat paradoxical manner that could be deemed strategic (Haley, 1987) in nature. Families with a child with FASD often appear as if the child is in control of the family system. However, when the child has serious neurocognitive disabilities this is likely an illusion. The child is likely not in control of her or his own decision making even on a subconscious level, and is in fact creating chaos in the family because of their brain's disorganized executive functioning.

The child will usually become more organized if the parents are empowered to improve the structure in the home environment. However, there are numerous situations when the most powerful intervention a parent can use is to ignore behaviour completely (to prevent inadvertent conditioning of the child's responses due to attention paid to the behaviour) or to use a very minimal intervention, e.g. 'You're swearing. Use this word.' Parents accustomed to punishing and consequencing children often find this kind of approach difficult or impossible. Structural frameworks can be very

helpful to reframe this for the family. It in fact takes a strong, powerful parental hierarchy to ignore behaviours or use simple, low-key interventions when the parents' gut reaction is to impose a complicated or strong punishment.

Psychodynamic therapy.

Grief was an issue that occurred in a number of families. A birth mother grieved her stillborn baby. Grandmothers grieved their daughter's actions that had led to the birth of alcohol-affected grandchildren. Birth fathers grieved their inability to stop their partners' drinking during pregnancies. Foster families grieved for children they felt they could no longer care for. Children grieved for families in which they could no longer live. Families worried about the future of the alcohol-affected children in their care, and some grieved what might have been for their children. Some of these issues were dealt with in therapy.

Some of the grief issues were related to FASD. Foster families that were relinquishing children or thinking about relinquishing children were grief-stricken. These were long-term placements. The foster mothers were strongly attached to the children with FASD, and felt a huge concern that children be moved to new homes that were competent and knew how to parent children with FASD.

One foster home had had a child with FASD leave shortly before therapy began. The foster family was very upset with the quick move with no pre-placement visits and no transition planning for the child. The family perceived quite strongly that the child was not happy with the move. Towards the end of therapy this child had broken down crying at the end of a visit, and had been warned by another child in the new foster home that visits would not be allowed if the child was found crying. This distressed

child revealed to the original foster mother that she knew how many months and days since she had moved, and how many days between sporadic visits to her original home.

The foster mother was actively grieving the relinquishment of this child. The child was grieving the move with no way to process this grief in the new home. To complicate matters, promises made that this child could return to the original foster home for respite were not kept. At one point workers and the receiving foster home decided that the child would bond better in the new home if visits were terminated with the old home. Although this child had left the foster home, the therapist was involved in meetings to work out a suitable plan to maintain contact with the child's primary attachment figure, the foster mother who had cared for her since she was an infant. The therapist provided school consultation to this child's school because of difficulties at school identified during the meeting regarding visits. Several attempts were made by the original foster parent and the therapist to have the child welfare professionals ensure this child could appropriately express and work through her grief.

Even with appropriate responses to this child's grief, there is no assurance that this will happen. Anecdotal evidence from the Interagency FAS Program staff (Kacki, 2003) suggests that some children with FASD do not process the fact that they are moving to a new home, and in various ways will indicate to previous foster homes that they are ready to come home, and are finished visiting this new home. Concepts such as 'permanent move', 'forever', and 'new parent' are presumably quite abstract and therefore may be difficult for a child with FASD to process. Interagency staff report that children will ask a former foster parent when they can come home 18 months after a move, or ask a current foster parent two years after a move if she is the child's new

mother. Children with FASD can take months or a few years to process what a child without FASD may realize within minutes or hours, and they frequently do not process abstract concepts at all. Concepts such as 'home' seem very simple in some ways. But the true meaning of concepts of a 'home' versus a 'house', or the affective meaning of the words 'home' or 'mother', are in fact very complicated linguistic concepts that most adults would have difficulty fully and accurately describing without some thought.

Another child with FASD was moved from the same foster home to a new foster home towards the end of the practicum. This child was given lots of time to transition, and the family was given social stories written together by the therapist and the parent to help the child to understand the process of moving. The child with FASD responded well to social stories, and was reported to keep one close to his bed at night. This child who had a severe reading disability was very happy that with visual cues, he came to be able to read the story to himself. He particularly read and re-read the story about how his foster mother still loved him and that he would have visits with her following the move. There were several pre-placement visits, including overnights, and the child had some positive experiences to look forward to at his new home. He was quite excited by a visit to his new school.

This move was also difficult for the foster mother, but she was less worried about this child because she knew some groundwork had been laid for a positive move. Visits back to her home were included as part of the treatment plan in the new home, and she knew she would have ongoing contact with the child. This move was still painful, but it was more hopeful for the family and the child.

This foster mother had a great deal of skill. She was able to process her grief away from the child while continuing to support the child in his struggles around moving. She creatively worked out plans with the new foster parent to support the child as he moved into the new home. The agency supporting the new home and the receiving foster parents were quite surprised to see a foster child move with more than one garbage bag. The foster mother grieved the loss of this child too, but being involved in a good transition process helped her to feel more competent with less need to question her decision that she could no longer foster him.

Another foster home was seriously considering relinquishing a foster child at the start of therapy. The child with FASD had recently confabulated a serious allegation about the family, which had been found to be untrue, and the child had recanted his story. The family was deeply hurt and felt very hurt by the child's actions. This child had no comprehension of the family's intense hurt and grief over this incident. This child also exhibited other difficult behaviours, including urinating all over the bathroom on a regular basis, leaving the parents with a lot of unpleasant cleaning on a daily basis. The 9 year old child did not understand the impact of this behaviour on the family despite numerous attempts by the family to explain it to him. Even with the horrendous difficulties the foster mother was having in continuing to care for this child, she was still firmly attached to the child, and was grief stricken at the thought of relinquishing him.

This family had originally been asked to foster the child short-term for a few weeks, but he had been left in the home for six years. The foster mother had dreamed of making a difference in this one child's life. Her hopes had been that if she parented

him well, he would avoid the difficulties that face so many adults with FASD. She grieved the thought of loss of a child she had come in six years to see as a member of her family, who she had parented as if he were her child. She also grieved the loss of her hopes and dreams of making a difference in the life of at least one child with FASD.

In discussing grief issues families with a child with FASD experience, Dubovsky (2001) talks about families' possible loss of a sense of security about the future. Particularly the grandparent and foster families in this practicum exhibited a lot of concern for the future for their grandchildren/children with FASD. They worried about what would happen to the child with FASD when they became older. They worried about what the child would be like as an adult. They wondered if the child would be better, or if s/he would be able to take care of her- or himself. These families wanted to hear stories of hope; they wanted to hear that at least some adults with FASD were doing well.

Perhaps the grandparent and foster families worried more about the future because the grandparent families had seen at least one other child grow up and have great difficulties as an adult, and foster parents often had had previous children with ongoing difficulties. Perhaps these families worried more because they were older and could foresee a time when they might not be able to care for a child that might need care for longer than other children. This was of particular concern for grandparent families. Relinquishing a foster child is not as socially stigmatized as relinquishing a biological child or grandchild.

Therapy for these issues involved validating parent's fears, and discussing and reframing the horror stories families had read in newspapers. The therapist shared

protective factors that these families' children with FASD had experienced that the long-term research has shown lead to better outcomes (Streissguth, Barr, et al., 1997). The grandparent families had children with FASD who had received early diagnoses, had lived in a stable and nurturing home for most of their lives, had not had multiple placements, and in one case the child qualified for children's disability services. Foster families had often provided a long-term, stable placement, and their children too usually had received a diagnosis.

The therapist shared stories of adults with FASD she had known and what was going well for them, how they had built on strengths, as well as the reality of the kinds of supports they continued to need from their families or others. Grandparent families realized their grandchildren would possibly need ongoing supports from the family or some other service as adults

Other grief issues that arose in families were not related to FASD. One of the birth mothers had a still born baby during the course of the practicum. Her original purpose in coming to therapy to was to get help with her adolescent children with FASD who were being reunified with her family. The stillbirth of a baby derailed the original purpose of therapy temporarily. The mother took a break from therapy for two months. When therapy resumed a variety of issues related to the original treatment plan were worked on, but so was the grief of the loss of the baby. Grief is a process that takes time to work through, and differs from one person to the next. For this mother making sense of the loss of her child, and integrating it into her life was important to her. She worked hard at this process on her own, and shared it with the therapist as it unfolded. At times, she needed to have the therapist validate that her process was

'normal.' As happens with grief, various events in the mother's life caused the grief to resurface, e.g. attending a funeral.

Another parent came to therapy with a direct purpose of working through issues of anger at her daughter who drank during her pregnancy causing the grandson to be born with FASD. Anger is often a symptom of grief. In this family grief was complicated by multigenerational themes of childhood sexual abuse. This parent was very angry at anyone who hurt children, whether it was her parents or her daughter. Her manifestation of anger was particularly problematic because she identified that at times it spilled and got confused with frustrations in parenting her grandson. In addition, to psychodynamic therapy for grief, this grandmother was also responded to strategically. She was asked to make an appointment with herself when her grandson was safely in day care to 'get angry.' Several ways of processing anger were discussed. She chose to buy inexpensive balloons to vent her anger. Even before she had had a chance to follow through on this plan her anger appeared to be less intense. When she did follow through on the balloon plan, she bought one so she and the grandson could get angry with the balloons together, and it became a fun family activity.

Psychoeducational therapy.

Many families who took part in this practicum had questions about FASD, how to manage various behavioural and learning symptoms, what the long term implications of FASD were, and so on. Learning more about the child's disability allowed these families to reframe their expectations for their child, making room for more opportunities for success for the child, and for feelings of competence and success for the parents. Psychoeducational approaches to therapy were used in response to

families' requests for more information generally or specifically about FASD. Other times these approaches were used by the therapist in response to situations families recounted that the therapist assessed to include areas of misunderstandings about FASD.

FASD is a disability that is primarily neurological in nature, and frequently invisible. Without knowledge about FASD and the underlying brain differences that cause children with FASD to learn differently, experience the world differently, or behave differently, families were sometimes very frustrated, concerned, or stressed by the child's behaviour. Accurate information helped families to make a paradigm shift (Malbin, 2001, 2000) which allowed families to feel more confident in their parenting and to adjust their expectations of the child with FASD.

Behavioural difficulties in special needs children have been found to be highly stressful for parents (Floyd & Gallagher, 1997). Parents are confused and frustrated when their children continually behave in ways that violate family rules or social expectations. Parents at times felt judged by others in their community, or judged themselves based on their perceptions of social expectations. Families have the sociological task (Macionis & Gerber, 2002) of socializing children and raising them to be productive members of society. Community and social sanctions of disapproval remind parents of this task. Parents may become extremely distressed and quite overly zealous in their attempts to have their child conform to these social expectations. Families needed information to understand that their child was not a bad child who *would not* listen, but a disabled child who *could not* perform the expected tasks without extra supports (Malbin 2000, 2001).

Many families with children in the 7 to 10 year old range or adolescents, had children who at times engaged in inappropriate behaviours which included swearing, being disrespectful, breaking rules, 'not listening', and in two cases urinating in inappropriate places in the house. These behaviours pushed parent's buttons, caused parents to be frightened for their children's future, and left families feeling deeply frustrated and confused when standard good methods of parenting failed to produce changes effectively in their children's behaviours. Understood through a lens of varying neuropsychological functioning and non-functioning, quite disturbing behaviours became less problematic for families because the meanings attributed to these behaviours by families had changed following psychoeducational intervention.

Swearing and disrespectful behaviour were seen as hurtful, embarrassing, and deeply offensive behaviour by parents who believed their children knew these were 'wrong' because they had taught and modelled appropriate behaviour to their children. Children and others with FASD frequently do not easily understand abstract concepts (Malbin, 2001). Concepts such as 'disrespect', or that some words are swear words and others are not, are quite abstract and difficult for children with FASD to comprehend. When parents saw the child's perspective of such behaviours was quite different from their own, they felt less hurt by the child's behaviour, and could move to creative ways of problem solving to stop or redirect the behaviour.

Many families were deeply confused and frustrated when children with FASD clearly knew rules, could repeat the rules, but failed to perform the expected behaviour indicated by the rule, sometimes over and over again. Understanding that one area of the brain learns what the rule is and another area (frontal cortex) puts rules into effect

(Malbin, 2000, 2001) was helpful for these families. The frontal areas of the brain have been increasingly found to have sustained damage from prenatal alcohol use (Connor et al., 2000; Kodituwakku et al., 1995; Kopera-Frye et al., 1996; Mattson et al., 1999), and this is the area of the brain that is involved in initiating activities (Banich, 1997; Jakobson, 2001) such as putting rules into effect. Recognizing that failure to put rules into effect was indicative of a failure of a neurocognitive loop in the brain rather than deliberate wilful misbehaviour allowed parents to become less frustrated. In time they were able to see such incidents as humourous, and not to feel resentful when they had to repeatedly remind their child of the rule, provide visual cues about the rules, use visual hand cues to remind the child of the rule, and so on. This allowed the child to be successful (with a reminder) in carrying out the rule, and parents to feel competent in effecting appropriate change in their child's behaviour.

Children with FASD frequently have difficulty processing auditory information, which usually looks like 'not listening' to parents or teachers who are unaware of this difficulty. Realizing that their children did not learn well from auditory stimuli or that their child frequently misunderstood auditory messages allowed parents to see their child was not being deliberately defiant in 'not listening' but rather was unable to integrate the auditory information. As parents came to recognize that the child truly did not comprehend requests or explanations, parents were willing to switch to short, concise verbal messages, to repeat these messages frequently, or to use visual cues such as hand signals or picture symbols to increase the child's ability to comprehend.

While the behaviours described above may be misunderstood as misbehaviour, other behaviours such as urinating in living rooms, on bathroom walls, or in basements,

were viewed as unpleasant, distasteful or problematic regarding normative social expectations for older children. These behaviours were seen in children aged 8-10 years in two different homes. These behaviours were deeply entrenched and proved to be difficult to extinguish. Parents' socially constructed meaning of inappropriate urination was abstract and difficult for the children with FASD to grasp.

One child stopped urinating in the house after temporarily sharing a bedroom with a child with enuresis. The smell at night was offensive to the child with FASD and gave him a concrete experience of how distasteful urinating inappropriately in the house was. Once he had a concrete experience, learning occurred, and this the behaviour stopped. While other factors were likely also at play, having a concrete experience of what was unpleasant about his behaviour helped him to understand why his parents were so upset by the behaviour.

Behaviours such as enuresis or encopresis are often associated with traumatic events such as sexual abuse and separation from an attachment figure (Delaney, 1991). These behaviours may indicate similar issues in children with FASD, and possible abuse or trauma should be carefully evaluated. However, different ways of learning can also influence the continuing display of behaviours such as urinating in inappropriate places.

In another family, there was no apparent connection to traumatic events to explain ongoing enuresis, encopresis, and intermittent urinating in the house. The child was separated from his birth mother and saw her for occasional sporadic visits. However, incidents that occurred during the therapist's involvement occurred mostly following changes in routine the day before behaviours started. Once the behaviour was

initiated it often continued for a number of days. This child had toilet trained with no difficulties. Urinating in inappropriate locations originally commenced when his father took him into the bush to urinate on a family hike. The child then attempted to urinate by a tree in the family's front yard. After several months the child stopped urinating in the front yard, but continued to urinate intermittently in strange locations in the house.

Therapeutic efforts for this family focussed on working out what triggered this behaviour. Initially, it was probably the confusion the child at approximately three years old experienced as to why he could urinate on one tree (in the bush) and not on another (in his front yard). Though the different meaning of these two events seems obvious to most adults, it is not necessarily apparent to a child with FASD to whom the different social meanings of these two events is highly abstract. The family was given several versions of visual 'no urinating' rules to post in problematic areas of the home. Whether this has a long-term impact on the child's behaviour remains to be seen.

Paradigm shift.

Diane Malbin (1993b, 2000, 2001) uses the term 'paradigm shift' to indicate the change in perceptions that are required to parent, educate, or work with individuals with FASD. Malbin states that the paradigm shift required to understand and support individuals with FASD has implications similar to redefining the world from a flat plate to a round sphere (Malbin, 2001). Without a paradigm shift, Malbin suggests parents are left trying to parent a child with FASD using good parenting methods, but ones that require a certain level of intact neurological functioning to be successful. Malbin (1993b) has compared this to trying to drive around a city such as Denver with a map of another city such as Minneapolis.

Individuals with FASD are frequently unidentified, especially those with no physical markers (Malbin, 1993a, 2001; Streissguth, 1997), and thus badly misunderstood by parents, teachers, community members, social workers, psychologists, or health care workers (Malbin, 1993b, 2000, 2001). One family who had cared for a grandchild for eight years was aware of the prenatal exposure to alcohol and drugs, but had not received any information or services to assist them in understanding what this might mean. This child had been very angry and prone to serious tantrums as a toddler. When the family consulted with a pediatrician they were told he probably had 'Oppositional Defiant' behaviour and the family was referred to a psychologist. The psychologist told the grandparents that their poor parenting was responsible for the child's behaviour. Hurt, angry and misunderstood, the grandparents did not return to the psychologist, and it was some years after before the child received a diagnosis of Partial FAS.

With accurate information about FASD, this family came to realize that many of the difficult behaviours their child displayed could be better managed by changing their parenting style and expectations. These parents started to look for alternate explanations for their child's behaviour. For sometime the parents had been getting quite angry with this child for poking holes in the lawn which the child stated he had not done. When their perceptions changed, they realized the child was in fact not poking holes in the lawn, but rather was removing ants from the lawn, a procedure that happened to leave holes. The child could not connect these two facts and honestly did not believe he was poking holes in the lawn.

Parents who had been parenting children with FASD for some time had for the most part changed their perceptions of their child and made a paradigm shift prior to therapy. Some of the families made a shift as psychoeducational interventions were used. At the end of several sessions one family invited the therapist to view a videotape that showed a parent talking about changing their parenting style so the child could learn to behave in more acceptable ways. Discussion with the client family allowed them to recognize that they too had changed how they perceived their child's behaviour and how they responded to the behaviour, which then allowed the child to function more acceptably. A paradigm shift had begun to occur.

Other families responded to intervention aimed at normalizing behaviour due to the child's disability. Diane Malbin (2001) has suggested a concept of 'dysmaturity' to explain behaviours displayed by children with FASD that usually occur more commonly in younger children. So for example, a fourteen year old may act more like a ten year old. Malbin suggests this is *normal* for children with FASD, and that viewing the fourteen year old as a very competent ten year is a more helpful approach than viewing her as a poorly functioning fourteen year old.

Families generally wanted to raise children with FASD to be healthy and productive adults. Grandparents were sometimes particularly concerned about doing everything they could for their grandchild, perhaps because they had concerns regarding their daughter's addictions or other behaviour. All the grandparents in this practicum had, in fact, raised other children quite successfully, and had ongoing relationships with their daughters who had given birth to children with FASD. Grandparents' paradigm shifts needed to include a space for themselves as already competent parents who had

successfully raised adult children, but who now needed to look at new and different parenting techniques to accommodate the special needs of their grandchildren with FASD.

Fears for the future.

Many of the families displayed some level of fear for their children's future. The stigmatization surrounding FASD (Malbin, 1993a), and sensationalist news reports had left many families feeling fearful, isolated, and very worried for their child's future. Parents stated that they were willing to do anything to help their child with FASD. Fears were discussed as realistic given the high levels of secondary disabilities such as mental health issues, conflict with the law, interrupted schooling, inappropriate social and sexual behaviour, or additions that are associated with FASD (Streissguth, Barr et al., 1997). However, protective factors such as an early diagnosis, a stable and loving home, and understanding the child's disability (Streissguth, Barr et al., 1997) were also discussed giving families tools and hope that while good parenting cannot 'cure' FASD, it can potentially decrease the risks of poor outcomes.

Parenting is a difficult pursuit requiring immense energy from parents (e.g. Elum & Elum, 1999, Wolf, 1991). It has been reported that parenting a child with FASD takes many times the effort of parenting a child who is neurologically intact (Streissguth, 1997). Floyd & Gallagher (1997) report high stress levels for parents parenting disabled or chronically ill children who have behavioural difficulties. One thing that enables parents to persevere through difficult stages of development in their children is the hope that the stage will pass and that in the end a happy, productive adult child who has a wonderful relationship with their parents will result (Wolf, 1991).

The long-term secondary disability study (n = 415, 61% who were over the age of 12) (Streissguth, Barr et al., 1997) reports that parents of children with FASD can expect that their child (over 12 years of age) has a 60% chance of being expelled from or dropping out of school, 60% chance of being in conflict with the law, 50% chance of confinement for mental health or drug/alcohol problems or incarceration because of conflict with the law, 50% chance of repeated difficulties with inappropriate sexual behaviour, and 30% chance of having drug or alcohol problems. As adults the same study indicates an 80% rate of dependent living and 80% rate of difficulties with employment. Out of 90 adults in their sample, only 7 were living independently and without difficulties with employment (Streissguth, Barr et al., 1997, p. 34).

Streissguth, Barr et al. (1997) report a number of protective factors that helped reduce the odds of the above difficulties. These factors in order of strength include living in a stable and nurturant home for over 72% of life; receiving a diagnosis before age 6, never having experienced violence against oneself; staying in each living situation for an average of more than 2.8 years; experiencing a good quality home from age 8 to 12 years; being found eligible for disability services; having a diagnosis of FAS versus FAE (ARND); having basic needs met for at least 13% of life (Streissguth, Barr et al., 1997, p. 35)..

Most of the children under the age of 12 seen in this practicum had a number of the protective factors reported to minimize secondary disabilities (Streissguth, Barr, et al., 1997). Four children were over the age of 12. None of them had had an early diagnosis. Two were diagnosed in their mid-teens during the course of the practicum. Both of these received a diagnosis of ARND versus FAS. Only one of these children

had been in one home since birth. The other three teens had been exposed to family violence as preschoolers, and had been in two or more foster homes before being returned to their parent. Two teens had already had disrupted school experiences and involvement with the criminal justice system. The three older adolescents (not in the same family and the oldest being 16) had all had some level of difficulty with alcohol use or other drugs. Two of the teenagers had sired children in their mid teens, a third had been counselled about birth control at age 14 because of repetitive sexualized behaviour, and a fourth at age 13 believed having a child would initiate child welfare placing him in independent living.

Parents' fears should be validated by professionals because the odds are high that at least one major problem will be encountered during adolescence. Professionals involved with families should assist and support families to provide as protective a parenting experience as possible for the child with FASD. Giving concrete tasks to help protect their children lets parents feel somewhat empowered and that they are doing everything possible to prevent their child having difficulties. At the same time, it must be recognized that these statistics speak to the huge costs children with FASD, their families, and society as a whole pay due to the lack of comprehensive services for this group of children.

The lack of supports that many of the foster families reported and their frustration and subsequent burnout because of this lack was in part because many of the foster families knew what the children needed to ensure the best possible outcomes, and they were unable to sustain raising a child when they did not have the resources to provide a more protective child-rearing process. Other families (birth, adoptive,

extended) have even fewer supports available to them. FASD is a disability with broad social consequences, and families with children with FASD require access to appropriate services that currently do not exist.

Talking with children about their disability.

The issue of how or when to tell a child about her or his disability came up with many families. Some of the children already knew about the disability, e.g. from a life book completed with child welfare workers. Some of these children had integrated this information; others did not appear to have integrated it. The adolescents who were diagnosed during the course of this practicum learned a bit about FASD and what it meant in their lives from their parents, from the Clinic for Alcohol and Drug Exposed Children, or from the therapist.

For the most part children aged 7 to 10 who did not already know about their disability had parents who were reluctant or completely opposed to talking with their child about the disability. Parents felt their children were 'too young' and should be told when they were older. Many of these parents had lots of questions for the therapist, and were quite receptive to discussing how they might go about talking with their child about FASD. However, none of the parents of 7-10 year olds involved in the practicum chose to tell their child about the disability, even though the child was sometimes asking questions about why s/he was different or why were they 'stupid'. Several parents were given information about talking with children about difficult information and about FASD.

Children in the age range 7-10 would not likely have important information about their own health withheld from them. Parents agreed that they would not expect

their child to have insulin injections daily without being told they had diabetes and what that meant. A five year old child with FASD and severe language and developmental delays had been told about his seizure disorder and the need to take his medication even though he did not completely comprehend this information.

One birth father was able to articulate that the difficulty in talking with his child about FASD was because of the social construction of FASD or 'what the rest of society thought' about FASD. The social stigmatization that surrounds FASD (Malbin, 1993a), addictions or alcohol/drug abuse (Pape, 1993), drinking during pregnancy (Malbin, 1993a) and parents harming or neglecting children (Swift, 1996) made it particularly difficult for parents to consider telling their child about FASD. In addition, some of the birth mothers had supported their drug or alcohol habit by working in the sex trade or were engaged in other high-risk lifestyles, which left parents feeling overwhelmed at the thought of explaining the issue of FASD to their child.

This is an issue that needs to be examined more closely. There are well-documented consequences from withholding other 'secretive' information from children such as their having been adopted (Keefer & Schooler, 2000). Jan Lutke (2003) strongly advocates for the need for children to grow up knowing about their disability and what it means for them. The children she has worked with can talk about what FASD means for them, what their symptoms are, what they are good at, what they find difficult, and what they would like others to do to help them out. Lutke (2003) has empowered a number of teenagers, young adults, and more recently older latency age children, to speak about their disability to educate others about how to help. Lutke

(2001) is a strong advocate for building on children's strengths, including their ability to educate others.

In the context of this practicum, the four children over 12 had not grown up knowing much about FASD. Some of them had grown up knowing they were exposed to alcohol during pregnancy, but had not connected that with FASD. One of the children who went through the diagnostic process assured the therapist that he did not have FASD because that would mean he had problems, which he said he did not have. The other teen that had been diagnosed was very concerned about meeting with the therapist with her family, because she expected to be told 'what was wrong with her.' One of the teens in serious difficulty with the criminal justice system told his mother and the child welfare worker that he wanted nothing to do with a diagnostic process, because he definitely did not have FASD. Without an accurate assessment for FASD, the criminal justice system cannot respond appropriately to youth or adults with FASD. The tragedy in this case was that this boy had not been diagnosed early in life when his mother had asked for help, and had not grown up knowing about FASD. Lutke (2003) reports that children with FASD need to learn to ask for help from others before they get into serious difficulties, and to learn that they may need to accept some level of supports to allow them to live happier, more productive lives.

Adolescence is a stage of development where parents have increasingly less control over their children's lives, and children are increasingly less interested in hearing what parents have to say (Wolf, 1991). This is not an appropriate stage of development for children to be told about a serious disability, and particularly not a disability that occurred because of a birth parent's behaviour. Adolescents frequently

display conflictual behaviour with parents (Wolf, 1991) and can not easily work through the grief of discovering their difficulties from FASD resulted from their mother's drinking behaviour. The protective nature of an early diagnosis before age 6 likely stems from caregivers being able to respond more appropriately to their children. It also allows for the possibility of a child learning about her or his disability at an earlier developmental stage, incrementally over a period of time as has been found helpful with other difficult issues (Keefer & Schooler, 2000).

Lack of supports and supportive services.

The flip side of the fact that multisystemic therapy was helpful was that the identified problem for many families was the lack of supports provided by various systems. This was a theme across family types. Foster families, who technically have access to a variety of supportive services including respite dollars, a foster home support worker, agency funding for recreation programs, and possibly access to support workers for the child, were by and large very dissatisfied by the level of services they had received. Two out of three foster families had either been asking loudly for a variety of services for the alcohol affected child for a number of years, or had been going it alone attempting to manage despite the lack of support and understanding from the child welfare system that was mandated to support the homes. Lack of supports were identified as contributing to burn-out on the part of the parents, and led to reluctant decisions about relinquishing children they were still well-attached to and were deeply concerned about. Burn out of foster homes is a serious issue with systemic roots that needs to be carefully examined by child welfare agencies (Steinhauer, 1991).

Birth families, extended family members with legal guardianship, and adoptive families do not have guaranteed eligibility for services as do foster families. They too reported a variety of issues related to lack of support. Birth families were frustrated that they had approached school and child welfare systems, in one case for over a decade, identifying that they had drunk during the pregnancy with the child and that they were concerned the child's difficulties had an origin in this exposure, yet received no services whatsoever. Only one of the non-foster families had respite services for their child, and these had not been provided despite the child's eligibility for such services until the family involved the Children's Advocate. The other families did not have access to respite even though it is a strongly-identified need for all families raising alcohol-affected children (Giunta & Streissguth, 1988).

Placement Breakdown

Some of the foster families were experiencing placement breakdown or potential breakdown when therapy services were started. Birth families had previously or were currently experiencing breakdown. Some extended family member and adoptive families had at least considered relinquishing the child hoping to improve outcomes for the child. In fact out of 7 families, both birth homes, two out of three foster homes, one extended family home, and one adoptive home had either experienced family breakdown and removal of a child, were seriously considering relinquishing the child, or discussed with the therapist whether the child would not have a better long-term chance with another family. Only one of the seven families, a grandparent family raising two alcohol-affected children, did not discuss this issue with the therapist, and

they were relieved that two other alcohol-affected grandchildren were being raised by other relatives.

Lack of supports to the family and to the child with FASD from the child welfare system, as well as unsupportive attitudes from schools, communities, and extended family members were indicated by all family types to some degree as an issue for parents. Considering several of the protective factors for children with FASD to reduce long-term secondary disabilities speak to the need for long-term, stable, and nurturing homes (Streissguth, Barr, et al., 1997) providing supports to all families raising alcohol-affected children could have positive benefits for families, communities, and society as a whole. Breakdown of non-foster families frequently means that the child welfare system has to take responsibility to place the child in a foster home, place of safety home, or group home. All of these options are financially costly, and could likely be avoided in many cases, by provision of much less costly support services. When a child with FASD is moved, not only is the child at risk because of disrupted attachment (as all children would be), s/he is also at risk that the new home and parents may not have the knowledge or skills to safely and effectively parent the child with FASD, further putting the child at risk while the receiving home learns about FASD and the specific child, and works on making a paradigm shift.

The child welfare system did not necessarily respond to potential placement breakdowns of the foster homes with much more than an offer of a quick and speedy move to a new placement. Workers were quick to offer to move a child rather than first exploring what could be done to strengthen and retain the current placement. While threatened placement breakdowns can mean a child is at risk, and this would necessitate

a quick removal, none of the families seen in this practicum were in any danger of causing harm to the child. The foster families that decided to relinquish children for various reasons asked that the worker spend time looking for a home that was a good fit for the child's special needs before moving her or him. Families were willing and possessed the skills to continue caring for the child for several months after requesting a new placement. They advocated for the child, including accessing the Children's Advocate, when quick, unplanned moves were contemplated.

One family's initial request for a new placement was assumed to be a joke by the social worker who did not talk to the family again for two months until the family called and asked how the placement hunting was going. Other workers were very responsive to such requests and put support workers in place for the child, linked the child to appropriate recreation programs, extended respite hours, and made referrals for appropriate counselling and therapy to support the family. Quick responses with supportive services were helpful in preventing placement breakdowns. Unfortunately families sometimes indicated that these were services they had either asked for or would have found helpful long before they considered relinquishing the child. With sufficient supports provided when families first identified the need, it is less likely that these homes would have considered relinquishing children at all.

Placement decisions.

For those children with FASD that it was decided would be moved to a new home, placement decisions were sometimes problematic. Children with FASD are highly influenced by their environment (Schwab, 1999). When a child with FASD is moved, they experience loss of attachment, fear of the unknown, feelings of having

been rejected or abandoned just like any child might (Steinhauer, 1991), but their actual perceived experience of these events may be quite different depending on the specific individual neurocognitive difficulties FASD has caused. Children with memory issues, and whose behaviour is strongly defined by their environment, may show distress about an impending move in one setting (e.g. in school) and show little or no distress in another (e.g. their current home). Failure to look at all these settings, and crisis mode decision making based on one system's information alone means that inaccurate assessments were sometimes made.

When a child is reacting in one system, there were sometimes other issues involved. For example, if the adults are particularly distressed or grieving about the child's impending move, this may influence any child's perceptions of the perceived move. A child with FASD may be completely overcome with the emotional state of an adult caregiver, because caregiver's behaviour and affect are a key component of the child's environment (Schwab, 1999). This means that a calm, positive approach to an impending move may be calming to a child, whereas a highly emotional, grief-ridden approach by the adults may cause the child to deteriorate emotionally very quickly.

In choosing new placements for the child with FASD, looking at the skills and approach of the new adult caregiver, as well as the physical environment of the new home, and composition of the receiving family are important. The paradigm shift concept is crucial here. Caregivers that have a sense of humour, and can immediately identify FASD-type behaviours because they have made the paradigm shift will be considerably less stressed, and more able to appropriately parent the child causing less stress to the child with FASD.

Alternately, caregivers who are deeply frustrated by the child's behaviours and interpret behaviours as wilful and deeply problematic can create a great deal of frustration and anger for the child. Such interpretations are frequently followed by various attempts at punishment or consequences, and adult rationalizations about the necessity of these. Children who are punished a lot become angrier. Children who are punished for behaviours that they have little or no control over become very frustrated and their behaviour may become considerably worse (Malbin, 2001). Jan Lutke (2003) points out that much difficult behaviour in children with FASD is created by the interventions of caregivers and educators. She states that to truly have some control in parenting children with FASD, the caregiver has 'to give up control to get control.'

'Transitioning' to new placements.

Many children with FASD have a great deal of difficulty adjusting to or 'transitioning' to new situations. One child had not accepted the move to a new foster home eight months later. This child was able to count in months and days how long it had been since the move, and was still stating s/he wanted to go back to the original home. This phenomena has been observed in other situations in which foster children with FASD have told their previous foster parent over a year later that they are done with their visit and could they now please come home (Kacki, 2003). Concepts such as a permanent move to a new home when the child clearly identifies the first placement as home and the parent as 'mom' or 'dad' appear to be very abstract and confusing for many children with FASD. It is possible that more careful 'transitioning' processes that take into account the child's learning style may help the child integrate the idea that they are truly moving to a new home.

Alcohol-affected children need slow, methodical 'transitioning' to new situations of all types. This is contrary to the fairly quick placement moves that are frequently done by child welfare agencies. Issues of abuse or neglect may necessitate a quick, unexpected move. However, in the context of this practicum, no foster child required an urgent move. It became apparent that many of the adults in the children's lives were unable to tolerate the longer transitions required by the child. Concerns were expressed that slower transitions were too difficult for foster parents, but the foster parents in the practicum who were relinquishing or considered relinquishing foster children were adamant that they would tolerate the longer transition time required to find a suitable placement for the special needs child, and to allow the child to adjust to the idea of a move. The foster parents themselves identified it was hard, but were committed to do what they believed to be best for their alcohol-affected children.

Other adults involved with the children were not always able to accomplish this. One child was moved two weeks earlier than originally planned because the school was unable to accommodate the child's behaviour, and requested that the child be removed. The school professionals were actively grieving the child's move and were unable to do what the foster parents were doing, perhaps because the foster parents had experience dealing with the grief of children moving to different homes.

Children with FASD are frequently very literal and respond very poorly to changes in plans. A child told that he would be moved at the end of the school year was quite upset when he was moved prior to the end of the school year. He repeatedly pointed out to his foster parent that his social story had said he was moving in July, and it was not yet July.

Child welfare staff also responded with concerns about longer transition times. While longer transition times can be excruciatingly painful for neurologically intact children, children with FASD frequently experience these things quite differently. Children with FASD often have little inner sense of time. They may show distress in one system (e.g. school) and show little or none in another (e.g. their home). Because their memory is not always working accurately, they do not always think about moving, and in the safe environment of their home may think about it very little and thus show no distress. Because the adults in an environment are a key component of the environment (Schwab, 1999), the approach adults take to an impending move or change can strongly influence the child's distress or lack of distress.

Families managing such transitions successfully processed their own grief away from the child, were calm with the child, and continuously gave the same brief simple story to the child about the transition. Social stories using visual computer programs were used to assist the families in this process. These families also made use of their detailed knowledge about their particular child, and carefully read the child's behavioural cues to predict potential difficulties and prevent them. For example, a child with high need for motor activity was provided access to ongoing and interesting activities to engage in throughout the transition period. As the impending move approached the foster mother increased the availability of motor activities. These families were available to help the child process the emotional impact of the transition when it arose. Therapy for this purpose included problem solving with the parent how and what to say when the child was open to it, and writing social stories in consultation with the family for their use with the child.

When the child was open to discussing these issues they were also discussed in the therapist's presence. FASD means children struggle with inconsistent learning styles that mean some days they can integrate something and some days they cannot, language processing difficulties that mean the child may misunderstand even simple information, difficulty processing questions making it difficult to elicit information on an adult's timetable or to answer questions at all, and memory difficulties that may mean the child cannot access information needed to have a productive conversation at a specific time. For all these reasons, intervention with the children occurs best as opportunities present themselves. Sometimes this occurred during a therapy session. Often this occurred between sessions with parents carrying out interventions that were previously discussed with the therapist and then processing these events with the therapist at a subsequent appointment. Families experiencing very stressful moves were able to call the therapist on an as needed basis. The families were respectful and responsible about using this, but on occasion did need to contact the therapist regarding difficult situations.

Child welfare system responses to fetal alcohol spectrum disorders.

Writing about the child welfare system's response to issues of FASD is not an easy task. The therapist enjoyed the working relationships that formed with all of the child welfare system workers she came in contact with. All workers showed more than appropriate regard for the welfare of the children in their care or on their caseloads, and often went beyond that, e.g. coming in on days off for meetings. The needs of the child were always at the top of the list in any considerations discussed between workers and the therapist. Individual workers were almost without exception well-trained

professionals grounded in their roles, with a strong interest in providing quality services to the families and children that they served. Workers were appreciative of recommendations, suggestions, and information given to them by the therapist, and carried out recommendations whenever possible.

However, the broader child welfare system's practices and expectations of workers, and the roles for workers often rigidly defined by the system, produced a huge number of issues that were problematic to families or to the child with FASD, and sometimes to the workers themselves. Delineating these issues in a critical manner is for the purpose of addressing systemic issues in child welfare practice, and does not imply any criticism towards individual workers who do a difficult and professional job in the context of a system that does not always support a collaborative response that might better serve the needs of families with children with FASD, and that is under resourced to provide the level of services families require.

Responses to FASD were noted with workers from the child welfare system before any clients were seen or contacted. The wait list in August 2002 at Elizabeth Hill Counselling Centre included only one referral that identified the child's FASD diagnosis as relevant to the referral. Over half a dozen child welfare workers were telephoned regarding referrals to Elizabeth Hill where the presenting problem suggested that FASD might be involved. The responses of these workers to being asked if FASD was an issue were interesting. Several workers said they did not know. One said FASD likely was an issue, but she was not certain. One worker was quite angry that the therapist had asked the question and stated that FASD was a taboo subject and she would never ask a family about prenatal drinking or suggest services related to FASD.

This response was very concerning as it suggests the worker had integrated a model of FASD as so highly stigmatized that it cannot be discussed. As silence and secrecy serve to further stigmatize issues (Keefer & Schooler, 2000), and because therapists are encouraged to discuss difficult topics with families even in strengths-based practice (Madsen, 1999), this position merits examination, and is hopefully isolated to specific workers and not common among child welfare workers in general. Birth mothers who spoke at FASD conferences in Vancouver in February 2001, and February 2003 spoke strongly about the silence and failure of professionals to ask them *the question*. It appeared these birth mothers waited a long time, sometimes years, for a physician, social worker, counsellor, teacher, or psychologist to ask them about drinking during pregnancy. Until these questions were asked and faced, these birth mothers were unable to get the help they needed for their children and themselves.

Birth mothers like Diane Malbin (1993a) asked their child's pediatrician many times about whether their child's difficulties could have resulted from prenatal exposure to alcohol. They were frustrated by the instant dismissal by doctors, and were relieved although grief-stricken when someone finally was able and willing to speak the truth and they were able to determine their child did in fact have FASD. It is important to note that birth mothers have almost always internalized their own version of stigma and guilt. Discussing such matters with birth mothers requires a non-judgmental approach by clinicians who have a good understanding of the issues birth parents face (Hornby, 1993; Malbin, 1993b).

It became quite apparent that questions about substance abuse in families were not being asked at intake, and that children with behaviour problems were being

referred without mention of whether prenatal alcohol exposure or FASD may have been part of the picture. It also became apparent that Child and Family Services workers were for the most part not considering FASD as part of their assessment, in forming treatment plans or making referrals for therapy. Only one referral from the child welfare system stated FASD as an issue.

Diagnosis.

Child welfare workers did not always understand the process of diagnosis of FASD, and the importance of a diagnosis for a child. Workers with large numbers of alcohol affected children on their caseloads had sometimes never attended a diagnostic appointment, were unsure if there was any purpose to pursuing a diagnosis, or failed to attend clinic appointments either for initial diagnosis or follow-up appointments to receive results. Child welfare workers did not appear to be knowledgeable about the protective nature of a diagnosis for children with FASD (Streissguth, Barr, et al., 1997), nor were they aware that a good assessment regarding FASD could help inform more successful treatment plans (Malbin, 2001).

Although diagnosis of FASD was not necessarily seen as important by child welfare system workers, workers who were legal guardians of children were willing to consent to a diagnosis once the therapist explained its importance. A diagnosis was not always used to improve case planning, usually because of a lack of knowledge about FASD, particularly of the subtle neuropsychological manifestations that may vary so widely from one alcohol-affected individual to another. The complete lack of supportive, comprehensive services that would need to be created to keep particularly

older children with FASD who are in care safe and functioning well also contributed to lack of the system's use of diagnostic information to help the child.

Knowledge of FASD.

During the course of the work with families, child welfare workers showed various degrees of understanding about FASD from very little to a reasonable level. Many workers were quite honest about their lack of knowledge about FASD and were quite appreciative of the FASD services the therapist was able to provide to the families. However, even workers that understood something about FASD were not always able to see this issue as relevant to intervention with the child or the family. Workers were quick to assume certain behaviours had meanings based on psychodynamic or attachment concepts, but failed to filter these assumptions through a lens that included the child's neurocognitive difficulties, resulting in faulty conclusions that then informed faulty treatment plans or interventions.

Knowledge about FASD is a complex matter. Workers who have attended a few hours of workshops may have a general understanding about what FASD is, a list of potential symptoms, and maybe a few generic intervention strategies. Workers who have worked with one or two individuals with FASD may believe they truly understand this issue, but may have a narrow viewpoint of FASD defined by what they have observed in the specific individuals they know. There is a wide spectrum of manifested symptoms with a great deal of variability between individuals with FASD (Lutke, 2002; Malbin, 2000; Streissguth, 1997).

A number of meetings were attended by the therapist with families and workers from the child welfare system. Most of these meetings did not mention the child's

diagnosis at all, and it is doubtful that without the presence of the therapist who did raise this issue when it was relevant to the meeting, whether it would have even been considered as part of the discussion and thinking process of meetings looking at school plans, placement transition plans, etc. The therapist had a number of lengthy telephone calls with various child welfare workers regarding various aspects of therapy and child welfare planning, and encouraged workers to consider the FASD aspect of the child's functioning as highly relevant. Through a collaborative exchange of information that looked at issues of FASD together with issues related to attachment, family system dynamics, and so on, workers did modify their treatment goals and plans for the most part.

Meetings between families and various child welfare workers that included adolescent children with FASD sometimes failed to accommodate the child's special needs. It was quite clear at a number of these meetings that the alcohol-affected teen did not remember previous discussions or incidents, and could not follow the jumble of words when family members and workers were all speaking in quick succession. Expectations were placed on teenagers with FASD to make decisions when they clearly could not comprehend what choices were available or the implications of choosing one over the other. Adolescents with FASD left meetings in which clear decisions had been made by adults about curfews or rules, and in which clear consequences for not following the rules were to be imposed. Yet it was quite unlikely that the adolescent with FASD truly comprehended these outcomes, or had understood most of the meeting content. In cases where teens presented with serious memory impairments, it is

doubtful whether they would even remember the parts of the meeting that they may have understood at the time.

When the therapist attempted to talk to child welfare workers about her observations, the therapist's viewpoint was sometimes dismissed and workers were adamant that the adolescent had understood exactly what was expected. This kind of interaction with an individual with FASD potentially sets the affected individual up for failure.

Need for a professional paradigm shift.

Professionals as well as parents need to make a paradigm shift regarding FASD. Diane Malbin (1993a, 1993b, 2001) suggests professionals need to shift their perceptions about FASD and about individuals affected by FASD, to have realistic expectations and to communicate and intervene effectively in ways that allow the individual with FASD to be successful. When individuals with FASD appear to fail, it is frequently caregivers and professionals who have failed to accommodate sufficiently for the issues related to FASD that have set the stage for failure (Lutke, 2003).

Individuals with FASD may have 'failed' to be successful over and over again in their lives and in interactions with a variety of systems, including their own families or schools, if caregivers and educators have not made a paradigm shift to see and do things differently (Malbin, 1993b; 2000, 2001). This ongoing failure and its consequences to individuals is likely the origin of some secondary disabilities that many children with FASD eventually exhibit (Malbin, 2001, Streissguth, Barr et al., 1997). Child welfare workers should make a similar shift if they are to provide optimal service to individuals who have been alcohol affected. This shift takes time. Diane Malbin

(2001) has estimated it takes the average professional at least 18 months to begin to make a paradigm shift. Without a paradigm shift, workers continue to do good work, but it may make little sense in the lives of children and families affected by FASD. In worse case scenarios, the lack of a paradigm shift can have huge negative consequences for individuals with FASD who pay the consequences of iatrogenic damage caused by well-meaning, but ill-informed professionals.

Compartmentalized services.

The workers from the child welfare system operated in a compartmentalized fashion for the most part that is supported by the system itself. A number of families were working in various capacities with two to four different workers from child welfare agencies. Many of these workers were focussed on one part of the family system and had specific goals they were pursuing. Families at times identified frustration with workers who would become distressed with families raising issues that workers saw as being the sole domain of another worker. Attempts to set up systems meetings with all the workers involved, even when initiated by families, were frequently met with suspicion by workers. Some workers left such meetings as soon as possible, leaving families feeling all workers were still not on the same page with the family.

The nature of FASD suggests the need for some form of a circle of support around the affected individual (Lutke, 2002; Malbin, 2001). Keeping children with FASD safe or managing difficult behaviours, usually requires that everyone involved with the child is responding in similar ways, with the same rules and expectations, and that there is ongoing supervision and/or support available to the child. 'Everyone' may

include all family members, including extended family who does not live with the child, community members and neighbours, day cares, schools, school and community recreation programs, faith communities, community agencies and staff, and all professionals who have contact with the family. Boyd-Franklin & Bry (2000) advocate for a similar multisystemic model of practice with poor, marginalized families, that takes into account the full ecological and systemic context in which families live their lives.

Ideally, collaboration would include all key people providing supports from outside the child welfare agency as well as various workers within child welfare agencies. This cannot be accomplished in a context where various workers are operating in isolation from one another, and reluctant to meet or blocked by systemic barriers from meeting together and working collaboratively together. Issues of confidentiality were sometimes cited to justify this even when families were clearly stating that they wanted all the workers talking with one another. Families found it frustrating having to explain the same information or situation over and over to different workers, or having one worker suggesting things that contradicted what other workers had suggested. Even in situations where potential harm to a child in a family was identified, workers at times cited roles as a reason that prevented them from calling another worker and alerting them to potential difficulties.

Need for multi-systemic collaborative services.

While child welfare workers were generally interested and willing to listen to recommendations from the therapist, subsequent actions and decisions would sometimes suggest that the worker had in fact not truly understood the ramifications of

the issue of FASD in an affected child's life. The therapist was frequently excluded from meetings, or had to invite herself to meetings that either the family wanted the therapist at or the therapist could identify multisystemic goals suggesting she should attend. Workers did not necessarily appreciate the need to work collaboratively to ensure a true circle of support was in place for the child with FASD and her or his family. Child welfare workers had been trained to work on focussed goals with families that at times excluded key issues that the family identified as important, or issues that had relevance to the child with FASD. When the issue of FASD was placed outside of the working area by the worker, problematic situations sometimes arose.

For example, attempts to enforce child welfare legislation requirements for a curfew for all permanent wards of the agency, without recognizing that the child with FASD may have little or no concept of time, and may or may not be able to read the time, was a set-up for failure. A lack of an inner sense of time is common in alcohol-affected individuals (Malbin, 2001) and causes a lot of difficulties with missed appointments, breeched probation orders, being late for school or work, or missed curfews. Without an understanding of this issue attempts to enforce curfews or consequence missed curfews can end in a great deal of frustration for alcohol-affected individuals.

In seriously affected individuals, time requirements will likely not be met without supports in place, which might include telephone call reminders, use of cell phones or pagers, use of alarm functions on wrist watches or cell phones, or a support person's presence. These kinds of supports can be costly or time-consuming to implement, but without them the curfew will be broken because of the alcohol-affected

individual's disability. Punishing children for being disabled is unacceptable in theory, but it often occurs in practice when professionals (or parents) have not made a paradigm shift (Malbin, 2000, 2001).

Child welfare workers' attempts to prioritize treatment goals especially without understanding where families were in their process of understanding their child also contributed to services that appeared uncollaborative. In one family, the therapist did have contact with the birth mother who no longer had contact with her children, although her active substance use prevented any appointments being kept, but she did not have contact information for the birth father who was sober and having visits with the children. This father was quite distressed that he had not had earlier access to the FASD information that the therapist shared with him a number of months later.

It was frustrating watching various decision making, case planning, and individual interventions occurring without some kind of a systematic plan to ensure that all relevant parties were included or consulted so good decisions were made that ensured the alcohol affected child was well supported with a circle of support. Recognition of the need for all professionals to work together as a multi-disciplinary team to avoid setting up individuals with FASD for failure is critical if families are to have the level of understanding and supports they need (Giunta and Streissguth, 1988; Streissguth, 1997).

Appropriateness of child welfare system providing services related to FASD.

In talking with a number of families, it became quite clear that the child welfare system was not always the best system to be providing services to families with alcohol-affected children. Birth parents in particular were reluctant to share their stories

honestly with child welfare workers. The birth parents in this practicum had all lost children at least for short periods of time to the child welfare system. They had a fairly clear idea what kinds of information would cause the child welfare system to apprehend their children, and were careful what they told workers because of this. Families who felt a great deal of anger and resentment towards the child welfare system, and who had felt mistreated by the system, were not likely to form therapeutic relationships with workers. The short-term, goal-oriented, and narrowly focussed work encouraged by the child welfare system does not always fit with the broader, multi-systemic, initially intensive work that families may need (Boyd-Franklin & Bry, 2000; Lutke, 2002; Madsen, 1999; Malbin, 2000, 2001; Streissguth, 1997).

While child welfare agencies provide crucial monitoring and supportive services to families, it is apparent that they are not resourced to provide sufficient levels of supportive services even to the foster families they license. They are completely unable to meet the needs for support services of otherwise well-functioning birth, adoptive, or extended families raising children with FASD. Other support agencies, such as Children's Special Services can provide some minimum level supports to some families, but children with FASD are eligible for their services only if the child's developmental quotient (DQ) is less than 70. Of the seven families seen in this practicum, only one child was eligible for and receiving services from Children's Special Services. Even with eligibility established the difficulty for that system to find respite workers meant that the family was left without a needed support for months, and eventually involved the Children's Advocate before services were provided.

Longer-term, flexible therapeutic services that can support families' needs for psychoeducational intervention, grief counselling, and family counselling or therapy cannot be provided without a trusting, therapeutic relationship and a therapist available to meet with the family more frequently for a period of time. The unwillingness of families to be really honest with child welfare workers because of the risk of children's being apprehended interferes with the formation of therapeutic relationships with families. The more directive approach of child welfare workers to ensure child welfare legislation is implemented is also not always conducive to the development of therapeutic relationships with families. Once a month appointments or scattered sporadic appointments that fit more with the case management approach of child welfare agencies is not sufficient to meet the needs of families with children with FASD when they are in crisis struggling with their child's behaviour or with intense grief issues.

Justice system issues.

Teenagers who have FASD, may have deficits in a variety of areas. This may include difficulties such as understanding instructions or other auditory information, poor judgement, not comprehending or predicting the possible consequences of their actions, impulsivity, and so on (Streissguth, 1997). These issues mean that adolescents with FASD are at much higher risk of becoming involved with the justice system (Streissguth, Barr et al., 1997).

The involvement with the justice system in this practicum was minimal. However, the therapist did sit in on a meeting with a probation officer regarding an assault incident. The adolescent had no memory of either assaulting anyone a few

months before, or of the individual who was apparently assaulted. The probation officer determined that without memory of the incident, alternative processes such as mediation were of no benefit. Child and family services workers and the therapist concurred with this assessment.

However, the meeting was completed with very minimal supports in place to make sure that the child had a circle of support in place. The birth mother was asked to continue reminding the child not to fight with people, and the therapist was asked to be involved with the family on a weekly basis. Without considerably more intensive supports available, these two interventions alone will not prevent further criminal incidents. Other decisions were later made about this teenager in terms of curfews, living arrangements, and rules, without the potential for further inadvertent criminal activity being considered.

The teenager in question was assaulted at a later date when out late at night. He was unable to make any connections between wearing clothing with gang colours and the assault, and was unable to identify any risks he might have taken that resulted in this assault. Without programming that can truly offer a circle of support, alcohol affected teens are at huge risk of being seriously hurt, or inadvertently causing harm to others.

Another teenager connected to one of the families was incarcerated for most of the period of the practicum. Typical of alcohol-affected teens, this boy was involved in a major theft incident, and then phoned and left a message on the victim's answering machine that he was sorry. Without sufficient supports, he walked away from a work placement, and within two days had been charged with a number of offences, and was returned to more intense incarceration. Without intense supportive programs in place,

this child's parents and child welfare workers were relieved he was incarcerated where he was perceived to be safer than he was unsupervised and unsupported in the community.

School system issues.

Families of all types indicated some level of difficulty with the schools their child attended. Four consultations were conducted with schools, and two others were considered. The remaining two children included a child in which the family had been able to successfully advocate for appropriate education services for their child, and another child who the family had delayed entry into the school system and had to strongly advocate against the school pushing the child into age appropriate grade levels when the child had been planfully withheld from school because of developmental and cognitive delays.

Schools were by and large receptive and appreciative of consultation services. Sometimes schools were able to integrate and repeat back the information they were given and then transform this into appropriate services to the child. However, in some situations the school would take actions that indicated they had not truly understood the child's disability. Being able to talk about FASD and about recommendations did not necessarily indicate that the school had made a paradigm shift in truly seeing the child's disability as underlying some of the difficult behaviour. At times the lack of understanding of FASD caused school staff to engage with children or attempt to enforce expectations in ways that created major conflicts with the child. Unfortunately the child was often blamed, and sent home, or punished when this happened. Schools

sometimes inadvertently set up children with FASD to fail to behave or learn successfully within the limits of their potential.

Schools in general were quite unaware of issues related to sensory integration (Schwab, 1999) that were frequently underlying difficulties with the child's behaviour. Children requesting a visual cue to remind them of a rule were interpreted as being controlling. A child with difficulties processing auditory information who shut down when asked lots of questions, or lectured with many words, was seen as resistant or noncompliant. Children who needed movement breaks were punished for fidgeting in circles, running from classrooms, or other apparently 'inappropriate' behaviour. Attempts to suppress fidgeting behaviour often resulted in a new behaviour as the child sought out sensory input their nervous system needed (Schwab, 1999). Lack of awareness of sensory issues led to referrals to counsellors to apply behavioural interventions rather than referrals to occupational therapists to apply sensory integration interventions, leaving the child unsupported and staff puzzled and frustrated by ongoing behavioural concerns.

When schools misunderstood children's behaviour, families were often extremely stressed. One birth family took it in stride that their adolescent was suspended from school for most of the school year, and an adoptive family had very successfully advocated for appropriate adaptations to their child's school program, allowing the child to experience considerable success in school. These were the extremes. Other families experienced varying levels of stress regarding their child's school. Families had communication books coming home at the end of the day,

sometimes with a litany of complaints about the child's behaviour, most of it completely understandable within a framework of knowledge about FASD.

One particularly striking incident was reported in a Grade 4 boy's communication book. The child decided to try to knock himself out by running into a brick wall. When asked, he said he wanted a Popsicle. Apparently another child had recounted being given a Popsicle when he went to the hospital. The alcohol-affected child's ability to plan was limited and he decided running into a brick wall would necessitate a trip to the hospital and get him the reward he sought. This child had previously shown a great deal of difficulty with school staff's attempts to motivate improved behaviour by offering him rewards for a good day. This quickly deteriorated into daily expectations for an expensive reward, and behaviour that deteriorated on days when the expected reward did not appear. Using standard behaviour modification with children with neurocognitive dysfunction can create a number of difficulties.

This boy, diagnosed FAE, looked normal, and would not casually be picked out of a classroom of children as different, unless he was observed for a period of time. In his class, he was observed to read his book during an activity that required his attention on the teacher. Later when the teacher was reading the same book to his class, he was fidgeting and on several occasions attempted to walk around the classroom when other children were attentively listening to a fascinating story.

Another boy with FASD with severe reading disabilities, memory deficits, and easily overwhelmed and agitated by questions, and too many words, was viewed as controlling by his school when he asked for visual cues. This boy was able to process and remember visual cues when he could not process written or spoken verbal cues.

The therapist suggested to this school that the boy was being insightful in requesting (politely) what he needed, and the school was encouraged to provide visual cues. This boy was doing what Lutke (2002, 2003) empowers her children with FASD to do: to ask for help when needed. Without a paradigm shift in schools, when children with FASD identify what they need, it may not be provided. They may even be inadvertently punished for asking.

Both these boys had skilled, knowledgeable parents, who had made a paradigm shift regarding FASD. Their families were stressed foster parents unsure if they could continue the intense job of parenting these very difficult children. The lack of understanding by school personnel, even though they were trying hard to find ways to teach these children, and the inability of schools to support children so they could be successful, put considerable extra stress on these families. Society cannot provide true circles of support for children with FASD without schools providing appropriate, knowledgeable services during the school day. This is a critical component of services required by children with FASD and their families.

End note.

Individuals with FASD are a fascinating group of people, who are frequently very appreciative of any attempts made by others to understand. This makes any extra efforts to accommodate their needs well worth the effort. However, it is also frustrating to attempt to meet the needs of individuals who the rest of the world has not yet come to understand well. Just as clients may have been chronically frustrated by others' failure to understand them, workers and therapists can become frustrated with attempts to access accommodations for clients other systems do not understand.

CHAPTER 5

Practicum Learning and Evaluation

This chapter looks at the learning experienced by the student therapist, and evaluates that learning, and the services provided to families.

The original learning goals were to (1) conduct an exploratory family therapy practicum looking at appropriate models of family therapy for families that include a member with FASD; (2) develop family therapy skills using structural-strategic approaches; (3) explore the use of other approaches to family therapy including multisystemic approaches, psychotherapeutic approaches and psychoeducational approaches depending on the need of individual families; (4) deepen self-awareness in working with families; (5) modify as necessary the family therapy process to accommodate an individual family member with a neurocognitive impairment such as FASD; (6) broaden my experience in working with families with an alcohol-affected individual, in particular families with school-aged, adolescent or adult members with FASD; and (7) integrate knowledge of FASD and/or other neurocognitive difficulties with systemic social work practice, specifically family therapy and/or counselling.

Explore different family therapy models for use with issues of FASD.

(Goals 1 and 3)

This practicum experience gave the student many opportunities to explore various family therapy models with families raising alcohol-affected children and adolescents. An important concept in looking at families raising children with FASD is Malbin's (2001, 2000) idea of a 'paradigm shift.' The paradigm shift can be further understood combining it with Prochaska, DiClemente and Norcross's (1992) Stages of

Change Model: precontemplation (I don't have a problem .), contemplation (Some days I think I have a problem; some days I don't think I have a problem), preparation (I know I have a problem; I'm gathering information about what to do), action (I'm implementing the information I have learned.) and maintenance (I'm working to continue to implement the new information and changes in my life.). Whether families had made a shift or not, or where they were at in terms of the process of making the shift was a helpful concept in deciding what methods of therapy to use, and to assess how well the families were doing. This concept can be combined with Weltner's Level 1-4 Families (Paquin & Bushorn, 1991) to some degree, to give a concept of overall functioning of the family and more specific functioning in terms of parenting the child with FASD.

Individual families varied widely where they were in terms of the paradigm shift (viewed through a Change Model) and levels of family functioning using Weltner's system. One of the highest functioning families was definitely at a Level Four on Weltner's scale. They were also the one family that had been able to effectively advocate for their child in the school, and were happy with the accommodations the school had made for their child. But they had not completely made the paradigm shift. They certainly were aware they had a problem. They found information given them by the therapist and by the Clinic for Alcohol and Drug Exposed Children helpful, and the mother in particular said it was good to remind herself of the information.

This family likely had made a paradigm shift a number of years ago, but was having some difficulties with Maintenance of a paradigm shift as their child moved into adolescence. In terms of separating out neurocognitive difficulties (e.g. memory and

language processing difficulties) from normative 'ratty' adolescent behaviour (Wolf, 1991) they had slipped back into a Contemplation stage, questioning whether FASD was the problem. This had probably contributed to the family's wondering whether they could continue to parent the child in the home. This family needed very little intervention. Some psychoeducational information about the neurocognitive bases for the child's behaviour, and some structural intervention to strengthen the parent's hierarchy by giving them permission to not use consequences that were not immediate and time limited, allowed this family to fine tune a pre-existing paradigm shift and bring it in line with adolescent development and FASD.

Two of the foster families had long years of experience raising children with FASD and/or working with adults with FASD. They had long ago made a paradigm shift and had probably left the change model altogether, with the paradigm shift a well integrated part of their daily interactions with children with FASD. In terms of functioning, both families had probably been largely operating at a Weltner's Level 4 for a long time. Both families were skilled at organizing and meeting the needs of all family members. One family was having some difficulty with boundaries in forming a stepfamily because of children with psychological needs from pre-existing trauma that were coming together in a new blended family, but overall the foster parent was showing a great deal of skill and insight in working these issues out too.

These families had increasing difficulties managing behaviour in the child with FASD, because of structural changes to the family (stepfamily formation, birth of baby) that had unsettled the child with FASD, perhaps intersected with developmental issues as the children with FASD moved into later latency stage childhood. Because of some

level of stress due to recent family changes, and because of long-term lack of supports in parenting these children, both families were considering relinquishing foster children with FASD. Foster mothers were dealing with a lot of grief at the thought of relinquishing a child and because of other losses such as loss of dreams in making a real difference with the child, or loss of belief in their own competency as parents. These issues were intervened with using a psychodynamic model of therapy.

Other key issues in both these foster families were multisystemic in nature. These were competent parents who were struggling as the children moved out into the wider world as they grew older, and who were now having difficulties because of the lack of community supports. One of the boys with FASD at age 9 had just started walking to school on his own, in part because there was a new baby in the house. Because he could not keep himself safe due to FASD, this new responsibility that most 9 year olds would welcome and be competent at caused major stress. The boy became involved with another child who encouraged him to not go to day care after school, and so on.

These foster families realized their children needed constant to frequent supervision beyond what most families would have to provide to a 9 or 10 year old. They needed help from the child welfare system that had placed the children with their family; they needed help from schools; and they needed supports in the community to keep these children safe. These families needed and welcomed multisystemic interventions with schools and child welfare agencies, as well as home-based therapy services to help them deal with their own intense feelings.

These examples illustrate some of the diversity of therapy models used with the families in this practicum. The Weltner model (Paquin & Bushorn, 1991) gave a useful framework together with other structural models (e.g. Minuchin et al., 1998) in assessing family functioning and structure, and looking at what interventions were appropriate for families. The paradigm shift concept (Malbin, 2000) and the Stages of Change Model (Prochaska et al. 1992) to assess where families were gave a useful model for determining appropriate interventions regarding issues of FASD. Multisystemic approaches allowed for broader ecologically based intervention (Boyd-Franklin & Bry, 2000) with schools, child welfare workers, and justice workers, when issues were partly or completely originating outside the family.

This eclectic model for intervention originally proposed for use with families with children with FASD for this practicum provided a framework that met the therapeutic needs of all the families in this practicum. It allowed the student therapist to explore appropriate models for use with families dealing with FASD, and to explore using all the proposed models in providing therapy services. Haley's (1987) models of assessment were used along with structural concepts (Minuchin et al., 1998), and Malbin's (2001, 2000) paradigm shift concept. The Stages of Change Model (Prochaska, DiClemente, & Norcross, 1992) was put forward by the student therapist as a way of conceptualizing the progression of a paradigm shift.

Modify family therapy to accommodate neurocognitive issues. (Goal 5.)

Just as parents, teachers, child welfare workers, social workers, psychologists, and health care workers need to make a paradigm shift in working with children and

adults with FASD, so too must therapists. A number of modifications to the therapeutic process were helpful in engaging with alcohol-affected individuals.

1. Sensory integration.

Difficulty in integrating sensory information can cause overwhelming sensations in alcohol-affected individuals. Children may exhibit extreme behavioural difficulties that arise from being overwhelmed by visual, auditory, olfactory, gustatory, or tactile stimuli (Schwab, 1999). If families had come to the Elizabeth Hill Counselling Centre offices, these issues may have needed to be addressed. Carefully choosing the colour of treatment rooms, deciding to turn off fluorescent lights, having fidget toys available, having organized activities or toys available one at a time in a structured way, and so on, could have been utilized. To some degree meeting in families' homes meant children were in their own environment and these issues were of less concern.

Sensory issues did arise during home-based therapy. One parent who identified prenatal alcohol exposure as an issue for herself was quite distracted by a brightly coloured file folder that the therapist had taken to the session. The therapist then engaged in a conversation with the parent and a teenage child about what kinds of colours overwhelmed the parent. The therapist was very attentive to what colours she wore, and the colours of anything she took with her to home sessions following this.

An adolescent with FASD in this same home was very sensitive to smells and was quite distracted one day in the kitchen looking for a smell while the therapist was there. No one else could smell anything, but it was disturbing to this child. Although no action, other than explaining the phenomena to the parent was required, it is quite

possible that therapists may need to be attentive if a client is disturbed by some smells or scents in an office setting.

Other possible sensory issues might include noises (from fluorescent lights flickering or fans) that could be present in a therapy room, a need for the client to move about a lot, to fidget with something in their hand to allow them to attend, or a need for oral stimulation (e.g. chewing gum, sucking on a candy, drinking with a straw from a juice box) to allow the client to attend to a session. These needs can be misunderstood as attempts to distract therapy, but are usually indicators of underlying biologically-based sensory needs that particularly in children can completely overwhelm the child's ability to function if not attended to. Adolescents and adults may have learned to avoid situations that overwhelm them, which can also impact therapy.

2. Language processing and auditory processing.

Adolescents with FASD and adults who identified prenatal alcohol exposure were seen during the course of this practicum. Different clients had different needs in terms of language. Some needed the therapist to talk more slowly than she would normally, or to use simpler language. The therapist was careful to check with clients if they appeared not to understand her. As much as possible the therapist took responsibility for misunderstandings recognizing that individuals with prenatal alcohol exposure have often been frustrated over and over by people who both misunderstand and punish the affected individual. If a client appeared not to understand something, the therapist would suggest that she had not explained things well rather than asking the client if they understood what she meant. Language issues are also pertinent when using standardized measures, such as the Parenting Stress Index (Abidin, 1995). When

clients identified this was an issue for them, the client and the therapist worked through the measure together. Again the therapist was careful to avoid the client feeling inadequate and would suggest that questions were confusing, acknowledging the client's perspective of the measure, rather than suggesting the measure was easy or simple.

One of the birth parents who identified she had been exposed to alcohol prenatally recounted feeling completely stupid every time she met with professionals, such as teachers or child welfare workers. She believed she did not understand the workers because she was stupid. The therapist helped her understand the concept of professional jargon, and told the mother a 'secret' that most professionals did not understand each other's jargon if they were from different professional backgrounds, and frequently had to ask one another what they were talking about. The mother was encouraged to not feel stupid, and to feel quite free to ask professionals to explain their jargon ('big words'). The mother was also told that it was not her fault she had not been to university to learn these other languages, and that it was rude if professionals used a lot of jargon with people who did not understand it. The mother appeared much happier with this explanation, and asked lots of questions of a doctor at the Clinic for Alcohol and Drug Exposed Children about medical jargon during an appointment following this.

Questions, particularly 'wh' questions, are problematic for many children with FASD. Although individuals sometimes improve their language skills as they grow older, sometimes they have learned to compensate by giving answers that they think the recipient wants. This might be analogous to passing a French test in high school by

knowing how to flip the words around from a question to a statement without comprehending what the words mean. Use of questions needs to be done with caution with some individuals with FASD. One of the ten year old children was happy to engage in a simple, play therapy form of a cognitive restructuring exercise, but covered his ears and asked loudly 'What's with all the questions?' soon into the exercise. The therapist did her best to use fewer questions, and took responsibility if he became agitated again. The boy was quite receptive to the therapist saying she was sorry she had used too many questions. (He actually smiled and nodded in agreement.) Simple adaptations like these allowed the therapist to join with a child who found it difficult to engage in interpersonal contact most of the time. Many adults viewed this child as 'needing to be in control' all the time. The therapist viewed him as a child who needed to be communicated with in a way that he could understand and take part in the interaction.

The therapist found herself thinking in terms of a cultural difference. Similar to the deaf community's view of itself as having a separate culture from the hearing community, individuals with FASD experience the world in a vastly different way, similar to speaking a foreign language or living in another culture. Dominant North American culture often expects everyone different to adapt to the dominant ways. Individuals with FASD are not able to do this. Their experience of language and interactions with others is determined by neurologically-based brain differences that the individual cannot control or easily change. Other authors have made similar suggestions. Dorothy Schwab (1999) suggests the first language of children with FASD is visual rather than auditory, and that most people communicate best in their first

language. Jan Lutke (2002) speaks about acting as an interpreter for children and young adults with FASD, and that children with FASD are frequently neurologically non-competent rather than non-compliant.

3. Memory.

Memory issues are common in individuals with FASD. Alcohol-affected individuals may have difficulties remembering appointments, and previous discussions or events. Several instances of this have already been described. It is important when working with alcohol-affected individuals not to assume they will remember previous sessions or topics without appropriate cues. It may make sense with some individuals for the therapist to begin a session by summarizing previous sessions, and seeing if that fits for the individual. Professionals and parents of individuals with FASD may become the memory banks for affected individuals at times. This can be very helpful to the individual with FASD, but also entails a huge responsibility on the part of the person doing the remembering for the affected individual.

Particularly for some children, memory gaps may lead to confabulation (Banich, 1997) in which the individual adds to a story to complete it. Sometimes these stories can be quite amusing, but they can also be deeply problematic for individuals. Individuals with FASD may implicate themselves in events in which they were not even present, or they may implicate someone else. One family in this practicum was investigated when a child with FASD confabulated a story about being beaten with belts. This was deeply disturbing to the family. Such an incident could have resulted in an unnecessary apprehension of the child. This speaks to the need for therapists and

professionals to very carefully check facts before making decisions based on information from a child with FASD, especially if there is a history of confabulation.

Memory is stored in different ways depending on how it is presented. The brain stores visual, auditory, and tactile information in different regions of the brain, for example (Banich, 1997). Music and songs are processed in completely different areas of the brain than spoken words (Banich, 1997). These different modalities of memory storage can be used to improve retention of important pieces of information. One parent with prenatal alcohol exposure made very effective use of a calendar and writing appointments down to remember appointments with a number of professionals. Children were helped to remember the facts about impending moves, or about how an event had happened using social stories that had visual cues as well as words. Coloured visual images seem to be better retained in memory than black and white images (Schwab, 1999). Rules for certain things (e.g. not urinating in the basement) were made into computer generated pictures that families could post to remind children of the rules. One of the families reported making extensive use of such symbols when their child with FASD was younger.

Working memory or short-term memory may be compromised in individuals with FASD (Malbin, 2000, 2001, Streissguth, 1997). This can cause individuals to become overwhelmed if they are being asked to process too much information at one time. Adolescents with FASD were observed to become overwhelmed when pressured to make decisions in part because it was difficult to hold too many pieces of information in working memory at one time. Too many questions, too many people talking at one time or in close succession in a meeting could all potentially be overwhelming. Being

attentive to the individual with FASD and how they are experiencing what is going on can be helpful. Adolescents with FASD may become angry or leave a meeting because they are overwhelmed.

4. Time.

Individuals with FASD frequently have difficulty with time. Adults with FASD may need professionals to provide reminders about appointments if they are to be attended. A message the day before the appointment and again the day of the appointment may help. Time issues were noted in adolescents in this practicum. An individual would miss the appointment time, and a family member would go and find her or him or phone her or him to come to the appointment. Such behaviour can easily be misinterpreted as disinterest in or resistance to therapy, or overtly oppositional behaviour. With individuals with FASD it is seldom any of these; it is more likely an example of a brain that works differently (Malbin, 2000).

Adaptations for individuals with FASD should be collaborative and respectful. Many adolescents and adults have suffered miserably in schools, families and communities. They have been teased, punished, misunderstood, frustrated, and inadvertently set up for failure. People with FASD may be sensitive to anything that makes them feel stupid. Such incidents can usually be avoided by asking what would be helpful, or suggesting that other clients have found a phone call the day before helpful and ask if this client would like the therapist to do this. The collaborative, respectful, 'appreciative ally' stance reported by Madsen (1999) can be very helpful with individuals with FASD. The therapist can role model this stance for extended family members or professionals that are still working on their own paradigm shift.

5. Making the abstract concrete.

Understanding abstract concepts such as 'disrespect' or 'rudeness' can be very difficult for individuals with FASD. Therapists need to work to make abstract concepts more concrete both in their interactions with individuals with FASD and in coaching families to deal with difficult situations. For example, asking a child with FASD to stop being disrespectful may have little meaning for the individual. Being concrete, the parent or therapist could ask the affected individual to say 'darn' instead of using a swear word, to speak quietly rather than yelling, or say 'please help' rather than a so-called disrespectful demand. Giving an affected individual a replacement phrase is more helpful than a long-winded lecture by a parent about insulting behaviour.

Develop family therapy skills using structural-strategic models. (Goal 2.)

The therapist had a number of opportunities to assess family structure, to strengthen family hierarchies, and internal and external family boundaries. A number of these interventions were reported in Chapter 4 under the section on Structural and Strategic approaches.

Minuchin et al. (1998) report that in working with families with multiple systems involved, that intervention sometimes needs to look at strengthening the family boundaries against other systems. This issue occurred in some of the families. A foster family who felt violated by child welfare and school professionals was helped to draw a boundary between her belief in her own competence as a parent, and the misperceptions that other systems had of her parenting. This parent had set a number of boundaries, but had been further criticized by the system for doing so. The therapist supported and validated the parent in her efforts to maintain her appropriate, healthy boundaries with

professionals who were not always being respectful or truly understanding the reality of raising a child with FASD.

One of the grandparent families with a huge number of systems involved was supported in setting boundaries with a child welfare support worker who had been invasive, disrespectful, and had failed to follow the instructions of the parent regarding issues such as bathing the grandchild. Social systems are powerful and families are often left feeling defenceless again them. The grandmother had done a good job setting boundaries; the therapist's validation of this helped the grandmother feel confident about continuing to set boundaries.

Boundary setting and strengthening of the parental hierarchy was also encouraged in a foster family in the process of blending her family with that of a new partner that was functioning at a lower level than the foster mother's. The foster mother described a well-functioning Level 4 family prior to the blending process, and was quite frustrated and grieving the loss of her former level of family functioning. During the course of therapy this mother slowed down the blending process, and set some very firm boundaries with her future stepchildren. The therapist discussed appropriate stepfamily dynamics with this mother to support her boundary setting efforts.

Joining with families is an important element of structural and strategic therapy (Haley, 1987; Minuchin et al., 1998). The therapist was able to successfully join with all the families in the practicum. Minuchin et al. (1998) describe a respectful joining process that truly listens to the family's perspective of events similar to that advocated by Madsen (1999). Similar to these reports in the literature, the therapist quickly became aware of systemic difficulties, often of long-standing duration, that families had

struggled with but had found difficult to get professionals to attend to. Being willing to listen and attend to these issues further increased the joining process, a process Minuchin et al. (1998) also report with their families.

Making therapeutic use of family enactment (Haley, 1987; Minuchin et al., 1998) was used. Literature on strategic and structural therapy (Haley, 1987; Minuchin et al., 1998) discusses encouraging families to re-enact in the office, interactions that would normally occur at home. For the most part, this occurred naturally in homes during the practicum. Adolescents came to see the therapist as a visitor to the home quite quickly and felt quite happy re-enacting their usual conflictual behaviour with their parents. One adolescent was quite insistent that the therapist was part of the family and should go for dinner with the family, which allowed the therapist to set a gentle boundary about her role with the teen. As suggested by Minuchin et al. (1998) the therapist stepped back and allowed the parents to deal with these situations for the most part. Parents frequently chose to discuss their reactions and sometimes frustrations about these incidents. The therapist validated the parent's skilful handling of the situation more often than not, but on occasion was able to suggest an alternative strategy or to assist the parent in examining their own reactions to situations to allow the parent to choose a response that was more helpful to them in the future.

Sometimes such situations presented an appropriate therapeutic moment for the therapist to intervene. When an adolescent with FASD stated his intentions to engage in an activity that could have been harmful to an infant, his mother effectively stepped in to discourage the activity. He stopped, but then resumed a few minutes later, unable to integrate the seriousness of the situation immediately because of language processing

difficulties related to FASD. The therapist then supported the mother's original request that he stop. The mother used the therapist's agreement with the mother quite skilfully to support her hierarchical role as parent in the family. The therapist reinforced the mother's effective handling of this situation, and later reminded the mother of her skill in this difficult situation when the mother was feeling powerless as a single parent of an adolescent.

There were times when repetitive behaviour was enacted but not dealt with by the parent, and the therapist gently suggested the parent take action to change behaviours in their children. Children in one family frequently played with lighters and bottles of pills, with the family relying on safety caps and features to prevent accidents. The therapist observed this for a while, and then talked to the mother about the therapist's own fears about these behaviours. The mother spoke about her own concerns—her older children had once set a house on fire—and was observed after that speaking with children about not engaging in this kind of play or removing potentially dangerous objects from younger children. This behaviour did slowly re-emerge a few months later, and needed to be addressed again.

Use of reframing of family assumptions (Minuchin et al., 1998) has been reported earlier in this report. This technique was used many times by the therapist, both with families and with other professionals. Parents and workers were encouraged to reframe their understandings of the behaviour of children with FASD, which is part of effecting a paradigm shift (Malbin, 2000). Families were also encouraged to reframe events and actions that were causing family conflict, e.g. reframing a child's confabulated stories that were causing family conflicts as 'mix-ups' by the child's brain

requiring adults to check facts before responding, rather than punishing a child for 'lying'.

In another family, the adolescent with FASD quite openly told the therapist that she enjoyed making other people angry, because it was fun watching the resulting fireworks. This teen could not understand her mother's concern for her safety when she repetitively made peers angry. But the mother was able to reframe being on the receiving end of this same behaviour. The mother had seen it as ordinary teenage behaviour (Wolf, 1991), but was able to reframe it during a therapy session as strange game playing behaviour due to the child's FASD. The mother identified that this was helpful because she could choose not to engage in this game in the future. The pace of a family session did not allow the therapist to reframe this same event for the teenager. It is uncertain whether the adolescent could perform this abstract reframing process, but it would require a fair amount of time to work out a way of making an abstract concept her mother had understood in a minute into a concrete concept that the child with FASD could also understand.

Minuchin et al. (1998) discuss helping families to break habitual patterns of interaction that have paralyzed the family's ability to function. One of the grandparent families was quite stuck on 'not putting up with disrespectful' behaviour. It was difficult for them to grasp that the child did not comprehend 'disrespectful' because it is an abstract concept, i.e. disrespect cannot be tasted, touched, or seen in a concrete visual way. It requires complicated cognitive gymnastics, that neurologically intact individuals do without thought, to understand an abstract concept. Those who are neurologically intact cannot easily understand how someone else who is not cannot

understand what the neurologically intact individual knows so easily. The brain of a neurologically intact individual performs such feats so quickly that the individual is unaware of the process by which they came to understand a concept. Drawing attention to times when parents have had difficulty with difficult abstract subject matter (e.g. if they did not find math easy when they were in school) can give parents a small taste of what their child struggles with daily.

The grandparents felt quite challenged when the therapist suggested the child may be unable to be respectful or understand respect in the way the parents expected. They remained adamant that it was worth the child's having major emotional outbursts or 'meltdowns' (Greene, 2001), and that they would not tolerate disrespect. The therapist encouraged the family to explore new ways of dealing with such difficult and unpleasant interactions (Greene, 2001; Minuchin et al., 1998). Between sessions the grandmother thought about this, and at the next session she reported having coached the grandfather to remake the child's toast the way the child liked it to prevent a meltdown. The therapist congratulated the grandmother for her hard work to make the family function more productively.

One mother frequently reported difficult situations with her adolescent child and then said that she 'didn't care.' Her adolescent with FASD was beginning to tell others that his mother did not care about him. The mother kept asking the therapist if she was doing anything wrong. The therapist continued to empower the mother's image of herself as a good parent, but gently suggested that her habit of saying she 'didn't care' when in fact she cared very much and was deeply frustrated was causing misunderstandings in her child and in workers in other systems. The mother started the

difficult work of trying to undo a much practiced habit. This mother was also coached to talk to her adolescent child differently. She was encouraged to continue to let her son know when she needed him to change his behaviour, but to imbed a message of caring about him into such interchanges. The mother identified this was difficult because no one had ever treated her like this, but she started to report to the therapist incidents where she had first told her son she cared about him before asking him to change his behaviour.

Structural and strategic approaches to therapy offer some powerful interventions to effect change in families. Providing therapy services to the families in this practicum gave the student therapist many opportunities to practice, develop and hone skills using this framework.

Develop therapist self-awareness. (Goal 4.)

As is always the case in doing clinical work with families or individuals, the therapist usually learns something about themselves. The most salient of these in this practicum involved processing the therapist's own frustrations with systems, and conceptualizing difficult and sometimes frightening situations with teenagers close in age to the therapist's own children.

The therapist chose to work with a population of families raising older children and adolescents with FASD because she knew from previous work with early intervention programs for young children with FASD that these families had no access to services. The therapist enjoyed the opportunity to provide some services that families would not otherwise have had access to, but the frustrations of connecting with families with huge needs that no program effectively meets were great. Sometimes it

was helpful to families who themselves were deeply frustrated to know that the therapist was also frustrated. It validated years of frustration for some parents. One foster mother reported she had told a child welfare worker years before that she was going to install a cinder block in her kitchen wall to beat her head against because she was so frustrated by her efforts to get her foster son's needs met. However, sometimes the therapist's own level of frustration was very intense and needed to be managed away from families through journaling or discussions with her supervisor, both of which she made frequent use of.

The other issue that the therapist had to contend with at times was her strong connection to adolescents who were only a few years younger than the therapist's own children. It was difficult at times for the therapist to manage her own reactivity to situations in which teens with serious cognitive and adaptive functioning difficulties were being asked to leave home, or considered for independent living. For the most part she was able to do this, and again at times used journaling and/or discussions with the supervisor to assist with this.

Broaden therapist's experience of working with families with older children and adolescents with FASD. (Goal 6.)

With one exception, all the families were parenting either adolescents or older latency aged children. The therapist was able to provide some in depth family therapy interventions and FASD interventions to families with older children. The learning related to this goal involved two major areas. One involved gaining direct experiential knowledge about adolescent's and older children's issues with FASD that had been

quite theoretical previously. This learning was pervasive through all of the interactions and interventions with families reported elsewhere in this report.

The other involved an in-depth experience of the systemic issues that influenced older children and adolescents with FASD and their families (Coles & Lynch, 2000; Miranda & Levine, 2000; Slinn, 2000). It became apparent very quickly that social expectations for older children to be more independent had a huge impact on this population. Families struggled to provide levels of support and structure to older children that would have been easy to provide to a preschooler. Families largely understood that their child was different and could not meet expectations that would be easy for a neurologically intact child to meet. Issues such as letting nine year olds walk to school alone or with peers in safe neighbourhoods were fraught with danger for families and their children. When a grandparent decided to walk behind the older child with a younger sibling in a stroller to supervise she worried she was being overprotective. Yet experiences of other families raising children with FASD of the dangers that nine year olds with FASD found on the way to school supported that this was a healthy compromise. He could walk alone to school so long as his grandmother was some distance behind to observe and provide assistance if it should be needed.

Out of four adolescents (aged 12 – 16) connected to the families all but the youngest had had serious problems with sexual behaviour. A baby was born to the girlfriend of a 14-year old boy during the course of the practicum. Discussions about birth control between the boy and his mother and the therapist revealed little understanding and a great fear of birth control. This fourteen year perceived all birth control as dangerous and not to be used. Concrete discussions gave him a picture of the

world without birth control. A relative of his mother's had had 25 children years ago. This seemed to have some impact on the boy who stated he only wanted 2 or 3 children. This was validated as a reasonable family size, but one that required the use of birth control to maintain.

An adolescent girl was prescribed birth control at her parent's request during the practicum because of concerns that she was engaging in sexual behaviours with a number of different boys. A sixteen year old adolescent boy was reported by his family to have sired at least one child, who he apparently had no contact with.

Adolescents normatively are much more engaged in broader social contexts than younger children (Wolf, 1991). This is hugely problematic for adolescents with FASD who cannot predict danger, plan for their own safety, or set appropriate boundaries with others (Malbin, 2000). Providing these youngsters with safe, social experiences at recreation or community programs with adult supervisors who have some connection to families and parents was not always easy for parents to provide when younger children in the home required higher levels of parental involvement, or foster families could not get support workers or funding for recreation programs from child welfare agencies.

It was very apparent in meeting with justice, child welfare, and school professionals that the intensive supports that adolescents with FASD need just do not exist. Many authors suggest the need for families with adolescents to have planned breaks with children being placed in group homes while maintaining connection to the family (Kleinfeld, 2000; McCreight, 1997). Discussions with child welfare programs regarding such approaches revealed that all such options in Winnipeg were fraught with danger for children with FASD who had been raised in strong intact homes because of

exposure to dangerous and problematic behaviours in such homes. The need for a safe, FASD-friendly, respite group home became apparent.

When child welfare workers had not made a paradigm shift, many adolescents with FASD were left to their own devices and viewed as needing to make their own choices. Frequently, systems just watched the adolescents move from one disaster to another, while recognizing the huge risk these teens were at for serious injury or even death because of impulsive behaviour that was disengaged from cognitive thought processes. If a comparison is made to adults with issues such as Alzheimer's in which it is recognized that their brains cannot keep them safe, great efforts are taken by families and communities to protect these individuals from their own disability. A similar social initiative is required to keep individuals with FASD safe as they grow older, while respecting the rights of those with FASD particularly as they become adults.

Integrate knowledge of FASD with social work practice. (Goal 7.)

This goal represents a long-term need for social work practice to make use of literature and knowledge about FASD that currently exists mostly in psychological literature (e.g. Streissguth, 1997) or in practice wisdom literature (e.g. Kleinfeld, 2000). The student therapist was able to begin to integrate the use of concepts such as Malbin's (2000) concept of a paradigm shift, and knowledge of neuropsychology (Banich, 1997) and sensory integration (Schwab, 1999) with the Stages of Change Model (Prochaska et al., 1992), family therapy assessment (Haley, 1987; Paquin & Bushorn, 1991) and family therapy intervention (Haley, 1987; Minuchin et al., 1998). This represents a very rudimentary start to the need for wider integration of a number of bodies of

knowledge. The difficulties individuals with FASD and their families had in broad ecological systems strongly support the need for more such efforts.

Evaluating the family therapy intervention and intervention goals.

The goals stated for the intervention were: (1) to provide a systems-based, family therapy intervention to families with a member who was prenatally exposed to alcohol; (2) to provide families with appropriate and accurate information about the disability experienced by the affected family member (i.e. psychoeducational intervention); (3) to help families restructure to accommodate to the needs of the affected family member (i.e. structural-strategic intervention); (4) to help families to work through issues of grief, guilt, etc. as required by each individual family (i.e. psychotherapeutic interventions); (5) to help families develop internal resources and link to external resources to manage stress in the family system.

Examples of provision of services that fit goals 1-4 are reported extensively in Chapter 4 and the first half of Chapter 5 exploring the learning goals for the practicum. Goal 5 has two parts. One was to help families develop their own internal resources to manage stress related to FASD issues. This was accomplished using psychoeducational intervention to help families make a paradigm shift to seeing their child's behaviour as more normative given that the child has FASD, by helping families strengthen parental hierarchies to provide more structure to the home to support the child with FASD, and to help the families advocate for children in schools to reduce stress spilling from schools to home. The second part was accomplished through educating families about potential resources related to FASD as discussed in Termination Considerations in Chapter 3. All families were left at the end of therapy with either ongoing services in

the case of three families or access to short-term consultation from the therapist in the case of the other four. All the families can make use of supportive newsletters, information series, and a support group through the Fetal Alcohol Family Association if they wish.

Families' responses to the therapeutic intervention.

Families gave positive reports about the services they received. Both foster parents considering relinquishing children were extremely appreciative of services they received. One foster mother told the therapist that the therapist had helped the mother in ways the therapist could never understand. The other said over and over again that she really appreciated the therapist coming to her home, the therapist understanding the issues her son with FASD was dealing with, and told the child welfare worker that linking her with the therapist had been the most helpful thing for the mother. The third foster parent was very appreciative of the information she received, particularly to do with sensory integration, which helped her to eliminate stressful hair washing sessions, and to better understand the children temporarily in her care.

The grandparent families were also very appreciative of services. One grandmother said she had learned an enormous amount about her grandson who she had been parenting for almost nine years. This grandmother was very pleased with her realization that the key to parenting a child with FASD was changing herself and her responses to him so that he could function better. The other grandmother appreciated the therapist coming to her home, and the supportive, collaborative services. She really appreciated the therapist's help with some of the difficult issues she faced during the course of the practicum. She was very pleased that she could make use of future short-

term consultations to do some boundary setting and family work with her daughters if and when this fit for them.

The adoptive family appreciated the therapist coming to their home, the written information on FASD, and several key pieces of information that they found helpful. Particularly the realization that some of the problematic behaviour appeared to be game playing which allowed the mother who was most often snagged into the game to remove herself from the game. The father appreciated the therapist confirming his feeling that consequencing his daughter by withdrawing privileges at the end of the week was not going to work. He was feeling pressured by other adults to use consequences, but he had already realized such techniques would not work.

The birth families received quite different services from one another. One family received intense, almost weekly sessions that were used to deal with a variety of family issues, grief issues, and support the family through the process of an adolescent being diagnosed for FAS. The birth mother shared a difficult life history, fears for her children, and hopes that other alcohol-affected family members could be assessed in the future. Because she had a younger child who was also exposed to alcohol prenatally, she will receive long-term services from the therapist through Interagency, and her termination process was different, entailing a process of transferring rather than ending services.

The other birth family was difficult to connect with. The birth mother had relapsed and returned to drinking, and her children were apprehended even prior to the therapist's involvement. The children were supported by connecting with their foster mother and providing her with information she needed to care for them. The birth

mother made several attempts to contact the therapist, but unfortunately the therapist was not available at those immediate times, and attempts to connect with the birth mother afterwards were not successful. It was only at the end of the practicum that the therapist had an opportunity to connect with the birth father who will likely take on parenting the children. He was pleased to connect with the therapist and quite frustrated that the child welfare worker had not connected him sooner to the therapist. He realized that information about FASD would be very helpful to him as he had visits with and took over the job of parenting his children.

CHAPTER 6

Conclusions

This practicum was an opportunity to work with a group of strong and creative families. These families are pioneers raising alcohol-affected children in a society that has yet to truly grasp what living with FASD means to individuals, their families, and to the communities they live in. The therapist was left with a high regard for the strength, the wisdom, the perseverance, and dedication of these families to raising children that many families would have been only too happy to relinquish to the care of the child welfare system.

These families spoke to the power of human attachment to children, even those children who are different, difficult to parent, or are not biological offspring of the parent. The children with FASD were wonderful, creative, fun-loving individuals. The therapist enjoyed every moment she spent with these children. The therapist has previously noted the huge discrepancy between the actual experience of spending time with young children with FASD and newspaper reports that leave the general public with a skewed, fearful viewpoint of individuals with FASD. She is not alone in this response. A child welfare worker shared how much she liked an adolescent with FASD, who was on the run.

The adolescents with FASD were honest and open, unaware that socially acceptable behaviour would encourage them to be less honest. One of the adolescents happily explained to the therapist how the cigarette lighter in her car could be used to smoke crack, and what procedures could be used to steal her car. Far from being frightening moments, these were some of the highlights of the practicum, touching

moments when a child with a serious disability freely engaged with the therapist as a fellow human being, and formed a connection for a moment.

One of the ten year olds being relinquished by his foster family had some very serious processing and behavioural problems. Without adequate supports, he had burned out a gifted foster parent. Yet the innocent way this boy engaged with his world, his absolutely heart-warming smile as he engaged in behaviour reminiscent of Malbin's 'think stretch toddler' (Malbin, 2000) caused the therapist to feel a strong positive connection to this child. When the therapist observed this child in his classroom, this boy's eyes lit up. He was a genteel host to the therapist in his Grade 4 classroom. His warmth of spirit was a true gift to experience.

Perhaps particularly because of the warm human experiences of working with this group of children and their families, the frustrations of what was not available were equally strong. There are a number of recommendations that arise from the experience of this practicum.

Recommendations

Child welfare.

1. Child welfare agencies or agencies such as Children's Special Services should be resourced sufficiently to allow all families raising children with FASD access to supportive services like respite, support workers or mentors for their children. Currently there is very limited access to any of these services for birth, adoptive, or extended families raising children with FASD unless there is an active child protection concern or the child has a low DQ.

2. Foster homes frequently are raising children with FASD with multiple issues and who have experienced disruptions of placements and exposure to trauma making them more at risk of secondary disabilities (Streissguth, Barr et al., 1997). These families require adequate supports. The long-term research is very clear about the protective nature of long-term stable homes for children with FASD (Streissguth, Barr et al., 1997), and homes should be stabilized if at all possible, even if this means a short respite vacation for the parents (McCreight, 1997).

Family therapy.

3. Therapy work with alcohol-affected individual children or adults should be adapted to accommodate neurological differences in these individuals and requires a sound knowledge base of FASD and/or neurological differences on the part of the therapist.
4. Individuals with cognitive and neurological difficulties require a 'gift of time' (Malbin, 2000) from workers and therapists just as they do from parents. Insights that may occur rapidly with good therapeutic methods with a neurologically intact individual may take lengthy discussion, use of creative arts therapies, or construction of visual stories or information to allow the alcohol-affected individual to make the same realization
5. Children and adults with FASD may have difficulties in all ecosystemic aspects of their lives, and thus therapeutic intervention should occur at all system levels in which difficulties are arising. This includes, but is not limited to schools, day care centres, homes, community programs, and justice programs.

Provision of services.

6. Direct therapeutic work with families with children with FASD cannot be solely provided by child welfare agencies, particularly to birth families, because of conflict between child protection roles of workers and families' needs to disclose histories of behaviour that may be perceived by families to place children at risk of apprehension.
7. Extended and adoptive families are frequently reluctant to use child welfare agencies for services too, frequently because of mandates to provide services if there is a risk of child protection issues in the family that make families feel stigmatized if they access these services. This suggests the requirement for services specifically directed toward this population that can collaborate with other existing services.
8. Foster homes would benefit from services provided by therapists knowledgeable about FASD, who could then also act as advocates with the licensing agency if required.

Professional training.

9. Knowledge of FASD should be integrated with social work (and other professional) practice in a broad way to avoid iatrogenic damage to families dealing with FASD.
10. The two or three hour workshops that most professionals may have some access to are insufficient to achieve an integrated knowledge base sufficient to benefit services to individuals with FASD and their families. More in depth training

and access to ongoing supervision or consultation with someone highly knowledgeable in practice and in theory with this disability is required to ensure that children with FASD and their families receive adequate services.

Social policy.

11. FASD is a life-long disability that requires life-long supports be available (Giunta & Streissguth, 1988; Streissguth, 1994; Streissguth, 1997). Individuals with FASD and their families require access to comprehensive, FASD related services throughout the life span.

12. Many of the above recommendations suggest a broad social policy response to the issue of FASD could ensure a coordinated, collaborative response to service provision for individuals with FASD and their families.

Further research.

13. Further research should be directed to empirically validate effective social work and family therapy practices provided to a population of individuals with FASD and their families.

Directions for social work practice and research.

Fetal alcohol syndrome was first described 30 years ago in 1973. Thirty years later Streissguth and a number of other psychological and medical researchers have studied various animal models and conducted psychological research on children, adolescents and adults with FASD (Streissguth, 1997). Much more is known than in 1973, but there is also an awareness of how much more is not known.

Social work has much to contribute to the field of FASD. Families require supports, resources, understanding, compassion, individualized and non-judgemental

services, accurate information, empowerment, systemic intervention, and ecosystemic circles of support in their communities to name just a few things. Many of these are things social workers have already been trained to provide, particularly to marginalized or stigmatized populations. To provide services to individuals and families dealing with FASD, social workers require extensive training in FASD and provision of services related to FASD, social service agencies require adequate funding to provide appropriate services, and social work practice research is required to empirically validate best practices models for this service group.

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APPENDIX A

Sample Questions from the Parenting Stress Index

Most questions are responded to with strongly agree, agree, not sure, disagree, or strongly disagree (Abidin, 1995).

Child Domain Subscales

My child appears disorganized and is easily distracted. (Distractibility/Hyperactivity)

Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house. (Adaptability)

My child rarely does things for me that make me feel good. (Reinforces Parent)

Think carefully and count the number of things which your child does that bothers you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted. 1. 1-3, 2. 4-5, 3. 6-7, 4. 8-9, 5. 10+. (Demandingness)

My child seems to cry or fuss more often than most children. (Mood)

My child doesn't seem to learn as quickly as most children. (Acceptability)

Parent Domain Subscales

Being a parent is harder than I thought it would be. (Competence)

I feel alone and without friends. (Isolation)

I expected to have closer and warmer feelings for my child than I do and this bothers me. (Attachment)

During the past six months, I have been sicker than usual or have had more aches and pains than I normally do. (Health)

Most of my life is spent doing things for my child. (Role Restriction)

When I think about the kind of parent I am, I often feel guilty or bad about myself. (Depression)

Since having my child, my spouse (male/female friend) has not given me as much help and support as I expected. (Spouse)

Life Stress

Have any of the following events occurred in your immediate family in the last 12 months. (e.g. divorce, pregnancy, moved to new location)

APPENDIX B

Sample Questions from the Child Behavior Checklist for Ages 6-18

Scored as 0 = not true (as far as you know); 1 = somewhat or sometimes true, or 2 = very true or often true (Achenbach & Rescorla, 2001). Name of subscale represented is shown in brackets after the sample item.

Cries a lot (Anxious/Depressed)

There is very little he/she enjoys (Withdrawn/Depressed)

Nightmares (Somatic Complaints)

Clings to adults or too dependent (Social Problems)

Can't get his/her mind off certain thoughts; obsessions-describe. (Thought Problems)

Acts too young for his/her age (Attention Problems).

Drinks alcohol without parents' approval-describe. (Rule-Breaking Behaviour)

Argues a lot (Aggressive Behavior)

Bowel movements outside toilet (Other Problems)