

An Investigation Into The Needs of Parents With Fetal Alcohol Spectrum Disorder (FASD)

Velma Abraham

B.A., Malaspina University-College, 2001

Thesis Submitted In Partial Fulfillment Of

The Requirements For The Degree Of

Master Of Science

in

Psychology

The University Of Northern British Columbia

September 2005

© Velma Abraham, 2005



Library and  
Archives Canada

Bibliothèque et  
Archives Canada

Published Heritage  
Branch

Direction du  
Patrimoine de l'édition

395 Wellington Street  
Ottawa ON K1A 0N4  
Canada

395, rue Wellington  
Ottawa ON K1A 0N4  
Canada

*Your file    Votre référence*

*ISBN: 978-0-494-28369-1*

*Our file    Notre référence*

*ISBN: 978-0-494-28369-1*

#### NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

#### AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

---

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

  
**Canada**

## **ABSTRACT**

This study sought the perspectives of parents with FASD, their advocates and service providers on parents' service and support needs. Two focus groups of service providers (1 group of 5 and 1 group of 4) and 6 interviews (n = 3 parents and n = 3 advocates) were organized to discuss the needs of parents with FASD. Focus group and interview transcripts and notes were coded and items grouped by themes to explore the needs parents have in meeting the dual challenges of parenting and having FASD. Three thematic categories emerged from the findings: (i) parental needs, (ii) desirable services and support, and (iii) barriers to service delivery. The results indicate that parents needed a number of services and support catering to their needs. The research indicates clearly the need for alternative or new service models that meet the needs of parents with FASD.

## TABLE OF CONTENTS

<b>ABSTRACT .....</b>	<b>ii</b>
<b>TABLE OF CONTENTS .....</b>	<b>iii</b>
<b>LIST OF TABLES .....</b>	<b>vi</b>
<b>LIST OF FIGURES .....</b>	<b>vii</b>
<b>ACKNOWLEDGEMENT .....</b>	<b>viii</b>
<b>CHAPTER ONE</b>	<b>INTRODUCTION AND OVERVIEW .....</b>
	<b>1</b>
	Rationale of the Study .....
	4
	Aim of the Study .....
	9
<b>CHAPTER TWO</b>	<b>LITERATURE REVIEW ON FASD.....</b>
	<b>10</b>
	What is FASD?.....
	10
	Clinical Description.....
	11
	Key Symptoms and Characteristics of FASD .....
	13
	Etiology .....
	13
	Diagnosis .....
	19
	Epidemiology .....
	23
	Adolescent and Adult Outcomes of FASD .....
	25
	Physical Characteristics over Development .....
	26
	Executive and Cognitive Functioning .....
	28
	Psychosocial and Emotional Functioning .....
	30
	Behaviour .....
	32
	Parenting by Individuals with FASD .....
	34
	What is Parenting and
	What Does Parenting Involve?.....
	35
	Parental Adequacy and Competency .....
	40
	Parental Competency and Child Outcome .....
	48
	Social and Ecological Aspects.....
	55
<b>CHAPTER THREE</b>	<b>METHOD.....</b>
	<b>58</b>
	Overview .....
	58
	Rationale of the Method .....
	59
	Participants .....
	60

	Service Providers .....	60
	Parents .....	60
	Advocates .....	60
	Measures .....	60
	Service Providers .....	60
	Parents .....	61
	Advocates .....	62
	Procedure .....	62
	Service Providers .....	62
	Parents .....	64
	Advocates .....	65
	Data Analysis.....	67
	Stages of Data Analysis.....	67
	Service Providers.....	68
	Parents and Advocates.....	68
	Integrated Analysis .....	69
<b>CHAPTER FOUR</b>	<b>RESULTS.....</b>	<b>70</b>
	Demographics and Background Data .....	70
	Service Providers .....	70
	Parents .....	78
	Advocates .....	78
	Analysis and Triangulation of Focus Group and Interview Data .....	78
	Parental Needs .....	79
	Desirable Services and Support Needs.....	87
	Barriers to Services and Support .....	96
<b>CHAPTER FIVE</b>	<b>DISCUSSION .....</b>	<b>101</b>
	Limitations.....	111
	Conclusions .....	112
<b>CHAPTER SIX</b>	<b>RECOMMENDATIONS .....</b>	<b>114</b>
	Support Services .....	114
	Training .....	115
	Service Coordination/Linkage or Case management ...	117
	Information .....	118
	Continuity of Service Provision .....	119

Review .....	119
Funding.....	119
Assessments.....	120
<b>REFERENCES.....</b>	<b>122</b>

**APPENDICES**

A. Focus Group Measures .....	142
B. Parents' Interview Guide .....	152
C. Advocates' Interview Guide.....	158
D. Service Providers' Information Letter and Poster .....	162
E. Service Providers' Consent Form.....	167
F. Debriefing Summary Form.....	169
G. Parents' Information Letter and Poster.....	172
H. Parents' Consent Form .....	177
I. Advocates' Information Letter and Poster .....	179
J. Advocates' Consent Form .....	183

**LIST OF TABLES**

Table 1	Key Features of Primary Disabilities Characteristic of FASD .....	14
Table 2	Key Features of Secondary Disabilities Characteristic of FASD .....	15
Table 3	Frequency of Activities Undertaken by Service Providers .....	72
Table 4	Working with Parents with FASD .....	73
Table 5	Usefulness of Specific Service Development.....	74
Table 6	Frequency of Service/Support Links .....	75
Table 7	Strategies Used to Provide Services .....	76
Table 8	Information, Service and Support Accessibility, Appropriateness and Relevance .....	77
Table 9	Needs Matrix .....	85

## LIST OF FIGURES

Figure 1	Desirable Services and Support.....	95
Figure 2	Framework of home and support services.....	116
Figure 3	A Conceptualized hierarchy of needs.....	121



## ACKNOWLEDGEMENT

A project such as this would be incomplete without thanking those people who helped make it possible. Cindy Ignas was pivotal in the initial conceptualization of the study and has continued to provide support and consultation. Her input into the development of this study has been invaluable. Jeanette Turpin, former Executive Director of Northern Family Health Society (NFHS), supported the research project by granting permission to recruit participants through NFHS. NFHS is responsible for providing social and vocational services for parents and children. Services include, but are not limited to parenting, classes for at risk parents, and vocational skills. Specifically, the researcher is grateful to the staff at NFHS for their generous assistance with this study.

Dr. Cindy Hardy, my thesis supervisor, significantly contributed to this study. Her helpful suggestions regarding the study and writing a masters thesis are greatly appreciated. Dr. Glen Schmidt, Associate professor Social Work and Dawn Hemingway, Assistant professor Social Work and members of my thesis committee, offered recommendations and suggestions for improving the study.

Many other individuals have contributed to the success of this study. The greatest thanks go to the parents, advocates and service providers that agreed to participate in this study. My Sincere thanks go to the BC Centre for Addiction Research for the bursary awarded to me, which provided much needed financial support. The dedication, hard work, and commitment of the undergraduate volunteers who assisted in data collection and focus group management cannot go unrecognized. Special thanks go to all of you, as well as the individuals who assisted with editing this thesis.

Finally, many thanks go to my parents. My sincerest thanks go to Robin Johnson, Mwansa Nyemba, Benjamin Shillingford, Steinberg Henry, Benjamin Mockett and my Sister Jo-anne for supporting, and encouraging me during the time of difficult challenges.

## CHAPTER ONE

### INTRODUCTION AND OVERVIEW

#### An Investigation into the Needs of Parents with Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) remains one of the most misunderstood developmental disabilities. This has been due largely to the historical development of the research methodology, paucity of research and the diagnostic approaches to its evaluation. Over the last ten years there has been a burgeoning interest particularly on the part of social scientists, governments, and other organizations in FASD research. However, those interests appear somewhat limited in scope. For the most part, the available data on FASD focuses largely on the challenges faced by children affected with FASD, and the challenges of parenting children affected with FASD. On the other hand, data on adolescents and adults who are affected by FASD and in particular, those who are parents, was and remains a mere trickle. Moreover, a modicum of present day data exists on the prevalence of adolescents and adults with FASD who are parents. Evidence from a number of studies (e.g., Canadian Pediatric Society, 2002; Lutke & Antrobus, 2004) suggests that there are probably between 317,146 to 1,902,878 (1% - 6% of the Canadian 2003 population of 31,714, 637) individuals with FASD in Canada and about 41, 586 – 249,518 (1% - 6% of BC's October 2003 population of 4, 158,649) individuals in BC with FASD. Of the approximately 25, 848,000 people in Canada, 15 years of age and older, it is estimated that about 258,480 to 1,550,880 (1% - 6%) may have FASD (Lutke & Antrobus, 2004). Therefore, the likelihood is high that many of the adolescents and adults in Canada with

FASD already are or will become parents. Thus, it can be hypothesized that there are a number of women and men affected with FASD facing the dual challenges of parenthood and living with FASD. A large majority of women and men with FASD go undiagnosed and those who end up in the 'system' pose major challenges to social services, health care systems, criminal justice systems, and other professional practices. Individuals affected with FASD have intricate and varying needs, which require access to a wide range of services. The distinctive needs of this population are often poorly identified and understood, therefore, individuals are likely to be shifted between social service programs in fruitless attempts to obtain suitable services and supports. Like parents who suffer from other developmental disabilities (e.g., mental handicaps, learning disabilities), parents with FASD are very vulnerable to losing custody of their children, to cycle between prisons and institutions, or to live in seriously substandard conditions (Boland, Burill, Duwyn, & Karp, 1998; Knowledge Network, FAS Community Resource Center, 2002; Lutke & Antrobus, 2004; Streissguth, Barr, Kogan, & Bookstein, 1996).

While there may be a considerable number of women and men with FASD who assume parenting roles, or make up the proportion of persons parenting children, the impact on these individuals in coping with the challenges of FASD and parenting has been largely unexamined. Policies and programs have not necessarily been developed with adequate information and human resource capacity to meet their needs. We lack specific information about who they are, the demography of mothering and fathering in the population of women and men affected with FASD, the number of children they have, the characteristics of their children (such as where they are living or in whose custody or care), how they function in their role as a parent, and the impact of parenting upon them. In particular, we

lack information on the perceived needs of these mothers and fathers with respect to their child(ren) and thus, know little about how to strengthen and support their parenting skills.

While on one hand, the experiences of parents with FASD are similar to those of all parents in many ways, on the other hand, the literature on adolescents and adults with FASD has emphasized their unique circumstances, and deficits. They are more likely than the general population to require additional emotional, mental, and social support. In particular, their limited cognitive and adaptive skills put individuals with FASD at risk for experiencing difficulties in their parenting role (Clarke, Lutke, Minnes, & Ouelette-Kuntz, 2004; Ladue, Schacht, Tanner-Halverson, & McGowan, 1999; Lutke & Antrobus, 2004; Rutman, LaBerge, & Wheway, 2002; Streissguth et al., 1996). They are least likely to participate in the labour force, more likely to have a history of living in unstable homes, and to be survivors of violence and victimization (e.g., physical abuse, domestic violence, sexual abuse), with consequences for their functioning as adults and as parents (Streissguth et al., 1996).

The fact that social services often overlooks the unique needs of parents with FASD who are in their programs suggests that they represent a somewhat “*invisible*” and underserved population. Consequently, the provision of services and support to assist these women and men in their parenting role has been lacking. Opportunities for supporting parents with FASD are quite often missed or lost for many reasons. Outcomes for parents with FASD and their children are likely to be compromised by the ways services are organized and policies implemented. The social and health system is often compartmentalized into child protection, welfare, mental health, and drug and alcohol abuse sectors. Thus, people with FASD whose experience transcends these boundaries have

difficulty obtaining services that holistically respond to their needs. Furthermore, the lack of an appropriate methodology for assessing, measuring and identifying individual needs tends to put individuals with FASD at a disadvantage. They often fall between constructed criteria and receive mediocre support, no support, or disjointed and possibly contradictory support. In this context, it can be argued that a clear understanding of parenting needs is essential for developing appropriate programs and support networks, as well as clinical practices and policies.

The difficulties in identifying the needs of these parents and providing services and support for them can be attributed to the fact that parents with FASD comprise a heterogeneous population, many of whom have varying deficits, strengths, and skills, as well as unique complexes of social, psychological, and health problems. Therefore, they require multi-agency coordination and interface between the legal and social service system. This calls for a systematic process of assessing the needs of parents who are affected with FASD as ambiguous statements about needs may be more harmful than beneficial to this population.

### Rationale of the Study

FASD is among the most common developmental disabilities of our times. It is caused by prenatal exposure to alcohol in utero. FASD is a leading environmental cause of birth defects and mental retardation, as well as one of the leading causes of permanent disabilities resulting in an attendant concern for the health, functional ability, and quality of life in this population (Streissguth et al., 1991; Streissguth & O'Malley, 2000). According to Lutke, "In the thirty years since FASD was first recognized, an entire generation of individuals has reached adulthood. Some are in their thirties. A second generation is now in

their twenties and a third generation is very close behind” (2004b, p. 1). This suggests that there are a large number of adolescents and adults from this population who may be in the position of caring for others. However, it is not known how many individuals affected with FASD in BC, or at the national level, are parents.

In recent years, some of the leading researchers in the field have noted that there is a large subset of individuals with FASD who are at the child-bearing age and are exercising their rights to be parents. In fact, service providers have also noticed that some of these families display a sort of ‘revolving door’ relationship with social service and child protection systems. Despite these facts, there has been very little research done in Canada looking at parental issues in individuals affected with FASD, and more specifically, very few research could be found that examined the needs of parents with FASD (Clarke, 2003).

Furthermore, current eligibility criteria necessary to obtain community living services and other government assistance make it difficult to access services. For example, the current definition of developmental disabilities, which usually includes mental handicap and intellectual disabilities, excludes most adolescents and adults with FASD from receiving the support and services they need (Clarke, 2003; Lutke, 2004a). According to Clarke (2003, p. 28), “one of the greatest difficulties faced by an adult with FASD in BC is obtaining support and services.” The BC provincial government criteria stipulate that to qualify for the supported living services an adult must have an intelligence quotient (IQ)  $\leq 70$ , with onset before the age of 18, and significant limitations in two or more adaptive skills (Ministry of Children and Family Development, 2004). Although adults with FASD meet the second criterion of limitation in adaptive skills, the vast majority of individuals with FASD are not mentally challenged ( $\text{IQ} \leq 70$ ). This observation is consistent with an

earlier study by Kerns, Don, Mateer & Streissguth(1997), that persons with FASD who are not mentally retarded often have difficulty qualifying for special education and vocational services. Professionals working with parents who have FASD and those suspected of having FASD are hampered by system-level barriers, timelines given to work with parents, and lack of community services in their attempt to support such families and meet their unique needs.

Clearly, a gap exists in service availability and appropriateness for parents affected with FASD and their needs, despite the growing interest in FASD research in Canada. Parenting programs such as Project Parent North in Prince George, BC; Healthiest Babies Possible in Prince George, BC; FOCUS in Burns Lake, BC; Structured for Success recently implemented in Prince George, BC; and Step-by-step in Edmonton, Alberta, are in place in some communities. However, anecdotal evidence indicates that only a small fraction of the affected population utilizes such services. The people who do use the services are usually referred to the program by social services. Therefore, many or perhaps most of the parents affected with FASD who need support, training or services fall through the cracks. Furthermore, the vast majority of the programs for parents do not focus on specific needs of parents with FASD. Intervention often includes general parenting classes and early childhood intervention programs in which the goals are normally stated as prevention of child abuse, neglect, and the prevention of out-of-home placements. In BC, this suggests a child protection orientation and a focus on the child's needs rather than the parent's needs or the family's need. Thus, the relevance and effectiveness of these programs for parents with FASD and their children is, for the most part, unknown.

Many adolescents and adults with FASD are likely to get into trouble with the law, have their child(ren) removed from their care, and demonstrate other disturbing behavioural trends and secondary disabilities (Clark et al., 2004; Lutke & Antrobus, 2004; Streissguth et al., 1996). The discussions in some of the literature reviewed (e.g., Streissguth et al., 1996; Rutman, et al., 2002), seem to suggest that traditional parenting programs and child protection strategies used to deal with child abuse and neglect have had limited rehabilitative impact on adolescents and adults with FASD. At best, it appears that they have been successful in temporarily helping with child protection issues such as child abuse, neglect and other parental issues. This dilemma clearly points to the need of government and professionals to shift the balance of effort in the direction of intervention programs that match the needs of parents with FASD; for without appropriately matched support and services, these parents are more likely to perpetuate a cycle of having children and having them taken away.

This research was initiated at the request of Cindy Ignas, Manager of Parenting Services for the Northern Health Authority, which provides onsite and in-home programming for parents and their children. Many factors make this research a timely and valuable contribution to the study of FASD in BC, and more generally, in Canada. The limited research and the lack of information on parenting by people with FASD appears to restrict the ability of professionals to access valuable resources, as well as determine the nature, level, and combination of support parents with FASD will need in order to achieve successful parental outcomes. Additionally, in the current climate of funding cuts and increasing case loads of social service workers, the system's capacity to provide the level of



ongoing support that may be needed for people with FASD to be successful in their parenting role is unclear.

In recent years, the federal and provincial governments have been stressing the importance of establishing programs to create awareness of FASD and have been increasing funding towards FASD research. In 2000, funding of more than \$11 million over three years was allocated by the Government of Canada to enhance activities related to FASD. However, the focus of most of the strategic planning on FASD has been on prevention, public awareness and education, early identification and diagnosis, education of parents (adoptive, foster and biological) and others (e.g., teachers) in dealing with children with FASD (Health Canada, 2000).

Moreover, in order to effectively and efficiently deal with the problem of FASD, information will be required on all segments and populations affected. While there have been many research papers ( e.g. Clarren, Astley, & Bowden, 1988; Dorris, 1989; Michaelis & Michaelis, 1994) addressing issues faced by children with FASD, parenting children with FASD, and the teratogenic effects of alcohol, what has been missing is research on the needs of parents with FASD. This reflects a systemic failure to respond appropriately to parents affected with FASD. Therefore, in considering how to respond to this need, the perspective of the service providers, the parents themselves, as well as their advocates would be very helpful. Thus, this study on the needs of parents with FASD will be useful:

- To understand the services and supports available to parents with FASD and what supports and services they would value.
- To identify areas appropriate for the development of programs and curriculum for working with parents who are affected with FASD.

- To help develop support services to enable parents to gain the skills and knowledge to care for their child(ren) appropriately to prevent distress and harm through neglect.
- To understand how current services fail parents with FASD and what solutions are available to address unmet needs.
- To provide baseline information that could be useful in assessment tools and policy development in this area.

#### Aim of the Study

In the context of the above discussion, the purpose of this study is to determine from the perspectives of service providers, parents with FASD, as well as their advocates, what kinds of needs parents with FASD have.

This study has the following objectives:

- To identify and document the needs of parents with FASD.
- To develop recommendations regarding appropriate support services to meet the needs of parents with FASD.

## CHAPTER TWO

### LITERATURE REVIEW ON FASD

#### What is FASD?

Prenatal alcohol exposure is perhaps one of the most serious and pernicious causes of developmental disorder. Current literature suggests that the effects of alcohol exposure in utero can be complex and pervasive, as alcohol tends to affect the brain and delay development, often resulting in significant long-term morbidity and functional impairment (Connor, Sampson, Bookstein, & Streissguth, 2000; Connor & Streissguth, 1996; Kerns, Don, Mateer, & Streissguth, 1997; LaDue, Streissguth, & Randels, 1992; Mattson, Jernigan, & Riley, 1994; Mattson, Riley, et al., 1994; Mattson & Riley, 1995; Michaelis & Michaelis, 1994; Streissguth, 1994; Streissguth, Ladue, & Randels, 1988; Streissguth & Kante, 1997).

Individuals with FASD are markedly diverse as a group, and as such, there is a wide variability in presentation of the impact of alcohol exposure from severely disabled through average functioning, with IQ scores ranging from  $\leq 70$  to 115. Almost all individuals with FASD have adaptive quotient (AQ)<sup>1</sup> < 70 (Lutke & Antrobus, 2004). All that individuals with FASD share are the characteristics that define the syndrome. Even here, though, in the defining criteria for the various disorders, there is considerable room for variance. Thus, the range of needs to be found within the spectrum is likely to be enormous.

FASD strikes across all barriers of race, culture, and class and there is no eradication of the effects of alcohol on the fetus is not possible. Once the damage has been

---

<sup>1</sup> AQ- measures one's ability to function day to day without supports in areas of communication, socialization, daily living skills (personal and community), time management, employment, critical thinking, judgment, etc (Lutke & Antrobus, 2004)

done in utero, the individual will continue to have some level of impairment into adulthood (Nunley, 2001). FASD is a permanent disability, and has been recognized as perhaps one of the leading environmental causes of birth defects and mental retardation as well as one of the leading causes of serious long-term disabilities. This has resulted in an attendant concern for the health, functional ability, and quality of life in this population (Stade, Clark, & D'Agostino, 2004; Streissguth et al., 1996; World Health Organization, 1997).

As noted in Stade et al. (2004), the Stade, Steven, Ungar, Beyene, and Koren study indicated that the quality of life for those with FASD was poor in comparison to those without FASD. Stade and her colleagues measured the quality of life of 126 individuals with FASD and 4423 individuals without FASD ages 8 to 21 years living in communities throughout Canada. The health-related quality of life scores of those with FASD ranged from -0.22 to 0.96, with a mean of 0.47, compared to a range of 0.91 to 0.95 with a mean of 0.93 for those from the general Canadian population. In addition, Stade and her colleagues noted that the health ramifications of FASD are enormous and there are substantial costs related to FASD on the health and social systems. The annual cost of FASD in Canada for individuals aged 11 to 21 years is estimated to be \$344,208,000 (Stade et al., 2004).

### *Clinical Description*

FASD is best described as a continuum of related alcohol exposed disorders. The various clinical pictures of FASD depend upon a combination of the different impairments or insults caused by alcohol exposure. The FASD continuum ranges from the most severe diagnosis of Fetal Alcohol Syndrome (FAS), to Partial Fetal Alcohol Syndrome, (pFAS), to Alcohol Related Neurodevelopmental Disorder (ARND), and to a diagnosis of Alcohol

Related Birth Defects (ARBD). The full syndrome (FAS) is identified by a combination of abnormalities including facial features, retarded growth and development both before and after birth, and central nervous system (CNS) impairments, as well as knowledge of maternal alcoholic consumption during pregnancy (Clarren & Smith, 1978; Stratton, Howe & Battaglia, 1996; Streissguth, 1994; Streissguth et al., 1991). Streissguth (1986) describes individuals with full FAS as being, on average, mildly retarded with IQ scores in the 60s. A relatively small proportion of individuals prenatally exposed to alcohol in utero have full FAS. It has been estimated that only 10 to 40% of offspring of alcohol abusing mothers meet the criteria for a diagnosis of full FAS (Greenbaum & Koren, 2002). Partial FAS is distinguished by the presence of some, but not all, of the characteristics of FAS when prenatal exposure has been confirmed.

On the other hand, individuals with significant exposure to alcohol in utero can lack the characteristic facial defects and growth deficiencies of FAS but still have alcohol-induced mental impairments that are just as serious, if not more serious, than those seen in individuals affected with FAS. Consequently, the term ARND has been developed to describe this condition. In addition, individuals exposed to alcohol prenatally who do not have the distinct facial features can have other alcohol-related physical abnormalities of the skeleton and certain organ systems; known as ARBD. In ARND and ARBD, there is also evidence of a complex pattern of behavioural, cognitive, and psychosocial abnormalities that are unusual for the individual's chronological age, but are consistent with their developmental age (mental age) (Budd, Ross-Alamolki & Zeller, 2000; California Fetal Alcohol Spectrum Organization, 2004; Greenbaum & Koren, 2002; Health Canada, Population and Public Health Branch, 1998; Streissguth, 1986).

### *Key Symptoms and Characteristics of FASD*

FASD is characterized by primary and secondary disabilities. Primary disabilities associated with FASD are those disabilities that are not reversible and appear in three domains: growth delay and retardation, cranio-facial anomalies, and central nervous system (CNS) impairments (Ladue et al., 1992; Streissguth, 1994; Streissguth et al., 1996). Table 1 lists the key features subsumed under primary disabilities.

Secondary disabilities are those disabilities that the individual is not born with, but those which manifest progressively with development, particularly when there are inadequate interventions in place to provide support around primary disabilities (i.e., additional disabilities or conditions that may result from having a primary disability) (Ladue et al., 1992, Streissguth et al., 1996). Secondary disabilities are frequently identified as barriers to vocational, educational, and social progress (Ladue et al., 1999). Table 2 lists the key features subsumed under secondary disabilities.

### *Etiology*

In the 30 years since FASD was recognized as a clinical syndrome, there have been major advances in understanding the teratogenic effects of alcohol, and a surge in public consciousness about the disability. A vast number of animal and human research studies have been undertaken in an effort to better understand the etiology of the disorder. Currently three mechanisms have been documented; abnormal migration patterns of cells on their way out of the cortex, reduction in cell adhesion once they have reached their destination, and abnormal cell deaths all along the way (Michaelis & Michaelis, 1994; Page, 2002). The extents to which these discoveries explain some of the outcomes of alcohol exposure are beginning to be unravelled. Alongside these advances in research on

Table 1

*Key Features of Primary Disabilities Characteristic of FASD*

Primary disabilities
<p><i>A pattern of facial anomalies</i></p> <ul style="list-style-type: none"> <li>• Small eye openings</li> <li>• Flat mid-face (cheek bone)</li> <li>• Flatten groove between nose and upper lip</li> <li>• Thin upper lip</li> </ul> <p><i>Growth deficiencies</i></p> <ul style="list-style-type: none"> <li>• Low birth weight</li> <li>• Decelerating weight over time, not due to malnutrition</li> <li>• Disproportional low weight to height</li> <li>• Height and weight below the 10<sup>th</sup> percentile</li> </ul> <p><i>Central nervous system impairment</i></p> <ul style="list-style-type: none"> <li>• Decreased head size</li> <li>• Structural abnormalities of the brain</li> <li>• Neurological problems (such as impaired motor skills, poor coordination, hearing loss, visual problem)</li> <li>• Behavioural and/or cognitive problems such as: mental handicap; learning difficulties, poor impulse control, problem in social perception, problem in memory, reasoning and judgment</li> </ul>
<p>Information for this table adapted from Astley, (2004), Clarren and Smith (1978), Streissguth et al. (1996).</p>

Table 2

*Key Features of Secondary Disabilities Characteristic of FASD*

Secondary disabilities
<p><i>Mental Health Problems</i></p> <ul style="list-style-type: none"> <li>• Depression</li> <li>• Attachment disorder</li> <li>• Autism</li> <li>• Suicidal threats/attempts</li> <li>• Conduct Disorder</li> <li>• ADHD</li> <li>• Oppositional defiance disorder</li> <li>• Pervasive developmental disorder</li> </ul> <p><i>Disrupted Schooling</i></p> <ul style="list-style-type: none"> <li>• Suspension</li> <li>• Expulsion</li> <li>• Dropping out</li> </ul> <p><i>Legal problems</i></p> <ul style="list-style-type: none"> <li>• Crimes against property</li> <li>• Shoplifting</li> <li>• Theft</li> <li>• Crimes against persons</li> <li>• Assaults</li> <li>• Domestic violence</li> <li>• Child molestation</li> </ul> <p><i>Confinement</i></p> <ul style="list-style-type: none"> <li>• Mental health in-patient</li> <li>• Substance abuse treatment</li> <li>• Jail</li> </ul> <p><i>Inappropriate Sexual Behaviour</i></p> <ul style="list-style-type: none"> <li>• Sexual touching</li> <li>• Sexual advances</li> <li>• Public masturbation</li> <li>• Promiscuity</li> <li>• Exposure</li> <li>• Phone calls</li> <li>• Incest</li> <li>• Voyeurism</li> </ul> <p><i>Dependent Living</i></p> <ul style="list-style-type: none"> <li>• A large number of FASD adolescents and adults may always need to live in a supervised setting</li> <li>• Lives in group homes, or with relatives</li> </ul> <p><i>Employment Problems</i></p> <ul style="list-style-type: none"> <li>• Holding a job</li> <li>• Getting a job</li> <li>• Being fired</li> <li>• Losing job without explanation</li> </ul>

Information adapted from Streissguth et al., (1996).



FASD, recent progress in brain imaging techniques, most notable functional magnetic resonance imaging (fMRI), have provided exciting opportunities to further delineate the impact of alcohol exposure on brain development. For example, Clarren (1986) provided one of the first published demonstrations of neuroimaging of the brain of an individual with FASD.

Recent work by Roebuck, Mattson, and Riley (1998) and Mattson, Jernigan and Riley (1994) noted a reduction in the volume of both the cerebellum and cerebrum. Other studies have also indicated disproportionate size reduction in the basal ganglia and corpus callosum (Archibald et al., 2000; Mattson & Riley, 1995; Riley, Mattson, Sowell, Jernigan, Sobel, & Jones, 1995).

For the most part, researchers (e.g., Goodlette & Horn, 2001; Mattson & Riley, 1995; Mattson, Schoenfeld, & Riley, 2001) have focused on the administration of alcohol to experimental animals (e.g., ethanol treatments of pregnant rats during all of gestation) and have evaluated the neurobehavioural and physical effects that may occur as a consequence. Friedler (1988) states that, in some studies, rats exposed to alcohol have shown delays in growth, hyperactivity, and deficits in learning and memory.

Further, it has been shown that exposure to as little as one dose of alcohol can hamper the ability of migrating brain cells to stick to their spot on the cortex. Thus, it is believed that each individual exhibits a different combination of alcohol-related effects, which is determined, by the timing, quantity, pattern, and duration of maternal drinking. Becker, Randall, Salo, Saulniers, and Weathersby (1994), for example, noted that rapid consumption of alcohol over a short period of time will result in a higher blood alcohol

level than sipping the same amount of alcohol slowly over a long period of time. In addition, Sampson, Streissguth, & Bookstein, (1989) claimed that maternal drinking patterns associated with the highest risk to the developing fetus are those in which drinking occurs early in pregnancy (i.e., the first trimester), and in which 'binge drinking' occurs.

Animal research on binge drinking using mice has revealed that ethanol exposure on only one day at a critical period of embryonic development can lead to specific damage of brain structures and other organ systems (Nunley, 2001). Randall and Taylor (1979) found that ethanol exposure on the 5th through the 10th gestational day (GD) resulted in structural neurological deficits with increased incidence of fetal wastage and birth defects. Another study conducted by Cook, Nowotny, and Sulik (1987) explored the effect of ethanol in mice on GD 7. They found that acute administration of ethanol resulted in a variety of eye malformations, however, these same malformations did not occur on GD 8 indicating a specific period of developmental disruption due to ethanol exposure (Nunley, 2001).

One of the more intriguing findings to emerge in the past few years is that overall brain size appears to be smaller and lighter in individuals with FASD (Mattson & Riley, 1995; Streissguth, et al., 1996). Likewise, Miller (1992) in his investigation of the effects of alcohol exposure during the second half of gestation in animals (equivalent to the second trimester in humans) noted a brain weight reduction.

It is not yet clearly understood whether all regions in the brain are equally affected by the reduction in brain weight or how brain size relates to cognitive functioning. There is also some variability in the magnitude of the effect. A decrease in brain size might come at the expense of interconnectivity between specialized neural systems, giving rise to a more fragmented processing structure. In fact, some studies have found that the corpus callosum,

the major fibre pathway between the hemispheres, is atrophied or absent in many FASD individuals (Mattson, Jernigan, et al., 1994; Mattson & Riley, 1995; Riley, et al., 1995). Other studies, such as Bookstein, Streissguth, Sampson, Connor, & Barr, (2002) have found that individuals with FASD have noticeably more variability of colossal shape than “normal” subjects. Moreover, abnormalities to the frontal lobe and microscopic changes have been reported in the location of cells within the brain, evidence of the abnormal migration pattern mentioned earlier (Goodlett & West, as cited in Connor & Streissguth, et al., 1996; Kodituwakku et al., 1995; Mattson & Riley, 1995; Mattson, Jernigan et al., 1994; Swayze, et al., 1997). It is not clear whether impairments in brain structure occur prenatally or continue to develop after birth.

The social, cognitive, and behavioural problems that occur with FASD suggest that the syndrome affects a functionally diverse and widely distributed set of neural systems. At the same time, however, the affected systems must be discrete, because prenatal exposure spares many perceptual and cognitive systems. Even though the full syndrome likely involves damage to multiple systems, it remains possible that the initial insult is localized, branching off into more pervasive impairments because of the highly interdependent nature of early developmental processes.

In addition to the impact of alcohol on brain factors, research by Streissguth et al., (1996) hints at the potential impact of environmental factors (e.g., neglect, stimulation, effectiveness of educational and therapeutic interventions) in determining behavioural outcomes in adolescents and adults with FASD.

When the evidence is considered as a whole, it is clear that prenatal alcohol exposure impacts the central nervous system. The animal models have demonstrated that at

least four categories of casual factors, including, timing, quantity, and patterns of drinking and duration, determine the kind and level of abnormalities that are likely to occur. Taken together, these findings provide strong support for an interactive role across many systems, including neurological, cognitive, affective, behavioural and environmental systems.

### *Diagnosis*

*Criteria for diagnosis of FASD.* For many years the focus of researchers in the field of FASD has been directed by the formal descriptions of Fetal Alcohol Syndrome (FAS) given by Jones and Smith in 1973. They identified the core triad of impairments mentioned earlier, which are now accepted by professionals all over the world. They include prenatal growth deficiencies (length and /or weight) that persist postnatally, facial anomalies (smooth philtrum, thin vermilion, and small palpebral fissures), and central nervous system dysfunction (structural, neurological, functional or combination thereof; Clarren & Smith, 1978. It should be noted that a confirmed history of maternal alcohol abuse during pregnancy is also necessary, strengthening the evidence for diagnosis.

The diagnostic criteria for FASD have been refined and made more objective since Smith and Jones (1973) first described the syndrome. FASD is now conceptualized as a spectrum of related diagnostic categories; classified along a continuum, ranging from cases of full Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neurodevelopmental Disorder (ARND), to Alcohol Related Birth Defects (ARBD) (Clarren & Smith, 1978; Connor & Streissguth, 1996; Stratton, et al., 1996; Streissguth, 1994; Streissguth, et al., 1996, Streissguth & Kante, 1997; Streissguth & O'Malley, 2000).

Currently, two major published sets of diagnostic criteria are being used to evaluate and categorize individuals prenatally exposed to alcohol. Both criteria have retained Jones

and Smith (1973) triad of impairments, along with confirmation of maternal use of alcohol during pregnancy. The first set of criteria was published by the Institute of Medicine (IOM) in 1996 as a result of a mandated study on FASD by the US congress (Hoyme et al., 2005).

The IOM criteria defined five categories for diagnosing FASD.

- Category 1 – FAS with confirmed maternal alcohol exposure.
- Category 2 – FAS without confirmed maternal alcohol exposure.
- Category 3 – Partial FAS with confirmed maternal alcohol exposure.
- Category 4 – Alcohol-related birth defects with confirmed maternal alcohol exposure and the presence of consistent physical anomalies.
- Categories 5 – Alcohol-related neurodevelopmental disorder with confirmed maternal alcohol exposure and neurodevelopmental abnormalities and / or behavioural or cognitive deficits (Stratton et al, 1996).

The second widely used diagnostic criterion; ‘the 4-Digit Diagnostic code’ was published by Astley and Clarren in 2000. These diagnostic criteria are commonly referred to as the Washington criteria because they were devised through reviews of the medical records of 1014 children diagnosed with FAS through the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (Hoyme et al., 2005). The diagnostic criteria reflect the magnitude of expression of the key diagnostic features. The degree of expression of each feature is ranked independently using a four-point Likert scale to provide a numerical reference to the absence or presence of certain FASD characteristics, with (1) representing the complete absence of the feature and (4) representing a classic presentation of the feature (Astley, 2004; Astley & Clarren, 2000).

*Issues in diagnosis of FASD in adolescents and adults.* Although considerable attention has been given to the diagnosis of FASD in recent years, clinicians and researchers in the field have often focused on diagnosing children, with limited research available regarding the issue of diagnosing adolescents and adults suspected of having FASD. Many researchers in the field have revealed that FASD may go unrecognized, misdiagnosed, and underreported in adolescents and adults. In fact, the available data (e.g. Clarke, 2003; Clark, et al. 2004; Lutke, & Antrobus, 2004) on adolescents and adults suggest that adults and the majority of adolescents are rarely formally diagnosed or evaluated, with only a small fraction seeking and obtaining help for impairments associated with FASD.

Adolescents and adults with FASD often come to the attention of health care professionals and others in the field because they become involved with social services and the legal system. Fetal alcohol spectrum disorder causes significant problems for many adolescents and adults, particularly in areas of work, school, and parenting; yet health practitioners and other social and health professionals have difficulty referring them for the proper assessments needed to gain a formal diagnosis of FASD.

Anecdotal evidence indicates that diagnosing FASD in adolescents and adults can be a complex process requiring special considerations (Chudley et al., 2005). In discussing this issue, researchers (e.g., Stratton, et al., 1996; Streissguth et al., 1996) noted that diagnosing FASD in adolescents and adults is a particularly difficult challenge for a number of reasons, but primarily because the physical features (facial features) that are common in children with FASD quite often disappear by the time children become adults. According to Streissguth, et al. (1991), facial appearance begins to normalize with age as continued slow

growth of face, chin and nose through adolescence compensates for underdevelopment of the mid-face. To complicate matters further, a large percentage of adolescents and adults affected with FASD have one or more coexisting conditions that may affect diagnostic and treatment decisions. Prevalence rates taken from the Streissguth et al. (1996) study for the most common co-morbid diagnoses are 61% ADHD, 51% depression, 35% substance abuse disorder and 29% psychotic symptoms. Other co-morbid disorders associated with adult FASD are conduct disorder, oppositional defiant disorder, attachment disorder, and pervasive developmental disorder.

Furthermore, differences in FASD among ethnic minorities remain understudied and are not mentioned in the IOM criteria or any guidelines. Cross-cultural differences in physical features may account for some differences in prevalence rate that have been noted among different ethnic groups. These differences have important implications for diagnosing FASD across cultures and have not yet been fully elucidated.

Despite the recent criteria by the IOM and the Washington criteria (Astley & Clarren, 2000), a number of concerns continue to complicate the diagnosis of FASD in adolescents and adults. The Washington criteria, for example, place much emphasis on the encephalopathy and neurobehavioural disorders present among affected children. These two findings, Hoyme and others claim, “are not specifically defined and as general terms they are not unique to prenatal effects of alcohol on fetal development” (Hoyme et al., 2005, p. 41).

One of the most challenging decisions for a primary care clinician, social worker, or other health and social service worker is when to refer an adolescent or adult for assistance in the diagnostic process. Indications for referral to other professionals might include

possible dysmorphic features, mental retardation, and psychosocial issues. Clearly, immediate referral to a diagnostic centre is needed for adolescents and adults suspected of having FASD. However, in practice, many adolescents and adults are not referred for diagnosis.

### *Epidemiology*

The limited availability of information regarding adolescents and adults with FASD means that detailed epidemiological data are difficult to find. For example, data concerning the number of individuals with FASD who have children are not routinely collected and, at present, there are no national survey data available about the number of parents with FASD in Canada. However, this lack of data may not be unique to Canada. Studies from the USA and Europe seem to indicate that no statistics are available to indicate what proportion of individuals affected with FASD are parents. The fact that parents with FASD have not been collectively identified as a group that may require some additional assistance in their parenting roles may be because the multiple levels of care-giving responsibilities required by parents with FASD often fall on their partners and extended family members, particularly grandparents, siblings and other relatives. Ignorance or oversight on the part of health and social service professionals, stigmas, and an unspoken denial of sexual activity and consequent child bearing among individuals affected with FASD is a likely contributor. In addition, attitudes still prevail in society that children of parents with developmental disabilities may be at increased risk of neglect or abuse; therefore, parents with FASD are quite often reluctant to approach the Ministry for Children and Family Development for support, or to discuss the need for help with parenting skills because of the fear of losing custody of their children (Glaun & Brown, 1999; Rutman, LaBerge, & Wheway, 2002).



Many different estimates of the number of individuals with FASD have appeared in the research literature. Currently, the Canadian Pediatric Society estimates that the number of people with FASD in Canada is 1-6 per 1000 (Canadian Pediatric Society, 2002; Health Canada, 1996; Roberts & Nanson, 2000). According to Szabo (as cited in Russell, 2002), as many as 520,000 babies are born in Canada each year; of these, approximately 1040 are born with FAS and approximately 5,200 are born with other alcohol-related birth defects. Research has indicated that incidence of FASD differs across Canada with some areas having much higher rates than others (Boland et al., 1998). In BC, the estimated incidence rate is said to be 1 in 500 births. This translates to approximately 96 children being born each year in BC with FAS (based on approximately 48,000 births per year). However, if all forms of alcohol-related birth defects are included, the resulting figure would be closer to 1 in 20 children (BC FAS Resource Society, 1998; Nanson, Bolaria, Snyder, Morse, & Weiner 1995).

Although there are no research studies specifically looking at the incidence and prevalence of FASD among different racial/ethnic communities, higher incidences of FASD have been noted in some Aboriginal groups (Abkarian, 1992). Sandor et al., (1981), and Bray and Anderson (1989), drawing from a study conducted by Asante et al, in 1985 illustrates high incidence rates among Aboriginals in some communities in BC. In the Sandor et al. study which consisted of 76 patients (69 of which were Aboriginal ancestry) in the Yukon Territory and British Columbia, a 10.9 to 1 ratio of Aboriginals with FAS to Caucasians with FAS was found. Similarly, Asante and his colleagues assessed 586 people in 36 Aboriginal communities in Yukon Territory and BC. Their results indicated that the prevalence of FAS and FAE combined was 46 cases per 1000 in the Yukon and 25 cases

per 1000 in BC and that prevalence rates for non-Aboriginals in these areas were 0.4 cases per 1000 (Bray & Anderson, 1989).

Although the studies mentioned previously have suggested that some of the northern communities in BC have larger FASD populations than other communities in Canada, the reported prevalence rates should be interpreted cautiously. One should bear in mind that these figures may be determined more by socio-cultural variables such as socio-economic status and drinking patterns than by racial or ethnic differences. In a recent Health Canada report, Clarke and Tough (2003) stated that the designs, sample sizes and populations used in these studies must be considered when prevalence statistics are interpreted. Furthermore, according to Clarke and Tough (2003), the prevalence and detection of alcohol use among populations, detection bias based on the socio-economic status of study population, ethnicity of study population, access to a qualified diagnostician, criteria used for diagnosis, and the methodological approach used for finding incident cases should be considered. Central to the diagnosis of FAS is prenatal alcohol exposure. Hence, if the method of identification of alcohol exposure relies on birth record data, the potential to miss cases exists as many women are not identified as having consumed alcohol during pregnancy. Moreover, the central nervous system and physical features that identify children may not be evident at birth (Clarke & Tough, 2003).

#### Adolescent and Adult Outcomes of FASD

This section presents an overview of the adolescent and adult outcomes of FASD. The kinds of adaptive problems that an adolescent or adult with FASD is likely to encounter will be discussed. Literature examining the long-term consequences of prenatal alcohol exposure is limited. Most of the research on the subject has been done by

Streissguth and her colleagues from the University of Washington in Seattle. The patterns of social and behavioural functioning, which often change in presentation with development, range from mildly impaired (e.g., difficulty interacting with peers or family members) to severely abnormal (e.g., physical aggression, mental retardation). Further, while some have difficulty with memory and cannot perform basic everyday activities such as cooking, a small percentage have higher functional capabilities and adaptive skills that enable them to ride a bus, follow concrete instructions and so on. Regardless of the level of functioning, all these individuals share basic disturbances in social, cognitive and behavioural functioning (Streissguth & Kante, 1997; Matson & Riley, 1995). The results of these studies suggest that FASD adolescents and adults are likely to perform significantly more poorly than non-FASD adults on global measures of mental ability.

The small number of studies that have pertained to adolescents and adults with FASD have evaluated the physical, cognitive, behavioural, and social functioning of these individuals into adulthood. For instance, Streissguth and Kante (1997) noted that 50% to 65% of diagnosed children continue to experience difficulties with core clinical symptoms and related behavioural problems as adults, with only a small minority estimated to be well functioning adults, somewhat free of psychiatric problems.

#### *Physical Characteristics over Development*

It has been shown that various developmental domains are affected by prenatal alcohol exposure (Streissguth, 1994). However, characterization of physical features associated with FASD in adulthood has been more difficult. The physical features which best differentiate adults with FASD from those without FASD are microcephaly, short stature, thin upper lip, smooth philtrum, and malformed or malaligned teeth (Streissguth et

al., 1991; Streissguth et al., 1988). Moreover, studies of the outcome of FASD in adulthood revealed that the facial morphology of many persons with FASD changed as they mature; with the small nose and small chin of childhood giving way to a very elongated face with a large nose, a large chin, and coarse features (Lemoine and Lemoine as cited in Streissguth & Kante, 1997; Streissguth, 1994).

More compelling data supporting this postulate are provided by Spohr and Steinhausen (1987), and Spohr, Willms and Steinhausen (1993) studies. Both studies reported that developmental changes occur in adolescents with FASD. Lessening of the growth deficiency and changes in dysmorphic features associated with FAS as individuals matured physically were noted. In Berlin, Steinhausen, and his colleague followed a group of children with FAS as they grew older; their findings have validated the diminished specificity of facial features and growth deficiency that has been reported with increasing age (Steinhausen, Willms, & Spohr, 1993).

Further, a complimentary study by Streissguth et al. (1991) of the long-term consequences of FAS in adolescents and adults showed that the physical features of FAS change after puberty. Sixty-one individuals ranging from age 12 to 40 (mean age 17 years) took part in the study. Four characteristics of the facial phenotype were noted: (1) continued growth of the nose in two dimensions (height of the nasal bridge and nasal length from root to tip); (2) continued growth of the midfacial region corrected the earlier midfacial hypoplasia; (3) improved soft-tissue modelling of the philtrum and upper lip; and (4) continued growth of the chin. In terms of growth deficiency, 75% of the adolescent and adult patients with FAS were growth deficient for weight, 84% were growth deficient for height; and 72 % were microcephalic. Furthermore, Novick and Streissguth (1996) also

found that by the time individuals with FASD reach adulthood, many of the physical characteristics were no longer apparent.

### *Executive and Cognitive Functioning*

Executive function, ascribed to the basal ganglia and frontal lobes, is an umbrella term used to describe functions such as planning, working memory, impulse control, inhibition, shifting sets, strategic plan of action sequences, mental representation of task, problem solving for the attainment of future goal, interference control, integration across space and time, and selection of appropriate responses in the face of competing and contextual inappropriate alternatives (Pennington & Ozonoff, 1996).

Recent work in the area of FASD research suggests that dysfunction of the executive system is widespread in adolescents and adults affected with FASD. According to the California Fetal Alcohol Spectrum Organization (2004), “Cognitive deficits are among the top difficulties FASD adolescents and adults cope with. Chronologically they may be much older than their cognitive age. Although they appear like they would understand consequences and the ramifications of their actions after repeated attempts to learn, professionals working with FASD individuals find they just don’t get it” (p. 2). It has been suggested that deficient executive functions such as planning, organizing, abstracting, impulse control, integration across space and time, strategic plan of action sequences, interference control, selection of appropriate responses in the face of competing and contextual inappropriate alternatives, and working memory may be primary cognitive deficits of FASD (Bookstein, et al, 2002; Connor, Streissguth, Sampson, Bookstein, & Barr, 1999; Sampson et al., 1997). Since executive functions such as planning, organizing, and integration are integral to normal processing of information in the environment; the

impact of executive dysfunction may be great for this population. This has led to the suggestion that executive function deficits may be responsible for a wide range of behaviour in adolescents and adults with FASD. One of the most widely used tests in the studies of executive functioning has been the Wisconsin Card Sorting Test (WCST). Investigation by researchers such as Connor et al. (2000) and Streissguth et al. (1996) have documented that the WCST performance of adolescents and adults with FASD is deficient relative to matched controls.

In a study looking at executive functioning, Connor et al. (2000) used a battery of tests (Stroop, Trail, Wisconsin Card Sorting, Ruff's Figural Fluency, and Consonant Trigrams) to compare 30 men who had been diagnosed with FASD with adults participating in a longitudinal prospective study ( $n = 419$ ) and 15 control participants. The findings suggest that executive functioning in FASD patients is impaired as the scores obtained on these tests appeared to be particularly sensitive to the effects of prenatal alcohol damage. Problems with language, attentional and memory processing, learning, and cause and effect have been noted as well. Researchers using the Peabody Picture Vocabulary Test found that, on average, written and verbal communication skills and expressive and receptive language skills were at the level of an eight year old and that adults with FASD often encountered difficulties understanding and interpreting information presented orally (Boland et al., 1998; Connor et al., 2000; Kerns, Don, Mateer, & Streissguth, 1997).

Recent neuropsychological investigations, as well as other findings from recent studies at the University of Washington, suggest that adults with FASD demonstrate limited cognitive abilities, which may be responsible for their functioning at lower levels. Virtually

all adults with FASD show specific cognitive deficits, even those with an IQ in the normal range (Kerns, Don, Mateer, & Streissguth, 1997).

### *Psychosocial and Emotional Functioning*

Studies indicate that adolescents and adults exhibit significant psychosocial deficits including poor occupational functioning, early childbearing, social difficulties and poor peer relationships, poverty, lowered life satisfaction, increased adversity, substance abuse and criminal arrest. Kleinfeld, Morse and Wescott, (2000), LaDue et al. (1992), and Rutman et al. (2002) have observed that adults with FASD have a hard time figuring out what is going on in social life and how they should behave in different situations. They exhibit difficulties in basic social-communicative behaviours such as an inability to sustain reciprocal relationships, which is most easily seen in the absence of friendships with peers, and difficulties in understanding affective states. Deficits in verbal comprehension are demonstrated in limited ability to reason and conceptualise information, limited knowledge of conventional standards of behaviour, poor social judgment, immaturity, and poor common sense. The Vineland Adaptive Behaviour Scale (VABS) has been used in recent studies to measure social and adaptive development. The daily living, socialization and community skills of individuals in the Ladue et al. (1992) study were evaluated. The work of Ladue and his colleagues illustrated that patients performed most poorly on socialization skills. For adults with FASD, it may be that the same cognitive deficits that make it difficult to process language, for instance, also make it difficult to process social information effectively. Failure to anticipate the consequences of their actions, lack of appropriate initiative, difficulty perceiving and understanding subtle social cues, inability to care for their children, and impulsivity were some of the other problems that were common to

patients with FASD who were technically not mentally handicapped according to IQ scores (Ladue et al., 1992).

In fact, in an extensive 4 year study examining the occurrence of secondary disabilities, Streissguth et al. (1996) provided evidence suggesting that adolescents and adults with FASD have problems with their psychosocial adaptation. It was noted that these adults did not appear to be functioning at a level of self sufficiency and independent living; rather they were often relegated to positions of dependence, having continually to look to others to have their needs met. A life history structured interview was given to the primary caregiver of these individuals to measure six secondary disabilities. The results showed that secondary disabilities (see Table 2) were abundant. More than 95% had mental health problems, more than 60% had a disrupted school experience, 35% had alcohol and other drug problems, 80% lived dependently, and 80% had problems with employment (Streissguth et al., 1996).

In one of the first studies looking at psychiatric diagnoses of individuals with FASD, Famy, Streissguth, and Unis (1998) made crucial discoveries that led them to suggest that adults with FASD suffer from substantial mental illness. Using the Structured Clinical Interview for DSM-IV Axis I Disorders and Structured Clinical Interview for DSM III-R Personality Disorders, they interviewed 25 adults who met the criteria for FASD and who had an IQ greater than 70. The results showed that 18 of the 25 subjects had received psychiatric treatment. The most common Axis I disorders were alcohol or drug dependence ( $n = 15$ ), depression ( $n = 11$ ), and psychotic disorder ( $n = 10$ ). The most common Axis II disorders were avoidant personality disorder (6 subjects), antisocial personality disorder (4 subjects) and dependent personality disorder (3 subjects).



Moreover, feelings of unhappiness and /or depression and suicidal ideation appear to be common among individuals affected with FASD. This may be particularly likely to occur in “better functioning” individuals with FASD, as they are painfully aware that they are different from others. A few develop a strong desire for friendship but may be totally unable to establish social relationships because they lack the necessary skills. Of interest in the study by Streissguth & Kante (1997), were the findings of a strong association of adult FASD with depression and attention deficit hyperactive disorder (ADHD) where the prevalence of the disorder was more than 50% for depression and 40% for ADHD. Furthermore, high suicide rates were reported among adults with FASD (40% were reported to have made suicide threats at some point and almost 25% made suicide attempts). Although there are no known studies examining the effects of comorbidity of FASD with depression, ADHD and other mental disorders, anecdotal evidence points to less positive social outcomes and may be related to high rates of psychopathologies that are exhibited by adolescents and adults with FASD.

In addition, the literature hints that low IQ and behaviour disorders are also related to each other. Some sort of overlap may exist between the psychosocial functioning (attention, dependency, daily living skills and personal communication) of FASD adolescents and adults and the cognitive measures (IQ and achievement).

### *Behaviour*

At the behavioural level, the most striking and consistent behavioural features identified in adolescents and adults with FASD are attentional and hyperactivity problems that include inattention, overactivity, and impulsivity (Clark et al., 2004; Streissguth et al., 1996). This leads to many adolescents and adults with FASD being labelled with attention

deficit hyperactivity disorder (ADHD). Literature suggests that these individuals may be susceptible to engaging in socially maladaptive behaviour which, in extreme cases may lead to criminal offences. Outcome studies by Streissguth and her colleagues (1996, 1997) reported a number of behavioural problems in individuals affected with FASD. They are unable to plan ahead, finish tasks, or be fully aware of what is going on around them. To their family and co-workers they seem to exist in a world of disorganized activity.

Lemoine (as cited in Streissguth, 1994) described persistent behavioral problems that prevent individuals affected with FASD from effectively using their intellectual potential and even their manual skills. He reported from his clinical observations that patients with FASD demonstrated problems with sustained attention or the ability to continue a task until completed. This inattention, in turn, gives rise to difficulties with work completion, forgetfulness, poor organization, distractibility, immaturity, considerable instability, and refusal to cooperate. Restlessness and hyperactivity concealed their lack of assurance and initiative and their need for assistance and protection.

As many as half of the participants in the Streissguth et al. (1996) study displayed significant behavioural problems, defiance, and antisocial acts such as stealing and vandalism. The most common maladaptive behaviours were attention/concentration deficits (77%) and impulsivity (57%). Similarly, Clark et al. (2004) found that 65% of the participants in their study had ADHD. More generally, 60% of the participants in the Streissguth et al study had been in trouble with the law, which was defined as ever being charged, convicted, or in trouble with the authorities for any of a list of criminal behaviours; while 50% had been incarcerated. Adults with FASD were more likely to have

been incarcerated than to have been in an inpatient mental health or alcohol and other drug treatment program (Streissguth et al., 1996).

Other maladaptive behaviours that may be associated with the increased involvement of individuals in the criminal system include teasing/bullying (53%), lying, cheating, or stealing (49%), being negativistic or defiant (43%), intentionally destroying own or another's property (25%), and being physically aggressive (19%). Further, a significant proportion of the participants from the Streissguth et al. (1996) study had legal problems including petty larceny (28%), grand larceny (4%), vandalism (27%), drunk driving (23%), and stealing (35 %). Clearly, the level of maladaptive behaviors among this population is high and presents a great challenge to the management of these individuals (Streissguth, et al., 1991; Streissguth, et al., 1996; Streissguth & Kante, 1997). These behaviours cannot be looked at in isolation without also considering the social, cultural, environmental, and developmental factors that are likely to have significant impact on the expression of both psychiatric and behavioural disorders in adolescents and adults with FASD. Stressors may be multiple and include loneliness, poverty and joblessness.

#### Parenting by Individuals with FASD

In the following section, issues of parenting by adolescents and adults with FASD are discussed. Parenting by people with FASD appears to be a difficult area to research. There is limited research on individuals with FASD who have children and data concerning the number of people with FASD who are parents are not routinely collected. Parents affected with FASD do not represent a homogeneous population, therefore, parents are likely to display varying degrees of functional abilities, with some requiring help while others may require minimal or no help. Moreover, many parents who have FASD are either

not receiving services that would identify them as having FASD, or they are not identified by the service system or program in which they participate. As such, most parents come to the attention of service providers because they have lost custody of their children or are actively seeking re-custody of their children. Finally, those working with parents with FASD have difficulties with proper assessments and effective treatment and intervention programs for such parents.

The following review drew on research on parents who are mentally ill and those who have other developmental disabilities (e.g., mental handicap and learning disabilities), as well as research from the literature on adolescents and adults with FASD. It should, however, be recognized that the research on parents with mental illness or other developmental disabilities is not representative of parents with FASD, but the functional abilities and experiences of mentally ill and / or handicapped parents may be similar to the functional abilities and experiences of parents affected with FASD.

From the literature reviewed, it became apparent that there were three distinct aspects, which had direct bearing upon the parents of this study as it relates to their parenting role. These were parental adequacy and competency, child outcomes, and social and ecological aspects. However, before a discussion of these aspects can occur, it seems fitting to address the question: what is parenting and what does parenting involve?

#### *What is Parenting and What Does Parenting Involve?*

It is difficult to discuss parenting without having experienced the challenges and pleasures involved in child-rearing. According to Kendziora and O'Leary (1993), parenting is "anything the parent does, or fails to do, that may affect the child" (p.177), and includes "playing, disciplining, teaching, caring for physical needs, and establishing a pleasant

emotional environment” (p.176). In the same vein, Turner and Helms (1979) described parenting as one of the most important, most exciting developmental challenges individuals encounter. On the one hand, having a child in the household is characteristically a joyous occasion. For those who have experienced this event, words cannot capture the feeling of pride, pleasure, love, and warmth that family members can share. This, of course, represents a comfortable situation.

On the other hand, what seems to capture the general situation is Burr’s (1976) statement that the transition from a dyadic to a triadic (i.e., child and two parents) relationship is one of the most complex, confusing and dramatic changes most people will ever make in their lives. It involves not only being responsive to the child’s needs, but being a model for the types of behaviour the parents wish the child to acquire, being a monitor of the child’s behaviour and environment, as well as being a mentor for the child as he/she learns and grows, to prevent problems from occurring along the way. For example, for one parent a child may represent not only a task but also an achievement. Words like a ‘blessing’, or ‘beautiful’ are frequently used to conjure feelings. For these parents, every development is an event worth looking forward to. For others, parenting is a paradoxical feeling. While it represents a challenge, it is also a source of insecurity and emotional turmoil and there exists uneasiness in knowing that a person is completely dependent upon him/her for support and survival (Turner & Helms, 1979).

Symbolically, parenting as a construct means responsibility for another or having the capacity to support the growth and development of their children. Parenting calls for the execution of new tasks and reorganization of daily routines. It involves an intense interplay between parent and child cognition and between parent and child emotional reciprocity.

The responsibilities associated with parenting are numerous and diverse. The first and most obvious obligation is maintenance; that is, the parents are responsible for supplying their children with food, clothing, and shelter. Other responsibilities include providing the children with continual attention, love, protection, secure attachment, nurturance, guidance, and a sense of family, language, and identity.

Historically and traditionally, parenting meant a mother and a father taking care of children, each with distinct roles, but with the common goals of providing food, safety, shelter, and guiding the children's cultural and moral development into positive outcomes by responding consistently and appropriately to their children's needs. Richardson (1993) claims that earlier generations of parents were primarily responsible for looking after the physical survival, moral welfare and development of their children. In some cultures, parenting involved a bidirectional relationship between members of two or more generations, extending through all or major parts of the respective life spans of these groups. Parenting is embedded in the history of a people as that history occurs within the natural setting within which the group lives (Ford & Lerner, 1992). In other cultures, it meant a "yard"<sup>2</sup> taking care of children's needs. In every culture, it could also mean a single man or woman assuming the role of both parents and maintaining contact with the child by holding, cuddling, looking at and speaking to the child, as well as meeting other needs of the child.

From a sociological, psychological and anthropological viewpoint, many scholars view parenting as being responsible for a children's developmental outcome. In this view, a

---

<sup>2</sup> Yard- composed of about six or seven households made up of mothers and fathers, aunts, grandparents, cousins in a some what symbiotic or cooperative relationship with each other being responsible for taking care of the needs of the children

parent erects a structure of parental support and guidance around the children's behaviour throughout the developmental process.

Moreover, Ainsworth and Bowlby's (1991) theory of attachment suggests that parenting reflects a behavioural system promoting survival and competent functioning. These theorists suggest that parents establish a secure base for children over the first year of life by being sensitive to cues emitted by infants, addressing the infant's needs, and providing emotional regulation. In the same vein, Hinde (1989) claims that parenting is a dynamic process, embedded within relationships, affected by preceding interactions and future expectation. It involves adaptation to changing children and changing environments over time.

Today the concept of parenting has evolved dramatically and ideas about parenting change quickly (Arendall, 1997; Richardson, 1993). Preoccupations with present world systems (changing environments, increasing cost of basic needs, transformation of social organization, transportation, migration, changes in family structure, and community systems) and modes of survival have fundamentally altered the state of the family. Trends in marriage, divorce, sexuality, teenage pregnancy, and fertility have altered family structure and stability while variation in cultures (norms, behaviours, attitudes, institutions that exist) and variation within and across generations, particularly with respect to child rearing, have shifted the nature of parenting, thus impacting the type of parenting practices that are encouraged and constrained (Bowes & Haynes, 1999).

In addition, the emergence of children's legislation such as the Convention on the Rights of the Child, child welfare legislation, and child acts have also impacted the way parents and society in general view their roles. There seems to be a stream of consciousness

that shifts the central role of parenting from merely supporting each child's natural unfolding of development to one that involves a complex and challenging set of responsibilities that are different from those experienced by previous generations. Today parents, especially mothers, are responsible for their children's social and intellectual competence, cognitive and moral development, and self-esteem (Richardson, 1993). Richardson called this the new job description of parenthood, which subsequently makes parents the target of blame when things go wrong. Moreover, there seems to be increased encroachment of governments and institutions within the family structure. In some cases, there is an explicit recognition of the responsibilities of 'government as parents'; while in other cases there is a 'partnership' and 'consultation' relationship with parents. This has resulted in an even greater shift in the concept of parenting as it relates to role / definition and who can parent. Together, these changes have led to a blurring of traditional parenting practices and roles.

Government social services are driving a number of initiatives to enhance the quality of parenting and child and family welfare, including articulating and monitoring good standards of care. Reder and Lucey (1995) claim that this is based on the view that the main goal of parenting is to raise children safely so that they become productive members of society as reflected in healthy interpersonal, emotional, and social development. Considerable emphasis is placed on the importance of parenting as it relates to children's outcomes. Social science research, mostly in the area of psychology, has highlights the parent's role as a major influence in child development (Richardson, 1993). Positive outcomes for children are associated with a number of parenting behaviours including



protection, support, encouragement, emotional warmth, and positive role modelling (Davies, 1999).

### *Parental Adequacy and Competency*

The concepts of parental adequacy and competency now play a central role in contemporary definitions of parenting. According to Azar and Benjet (1994), and Azar, Lauretti and Loding (1998), these concepts largely influence decisions regarding children's needs and custody issues within the context of the child protection system.

Adequate parenting requires an emotionally sensitive and responsive adult who has the ability to form an attachment with a child, plan and organize a home, ensure safety and provide adequate care, nutrition, shelter, and medical care (Ainsworth, Blehar, Waters & Wall, 1978; Bornstein, 1995). Similarly, the concept of 'parental competency' is often described as requiring significant cognitive and adaptive capabilities, including the ability to process information and make judgments, to use language for accurate communication, logically assess and solve problems, retain information, and make decisions after having considered probable consequences and outcomes. As such, there is a general consensus that parental adequacy involves a number of activities including: sensitivity to the child's needs, positive emotional expression, child-centred interaction, provision of resources for healthy growth and development, predictable routines, a safe environment, appropriate sensory stimulation, and appropriate boundaries and limits in family interaction (Ainsworth et al., 1978; Bornstein, 1995; Hurley, Chiodo, Leschied, & Whitehead, 2003).

It's within the context of these frameworks that the parenting capacity of parents with developmental disabilities is often scrutinized (Feldman, 1994). Greater variations have been observed in their parenting behaviours compared to the parenting behaviours of

parents without developmental disabilities. They are widely presumed to present a high risk of parenting breakdown and their children are cited as being at risk for developmental delays, maltreatment, and neglect (Booth & Booth, 1994). Thus, for parents with FASD involvement with their children becomes particularly important in accounting for differences in child well being.

While we cannot yet examine the full extent of the effect that a parent affected with FASD may have on children's well being with the data we have available, the discussion below will provide some insights into what can be anticipated, and likely outcomes for children whose parents are affected with FASD if adequate support is not given.

*Literature on adequacy and competency in other groups of parents.* Historically, parents with developmental disabilities have been regarded as being unable to fulfil normal social roles such as parenting. For example, Anthony, as cited in Westbrook & Chinnery, 1990) wrote that a disabled father tends to function as a non entity or a younger sibling, while a disabled mother is perceived as a greater source of danger in the family because she is unable to perform her socio-emotional role of promoting family security and solidarity (Westbrook & Chinnery, 1990). Thus, parental adequacy has been a major focus for researchers (Feldman, 1986) because much concern has been expressed about the ability of individuals with developmental disabilities to adequately care for their children. The common assumption is that these parents will at some point neglect their children since they lack the intellectual abilities to handle the complexities of child-rearing, particularly in providing a safe, nurturing, and stimulating home environment and in being able to handle emergencies.

In one study, Feldman (1986) compared eight mothers with a history of mental handicaps interacting with their children with a group of non-handicapped mothers interacting with their children. His findings revealed that mentally handicapped parents demonstrated significantly less overall interaction with their children on five maternal behaviours than did non-mentally handicapped parents. The non-mentally handicapped mothers, as contrasted with the mentally handicapped mothers, were more interactive with their children, issued more verbalizations to their children, and praised their children significantly more. In addition, mentally handicapped mothers were less responsive to their children's vocalization. From a social research perspective, this study highlights what we may consider to be ineffective child rearing practices and suggest that parent-child interaction affect the probability of delayed development in children raised by parents with FASD if appropriate support is not given to the parents.

A number of studies have reported incompetence among most parents with developmental disabilities; however, other studies have found that the majority of parents with developmental disabilities were providing adequate care. Tymchuk, Andron, and Rahbar (1988) conducted a multiple baseline study examining the decision-making abilities of mothers who were mentally handicapped. Further, the authors examined the effects of the training mothers received from the study on the appropriateness of the decisions made by these mothers. Using child-care situational vignettes drawn from the experiences of the mothers who were part of a parenting project, Tymchuk and his colleagues trained nine mothers to follow a six-step decision making model and assessed what decision they would actually make in a given situation. The results demonstrated that parents with mental handicaps could learn to apply basic parental skills. For example, the authors noted that

while all mothers always made rapid decisions before training, decision making after training was more deliberate. Moreover, the appropriateness of decisions made improved significantly from baseline to the end of the training for the subset of training vignettes designated as high risk. Tymchuk and his colleagues noted that improved decision making was maintained at a one month follow-up (Tymchuk et al, 1988).

The existing research on parents with developmental disabilities must be viewed cautiously because these parents are not necessarily representative. The range of definitions used, and the differences in the weights given to some measurement tools over others pose some problems for research on parenting. The skills and abilities vary from one individual to the next and most of these individuals have, at the very least, experienced poverty, unemployment, and other mishaps (Gath, 1988). Many are parents, already identified by child protection agencies as having serious difficulties and needing assistance (Wald, 1975). Further, Booth and Booth (as cited in Llewellyn, 1994) noted that researchers have failed to listen to the parents themselves and to represent parents' views, experiences, and needs.

*Literature on adequacy/competency in parents with FASD.* Although specific literature concerning parenting by individuals with FASD is scarce, anecdotal evidence drawn from adolescents and adults with FASD, as well as literature on parents with other developmental disabilities (e.g., Streissguth, et al., 1996; Feldman, Case & Sparks, 1992) suggests that parents with FASD are likely to experience a number of parenting difficulties. These include failure to adjust parenting styles to changes in their child's development, lack of verbal interaction with the child, insufficient cognitive stimulation especially in the area of play, a tendency to over generalize instructions, inconsistent use of discipline (and in

particular, a reliance on punishment at the expense of praise), a lack of expressed warmth, love, and affection in the relationship (Feldman, Case et al., 1992). These parenting deficits put their children at risk for neglect, maltreatment, environmentally-related developmental delay, and behavioural problems (Feldman, et al., 1992; Feldman, Case, Towns & Betel, 1985).

An example from Page (2002) provides a useful illustration of how parents with FASD may demonstrate low parenting capacity.

At a show-cause hearing in Texas not too long ago, the parents of a tiny baby removed from their custody brought in a photo album to document their parenting skills and dedication to the child. The judge took the album, started flipping through the pages, and called the bailiff over. There, on the first page, was a picture of the baby, sitting in a carrier on the kitchen table—nestled amid an assortment of glass pipes, powdery little baggies, and other items not normally associated with exemplary child rearing. As he leafed through the pages of adorable smeary smiles on family outing, another shot caught the judge's eye: dad apparently swinging the 6-weeks-old baby by the foot. Asked to explain this behaviour, dad said, "I was holding the baby and reached into the fridge for a beer. I started to drop the beer, so I dropped the baby instead." This baby has since been adopted by a loving family whose first task was to have his several bones fractures (suffered on different occasions) repaired. His birth parents continue to complain bitterly about "Big Brother's" interferences in their family life. They give no indication of ever understanding why the baby was removed from their care (p.1).

This case description brings into perspective the gap in competencies that are likely to be displayed by parents affected with FASD.

The co-morbidity and trajectory of FASD suggests an increased risk that adolescents and adults with FASD will show signs of difficulty in coping with their parenting role. As such, child-rearing issues and social issues that confront parents with FASD may be more perplexing and are more complex than those encountered by parents who are not affected by FASD. The support that a parent with FASD may need to provide for his/her child and family can cause dilemmas for support services. For example, the fact

that adolescents and adults with FASD have problems with the abstraction and generalization of materials hints that parents with FASD may experience some difficulties with instructions on, for example, labels. Thus, they may be unable to make appropriate decisions or to ensure that the child's physical and safety needs are met.

Furthermore, although to the researcher's knowledge there has been no research that examines intelligence and parenting by people with FASD, some researchers (e.g. Tymchuk & Andron, 1990) have suggested that the provision of safe and adequate child care requires a minimum level of intellectual capacity, although it is unclear what that level actually is. For the most part, studies have not produced a convincing correlation between IQ and parenting capacity, although it has been suggested that when intelligence falls below the mildly handicapped category, parenting competency is brought into serious question. In a review of parent training programs for the intellectually disabled, Ray, Rubinstein, and Russo (1994) identified a group in which cognitive and other disabilities of the parent seemed too great to overcome. Such parents were able to do particular tasks in isolation but could not cope with the accumulation of parenting demands and the organizational skills involved in matching these demands to the needs of the child.

In addition, the gap in education that is usually seen in adolescents and adults with FASD due to disrupted school experiences (e.g., drop out, suspension, expulsion) (Streissguth et al., 1996) may have implications for the way these individuals parent. These parents may lack knowledge concerning appropriate developmental expectations and effective positive strategies for child management which, according to Feldman and Walton-Allen (1993), increases the risk of child abuse, as well as behavioural, emotional, and social maladjustment.

Education is significantly linked to both playing games such as “peek-a-boo” and reading to the child. Thus we can draw the conclusion that well educated parents are more likely to play games and read with their children than are parents with less education (Carlson & McLanahan, 2001). As such, children born to parents with FASD are likely to be regarded as being at substantial risk and consequently, these parents may come into contact with child protection services and lose custody of their children (Lutke & Antrobus, 2004). A common outcome of losing custody is court-ordered parent attendance at family support or parent education services as a condition of keeping the child or proving parental competence to regain child custody (Taylor et al., 1991).

Furthermore, FASD is a disorder that affects one or more of the basic processes involved in understanding or using written or spoken language. Specific deficits were noted by Steissguth et al (1996). Adolescents’ and adults’ ability to listen, think, speak, read, write, or to do mathematical problems were limited. They had trouble integrating information and understanding cause and effect, all of which are essential to an individual functioning independently and making decisions that are relevant to the child’s well being.

Moreover, although depression and mental illness have not been systematically addressed in parents with FASD, Streisguth et al. (1996) noted that mental illness, depressive affects, and more severe incidents involving suicide attempts were prevalent among adolescents and adults with FASD. This may have some significance when considering issues or concerns as it relates to parenting by individuals affected with FASD. Researchers such as Cunningham, Benness, and Siegel (1988) and Zahn-Waxler, Iannotti, Cummings, and Denham, (1990) have frequently associated depression with impairments in parents’ child management techniques. In comparison to non-depressed parents, depressed

parents have been reported to be more inconsistent, lax and generally ineffective in monitoring children's misbehaviours and administering discipline. Discipline strategies that required the least effort tended to be used by depressed mothers. Depressed mothers, according to Fendrich, Warner and Weissman (1990) and Kochanska, Kuczynski, Radke-Yarrow and Welsh (1987), are more likely to avoid conflict by submitting to their child's non-compliance, but when not yielding to the child's demands these mothers use more forceful control strategies and are less likely to end disagreements in a compromise. Problems are also created by depressed parents alternating unpredictably between lax and harsh but frequently ineffective attempts at coercion. In addition, Bugental and Cortez, (1988) noted that depressed mothers who believe they have little power to control events in their lives do not deal effectively with uncooperative children. Thus, a depressed parent's negative impression of him or herself can influence his/her behaviour towards his/her children, making him/her more critical and selectively attentive to their misbehaviour (Cramer, 1987).

Gelfand and Teti (1990) identified various mechanisms that can occur within the depressed mother-child relationship to place the child at risk for behaviour problems: (a) modelling of mother's depressed facial expressions, altered motor behaviour, and faulty causal attributions and evaluations of self; (b) decreased positive reinforcement for the child plus inconsistent, coercive discipline practices; (c) insecure child attachment due to mother's insensitivity and disengagement; (d) indirect effect of mother's depression through its effects on her marital relationship, family stress and social isolation which then influence the child's behaviour.



Given that 51% of the participants from Streissguth et al., (1996) and 47% of the participants from Clark et al. (2004) were depressed, the possibilities are great that the quality of parenting by an adolescent or adult with FASD is likely to be compromised. Adolescents and adults with FASD experience all of the challenges faced by parents without FASD (e.g., attempting to balance the roles as parents, spouses, their own development, and work). They also face the challenge of managing cognitive/executive dysfunction in which the symptoms tend to interfere with the basic tasks (e.g., supervision and interaction) that are central to the care giving role, which inhibits their ability to maintain a balance in the home.

Streissguth et al. (1996) provided some interesting data on problems with parenting as experienced by individuals with FASD. They found that between 30% to 45% of parents in the study had their children removed by child protection services or gave up raising their children. Based on this study, we might predict that children of parents who are affected with FASD are likely to be at great risk of abuse and neglect. In part, this is because adolescents and adults remain vulnerable and may find it difficult to protect their children. However, it must be acknowledged that parents with FASD can abuse their children, as can parents without FASD (Clark et al., 2004; Streissguth et al., 1996).

#### *Parental Competency and Child Outcome*

Research to date suggests that child outcomes are linked to parenting competencies. Kendziora and O'Leary (1993), for example, noted that children exposed to harsh and explosive discipline have been found to be at greater risk of developing disruptive behaviour. While the direct effects of parental FASD and child outcomes are yet to be disentangled, existing research on other groups of parents with developmental disabilities

and research on adolescents and adults with FASD to date hints at less than optimal parenting and higher levels of developmental and psychosocial problems in children of parents with FASD.

According to Levine (as cited in Bornstein, 1991) parental behaviour must be considered in its socio-cultural context. It has been suggested that a competent parent will be competent only within his/her own culture (Bornstein, 1991) as the differences in child rearing practices across cultures are multifaceted and include dimensions such as care taking, stimulation, hygiene, choice of toys and so forth. In addition, parents' self-efficacy and perceptions of developmental processes vary across cultures. Thus, it is important to look at normative parenting beliefs and behaviour towards infants and belief-behaviour relations among different Canadian cultural groups in order to gain a better perspective of the factors which influence infant development and parenting.

*Parental competence and child outcome in other groups of parents.* In a study examining court records of more than 200 abused or neglected children and their families, Taylor et al. (1991) concluded that intellectual and emotional impairment among parents is a significant factor contributing to neglect and abuse. Parents of low intelligence were more likely than parents with high intelligence to be reported for child maltreatment and or to have their children permanently removed from their care. This, however, begs the question of whether parents with developmental disabilities are scrutinized more carefully because of their social class as well as other socio-economic factors and also, whether the reports are suggestive of the parents' isolation or lack of knowledge regarding child care and development. This is further collaborated in a study by Kaatz (1992) who argues that children of mentally retarded parents are at risk of nutritional problems due to inappropriate

nutrition and poor feeding schedules. She also points to the parents' inability to recognize medical needs of their children due to cognitive limitations.

More compelling data, supporting the postulate that children of parents with developmental disabilities are at risk of child abuse and neglect, is provided by Feldman, 1998; Feldman, Case, Garrick, MacIntyre-Grande, Carnwell and Sparks, 1992; Feldman, Case, & Sparks, 1992. These studies reported that often the parents' lack of knowledge and skills result in their children suffering from: (a) untreated diaper rash; (b) malnourishment (due to improper feeding techniques, formula preparation, and/or nutrition); and, (c) gastrointestinal infections (due to poor or absent baby bottle cleaning and sterilization techniques). Based on their findings, the children are endangered when, for example, the parents do not know how to hold or bathe the child safely, make the home environment safe, provide emergency first aid, or when to take the child for medical treatment.

A review of study done by Gillberg and Geijer-Karlsson (1983) noted that 7% of children were reported to have been subjected to 'neglect/abuse'. In line with Gilberg and Geijer-Karlsson, Mickelson's (1947) of 90 family cases found that 26% of the families were rated as having provided "unsatisfactory" care. This term is defined by the author as meaning "either that the children had been removed as neglected... or that their care was sufficiently poor to justify consideration of such action" (Mickelson, 1947, p.645).

In contrast to the previous results, other studies such as, Brandon (1957) claim that mothers with developmental disabilities were not precluded from having the capacity to provide love and affection for their children. He also suggested that women with learning difficulties may possess the capacity to successfully carry out housekeeping duties. To substantiate this claim, Hertz (1979) made reference to the common institutional practice of

employing mentally handicapped residents to perform cooking, cleaning, laundry and other household work for the institution.

Booth and Booth (1994) contended that on the surface the results from several studies appear to lend support to the idea that mothers and fathers with developmental disabilities characteristically exhibit a range of skill deficits that makes it difficult for them to function as competent parents. However, A closer examination of their personal stories may reveal a more complex picture that suggests any such unqualified interpretation may seriously misrepresent their experience. These parents normally have living conditions that are substandard, are single parents, and do not have the necessary social support network (Feldman, 1986). Consequently, their limited experience of family life or lack of parenting models is reflected in their behaviour (Gath, 1988). In addition, Brantlinger alludes to the effects of confounding variables such as social class (poor socio-economic circumstances, inadequate incomes, unemployment, and poor vocational skills) as opposed to the developmental disability itself (as cited in Booth & Booth, 1994).

It is therefore difficult to assess the extent and/or effects of parental abuse on the children of developmentally disabled parents. Dowdney and Skuse (1993) argue that, "Unrepresentative sampling and methodological problems in many studies make it difficult to estimate the extent of child abuse by mentally retarded parents" (p. 30). The practice of sampling from biased populations, such as those parents who have previously been referred to social agencies in relation to parenting problems, immediately increases the likelihood of there being a higher rate of child abuse and neglect than in the general population. Further, reported cases of child abuse and neglect may be complicated by the fact that studies to date generally fail to define the concept of abuse. Thus, when interpreting the evidence from

these studies, we should bear in mind that the reported cases are based on the subjective perceptions of, for example, doctors, spouse, teachers, caseworkers, and neighbours and may be clouded by biases from labelling this population.

*Potential for negative child outcome in parents with FASD.* Over the last couple years, parenting by adolescents and adults with FASD has provoked some concerns and attention is now being paid to issues concerning adolescents and adults with FASD due to frequent evidence of negative social, vocational and educational outcomes for these adolescents and adults. Research reviews (e.g., Connor et al., 1999; Sampson et al., 1997; Streissguth, et al., 1996) have found that adolescents and adults with FASD display cognitive deficits and other behavioural dysfunctions. Thus, managing their FASD, advocating for themselves and their children, taking steps necessary to ensure their wellbeing, quality of life, and positive outcomes for their children may drain individual and other resources. For example, obtaining services and support, implementing routine, and maintaining relationships require time, energy, adaptive and social skills that are often lacking in parents with FASD. In aggregate, these observations strongly suggest that childcare may be unpredictable and inconsistent, thereby leading to attachment and behavioural issues.

Psychological problems associated with adolescents and adults with FASD such as depression, mental illness, and substance abuse are also likely to have important implications for children. As is indicative in several research reviews of parenting, children of parents who are experiencing psychological problems are at greater risk for a range of psychosocial and developmental problems and are probably less likely to benefit from mainstream parenting efforts.

Results from the Streissguth et al. (1996) longitudinal study show that approximately 94% of adolescents and adults with FASD have a mental health problem.

Another finding with significant implication for parents with FASD is the study by Clark et al. (2004), which found that 92% of the participants in the study had a mental health problem. Thus, the likelihood exists that dependent children of parents with FASD will manifest problems in cognitive, social and emotional development.

In fact, since 94% of the parents in the Streissguth et al (1996) study and about 92% of the Clark et al. (2004) studies had problem with mental illness, we can usefully begin this discussion by considering the large body of literature documenting the effects of parental depression and parental mental illnesses on children's well being. Abramson, Metalsky and Alloy (1989), Beck (1967), and Cicchetti, Rogosch, Toth, & Spagnola (1997), observed that abnormalities in cognitive, biological, socio-emotional, and representational developmental systems are often present in varying degrees among individuals with mental illness or depression. This, they believe, exposes children to sad and dysmorphic affect, cognitive confusion, helplessness, hopelessness, and irritability that consequently leads to problems in development. The adverse impact of parental mental illness and depression also appear to be mediated by negative behaviours that these parents frequently direct towards their children in that depressive symptom that often occur act as a catalyst for the display of various negative parental behaviours (e.g., yelling, and spanking) and a reduced frequency of positive behaviours (e.g., hugging, reading and playing).

In other studies, communication difficulties, including less mutually responsive patterns of interaction between depressed women and their 13-to-29-month-old children compared to non-depressed mothers and their children were observed (Stein et al., 1991). At age 2, children of depressed mothers were noted as having more difficulty with emotional regulation. Their self-esteem tends to be lower, they show more aggressive

behavior toward their parents and peers at ages 3-5 years, and display more negative affect towards others at ages 5-7 (Alpern and Lyons-Ruth 1993; Lyons-Ruth, Easterbrooks & Cibelli, 1997; Nolen-Koeksema, Wolfson, Mumme & Guskin 1995; Sinclair & Murray 1998; Zahn-Waxler, McKnew, Cummings, Davenport, & Radke-Yarrow, 1984). Further, young children of depressed mothers are at risk for insecure attachment with the mother (DeMulder & Radke-Yarrow, 1991; Lyons-Ruth, Zoll, Connell, & Grunebaum, 1986; Murray, 1992; Radke-Yarrow, Cummings, Kuczynski, & Chapman, 1985; Teti, Gelfand, Messinger, & Isabella, 1995).

Moreover, many of the characteristics identified by Bolton, Laner, and Kane (1980), Kinard and Klerman (1980), and Zuravin (1988) tend to be associated with perpetrators of child maltreatment, neglect, and abuse (e.g. low educational achievement, low IQ, depression, mental illness, inappropriate sexual behaviours, poverty, substance abuse, history of abuse, and living in substandard housing) are also true of adolescents and adults with FASD. Consequently, this may contribute to the assumption that adolescents and adults with FASD are likely to abuse or neglect their children.

Although research investigating the association between parents with FASD and parental child maltreatment is difficult to find, questions may be raised concerning the ability of adolescents and adults with FASD to provide appropriate nutritional care for their children. A documentary done by the Knowledge Network that looked at FAS in adolescents and adults highlighted patterns of forgetfulness among this population. The authors of the documentary noted that a network of family was needed to help young adults affected with FASD care for their children as these parents are likely to forget to feed their

children and are likely to forget the procedure for preparing a meal (Knowledge Network, FAS Community Resource Center, 2002).

Another frequently identified correlate of child abuse and neglect is low educational attainment of the parents (Milner & Chilamkurti, 1991). Low educational attainment is associated with difficulties in abstract reasoning, problem solving, and flexibility in understanding children's behaviour. Cognitive deficits, along with poor academic achievements are said to be typical of adolescents and adults with FASD. In the Streissguth et al., 1996 study, about 90% of fathers and 80% of mothers had disrupted school experience. Thus, it is reasonable to assume that when the head of the family is an adolescent or adult affected with FASD, the children have an elevated probability of experiencing neglect and abuse, as well as negative developmental outcomes.

Although there is substantial research linking mental illness, depression, substance abuse, low education, and cognitive deficits to impaired parenting, no research in this area has been conducted with parents affected with FASD. For example, depression and parenting have not been studied in individuals with FASD. Thus, the findings from these studies are only suggestive of the likely outcomes for children of parents with FASD.

### *Social and Ecological Aspects*

A number of measurable social and environmental correlates have been noted as potential influences on parenting capability. Among the most central are gaps in social support, socio-economic status, living in neighbourhoods with few social and economic opportunities, parental stress, including stress relating to needs of a child, an ability to sensitively read and respond to the child's cue, culture, and interpersonal factors such as troubled relationships, and history of abuse. Booth and Booth (1993) suggest that parents with developmental disabilities can face a 'double' jeopardy. They are likely to raise their families



under conditions of adversity such as poverty, unemployment, inadequate housing, the stigma of having a disability, single parenthood, and poor marital relationships whilst at the same time being more susceptible to the stresses resulting thereof.

More generally, adolescents and adults with FASD are far more likely to be more socially and economically deprived than the general population. This is reflected by their complex financial situations, such as receiving little or no disability benefits, lack of employment, inadequate and poor level housing, lack of transportation, lack of education, and a reduced ability to pay for socialization activities (Lutke & Antrobus, 2004). Thus, people with FASD are unable to exercise choices in how their financial resources are allocated in terms of housing, education, leisure pursuits, childcare, living expenses, or other important life activities. Given the limited disposable income, they are neither able to adequately provide for their own needs, nor their child's needs and subsequently the children are likely to become vulnerable to negative outcomes. Further, individuals with FASD are vulnerable to rapid, unplanned changes in their environment and may have difficulty assimilating new environmental contingencies into their life space. As a result, parents may be reluctant to seek help or do not have the organizational skills necessary to access services.

Over the years a considerable body of research literature has accumulated on social support networks of people with developmental disabilities. Lack of support (family, friends, and institutions) has been implicated as a possible contributor to a parent's inability to appropriately care for his/her child. Support systems, such as the proximity of family or the guidance of friends or neighbours, also influences parental competency (Leach & Braithwaite, 1996; Miner & Uhlenberg, 1997). Parents who have assistance with the responsibilities of parenting fare far better than those who do not. This assistance might be

in relation to caring for a child or it might be in the form of advice or a sounding board for parents who may be uncertain as to what they should do in a given situation (Fauber, Forehand, Thomas & Wiersen, 1990).

The encouragement of a person's spouse or extended family is such a crucial determinant of parental competency that it has generated a plethora of research and is believed to be the foremost contributing factor in parental competency (Belsky, 1984; Belsky, Crnic, & Gable, 1995). As one might conclude, such a relationship would greatly affect a person's self esteem, stress levels, and entire support system. If the relationship provides a certain sense of confidence for parents, it will reinforce their ability and efforts to be competent parents. If the relationship proves dissatisfying, then parental competency tends to decrease (Belsky & Isabella, 1985).

The discussion above, along with anecdotal evidence, hints that parents with FASD and their children are at risk of long-term disadvantage due to a lack of education and adaptive skills, social isolation, financial difficulties, and other environmental variables experienced by adolescents and adults with FASD. This, in turn, has significant economic and social implications for society in general. Although it is not clear how because of limited research in the area, we can assume that the quality of parenting by individuals with FASD is likely to be less competent as compared to individuals without FASD. Therefore, the negative impact of socio-demographic variables (e.g., poverty, low education, homelessness) cannot be understated.

## **CHAPTER THREE**

### **METHOD**

#### **Overview**

This chapter will provide a brief overview of the research methodology, explain the rationale of that methodology, and describe the methods used to collect data. This study has employed a variety of data collection techniques including focus groups and a combination of in-depth and semi-structured interviews. Information has been obtained from Northern Health Authority caseworkers, parents with FASD, and their advocates.

In view of the range of geographical, demographic, cultural and community context within which the study participants live and work, the researcher considered it important that the questions addressed be grounded in the everyday experiences of living with FASD as well as working with FASD issues. Thus, a study, which sought to identify FASD parents' needs without examining the context in which those needs arise, is likely to elicit abstract ideas based on resources already available. For this reason, data were collected within a qualitative paradigm comprising in-depth interviews with parents themselves and their advocates and a series of focus group discussions with family caseworkers.

The focus group of case workers was conducted to provide initial insight into and corroboration of the contextual issues contributing to parenting experiences, service utilization, and outcomes for themselves and their children. Caseworkers who work for NHA were selected because they were viewed as having knowledge of the daily lives of parents with FASD.

### Rationale of the Method

This study is a needs assessment of parents with FASD. Needs assessment is about collecting information that will give a good indication of a particular group's or community's demands and lay the essential foundation that will facilitate decision-making in policy, service planning, and delivery. A needs assessment has the distinct advantage of allowing researchers and professionals in the health and social science fields to engage in the process of assessing the needs, opportunities, readiness, capacity, and resources necessary to initiate changes in already existing programs as well as develop and implement new ones (Bradshaw, 1972). Despite the various levels of analysis afforded by a needs assessment, this study will only focus on assessing the needs of parents with FASD. Assessing parents' needs is essential to provide information that will help to determine whether:

- Current services and initiatives are responding appropriately to parents with FASD;
- There is a gap in service, training, education, and support for parents with FASD;
- New services are necessary to remove existing inequities, and how
- Community structures affect the general quality of life for parents with FASD

This research study employed qualitative methods for collecting data as qualitative methods are recognized as increasingly important methods in social research and can be powerful tools for understanding the social, community, and cultural dynamics that may not be immediately discernable by other methods such as surveys (Avis, Bond, & Arthur, 1997; Callery, & Luker, 1996; Pope, Ziebland & Mays, 1999).

## Participants

### *Service Providers*

A total of nine participants took part in two focus groups (  $n = 5$  and  $n = 4$ ). All were experienced in working with parents and families deemed *at risk*. Their years of experience ranged from 3 to 35 years. These workers comprise the occupational group who have close contact with, and provide support for the families, and whom the family members themselves may consider to be their most important source of support.

### *Parents*

There were 3 participants involved in the interviews. All three were mothers who had been using the services of the Northern Family Health Society at the time of the study. The participants ranged in age from 22 to 28 years, with an average age of 24.3 years.

### *Advocates*

A total of three advocates took part in the study. The average age of the advocates was 43.3 years with a range of 27 to 54. The criteria for a person to be considered an advocate was that he/she is helping the parent in the parenting role, does not have FASD, and is above the age 18. This cut off age was chosen to avoid including minors in the study and to ensure that advocates selected for participation in the study are in a position to comment upon the parents' life situations and parenting skills.

## Measures

### *Service Providers*

The data from the focus group discussion were gathered in three different ways in order to achieve a detailed analysis of the opinion of service providers on the needs of parents with FASD. A 20 item focus group question guide (See Appendix A) based on

guidelines suggested by Morgan (1998) and Stewart and Shamdasani (1990), demographic self-administered questionnaires that were answered in a forced choice and agree/disagree format, and a debriefing form were used to assess service providers perceptions (See Appendix A). Essentially, the debriefing form was used to give participants another chance to add any detail that they were not comfortable discussing as a group and to comment on the session strengths and weaknesses as well as the participants' responses to the focus group meetings.

The demographic questionnaire was developed to obtain background information about the service providers in order to substantiate the workers' knowledge and ability to comment about parents with FASD, to obtain qualitative information that could not be addressed in the discussion because of time constraints, and to understand the group dynamics. Section (1) of the demographic questionnaire was included to obtain information about service providers themselves, such as what is their professional background, who they work for, and their years of experience working with families. Sections (2) and (3) were included to ascertain how people work with parents with FASD and their opinion of the structure and content of services provided to parents with FASD. The questionnaire sought to establish what activities they were involved in, what sources of information and support they used, and what resources they would like to see developed for parents with FASD. A debriefing form (Appendix A) was designed for the facilitator to record information about the discussion at the end of the session.

### *Parents*

To facilitate an environment conducive to free and open discussion by parents and their advocates, semi-structured interviews were used (See Appendix B for Guidelines to

Interview). The instrument contained two parts designed to gather valuable qualitative data. The first part was used to identify demographics and other background information, including the number of children parents have. The second section was used to identify services currently used by parents and parents' perceptions of their support and service needs. The questions, affording both closed and open-ended responses, were designed to be understood by participants with low literacy skills.

### *Advocates*

A questionnaire to obtain information on the needs of parents with FASD was designed. The questionnaire was organized into three sections. The first section was developed to obtain demographic variables about the advocates. Section 2 contained a combination of open and close-ended questions used to guide the interview, and section three contained a table to obtain information about advocates' opinions on parents' daily living skills. The items in the table covered a broad domain of: (a) communication skills, (b) domestic activities (shopping, cleaning house, money management, cooking, home safety for children), and (c) social and community adaptation (ability to solve problems, access health care, interpersonal skills). Refer to Appendix C for a guide to the interviews with advocates.

## Procedure

### *Service Providers*

Participants for the focus group discussion were recruited through the Northern Family Health Society. Potential participants were contacted and asked if they would like to participate in the study and an information letter (Appendix D) was sent to all potential participants. After receiving feedback from potential participants about their interest in the

study, suggested dates and times were sent to all participants so that they could select a date and time that was convenient for all. Once the date, time and place were scheduled, and at least one week prior to the scheduled session, participants were sent a copy of the key questions and demographic questions to be addressed. The focus group ran for approximately 1 to 1 1/2 hours. At the beginning of the discussion, the researcher provided an overview of the process. This included an explanation of the purpose and background of the study and what the participants were expected to do as part of the study. The researcher then established the group guidelines, including those relating to confidentiality, a reminder that there are no right or wrong answers, clarification that all comments and opinions are welcome, and a reminder that any participant was free to leave the group at anytime. Participants were also informed of a follow-up session (confirmatory focus group) following the analysis of these first sessions and that they would again be contacted to participate in it. The purpose of the confirmatory focus group was to allow the participants to hear and respond to the preliminary results of the research, thus giving the participants an opportunity to confirm, clarify, and expand the findings.

Before obtaining consent to participate in the study, the researcher asked the participants if they had any questions or concerns they would like addressed. Consent and willingness to participate in the study were obtained and participants were then asked to sign a consent form (Appendix E). The researcher's thesis supervisor facilitated the first focus group. Participants' responses were recorded on audiotape and handwritten notes were taken on note taking forms prepared by volunteers who were trained about focus group and note taking procedures. After the first focus group, feedback was collected on the basis of answers to the debriefing summary form (See Appendix F), which was designed



for use by the research team. Some of the questions were subsequently revised to allow for more in-depth discussion and richer, qualitative data. A follow-up session was held with group one. With the second group, the revised version of the questions was used. A follow-up session was not conducted with the second group due to their work schedules and time constraints and because they felt that the first session provided them sufficient opportunity to discuss their perceptions and ideas about the support and service needs of parents with FASD.

### *Parents*

Parents were recruited through Northern Family Health Society (NFHS; Refer to Appendix G). Service providers at NFHS were given information packages about the study. Potential parent participants were approached by Northern Family Health Society caseworkers who explained the study. The contact information for parents willing to participate was given to the researcher. According to the preferences of the participants, one parent was interviewed at home and two were held at the agency. The interviews ran for approximately forty-five minutes to one hour. The researcher began each interview by providing the participants with detailed information about the study, including the purpose and procedure, in order to reduce any concerns they might have about the interview process. Participants were informed that they were free to change their mind about being in the study at anytime, in which case all notes and records about him/her would be destroyed. Participants were also informed of the option of a follow-up interview once the data had been analysed. This would give them a chance to review and validate the information drawn from the first interview. All participants opted to skip the follow-up interview citing that they were satisfied with the outcome from the first interview.

Before obtaining consent to participate in the study, the researcher asked the parents some questions to check for comprehension of information and concluded that all participants comprehended sufficiently to give informed consent themselves. The researcher verified participants' consent and willingness to participate in the study and asked them to sign consent forms (Appendix H). The researcher began the interview by asking demographic questions to describe the characteristics of the participants as well as to establish rapport and to give the participants practice at answering questions. The next section of the interview focused on the individual's views regarding their needs as parents. In this section, each interview started with an open-ended question asking parents to describe what it is like to be a parent. Specific/probing questions were sometimes asked to obtain further information or clarification about the content of the information given. Additional comments from parents were noted against each item. At the end of the interview, an open-ended question asked if parents had anything else they would like to suggest or talk about with regard to their service and support needs other than what we had talked about. One interview was audio-tape recorded; however, the other two were not audio recorded because the participants appeared uncomfortable with the idea, thus in order to create a comfortable environment the research decided not to audiotape. In-depth notes were taken at all interviews.

### *Advocates*

Advocates were recruited through the Northern Health Society and by asking the parents if there was anyone who helped them in their everyday parenting that would be interested in the study. Potential participants were contacted to see if they would be interested in taking part in the study. After the initial contact, potential participants were

sent an information package (Appendix I). Once the participants expressed an interest and a willingness to participate in the study, interviews were scheduled at a time convenient for all participants. The interview ran for approximately one hour. One interview was conducted at the home of the advocate, one at the agency, and the other at a selected location chosen by the participant. The researcher began the interviews by providing the participants with detailed information about the study; including the purpose and procedure. Participants were informed that they were free to change their mind about being in the study at anytime; in which case, all notes and records about him/her would be destroyed. Participants were also informed of the option of a follow-up interview once the data had been analyzed which would give them a chance to review and validate the information drawn from the first interview. All participants opted to skip the follow-up interview citing that they were satisfied with the outcome from the first interview. Once participants had a chance to review the details of the study and ask questions, consent to participate in the study was solicited. A consent form (Appendix J) was then signed by the participants. After signing the consent forms, demographic data were collected. The interview proceeded with a combination of open and close-ended questions. At the end of this segment of the interview, participants were given a table that looked at the daily living skills of the parents and were asked to provide a response they felt appropriately suited the said parent. In-depth hand-written notes were taken in all the interviews on note taking form designed for the purpose of the interview. Two of the interviews were audio-taped; the other was not audio-taped due to physical location constraints.

## Data Analysis

### *Stages of Data Analysis*

In order to synthesize the data into a logical and coherent whole, the analysis process was based on guidelines as set forth by Colaizzi (1978) and Osborne (1990). Although a lengthy and arduous process, this specific form of analyzing the data was considered ideal because it allowed the researcher to remain close to the information that was gathered and sensitive to the common themes that eventually emerged.

First, immediately after each interview, the audio-tape was carefully listened to and reviewed in an attempt to gain an awareness of the experiences and issues as it relates to parental needs described by the study participants. Each interview was transcribed and was then read in its entirety several times. Second, the purpose of the study was reviewed to help identify key questions that the analysis should answer. The data was then organized by questions to look across all respondents and their answers in order to identify consistencies and differences between participants.

Third, the significant statements, paraphrased meanings, and thematic descriptors were identified and placed into coherent categories. This was essential in order to capture the unique experiences of parents and to compare experiential similarities and differences among participants.

Fourth, patterns and connections both within and between categories were identified. Information pertaining to particular themes was summarized and similarities and differences within categories were also captured. The various themes that emerged from each were reflected upon, and reviewed to ensure consistency. This process provided a way of understanding the essential structure of each category.

Thematic clusters were developed which involved clustering identified parent themes into three main themes. The first main theme was placed in tabular form (needs matrix) with the inclusion of general phrases. These descriptions reflect the essence of the experience within the prepared themes of each participant group. Data was further triangulated. Triangulation has been broadly defined as "...the combination of methodologies in the study of the same phenomenon" (Denzin, 1978, p.291). Triangulation was done by data source (e.g., service providers, parents, and advocates), as well by methods (focus group and interview). This allowed the researcher to measure the construct in a more proximal manner, thus allowing a clearer understanding of the issue.

#### *Service Providers*

After every focus group, all the data were transcribed and coded with focus group identity codes and the date of the focus group discussion. Each group was assigned a colour. Coloured stickers were used to mark the groups' tape for easy identification. The stickers were also used to mark the sides of the tapes that had already been used so as to safeguard against taping over already recorded information. Duplicate tapes were made for back-up purposes. The researcher reviewed the transcript using the audiotape to verify its accuracy. Verbatim transcriptions were then analyzed for thematic content and coded items were grouped by themes as patterns among items became apparent. The handwritten notes were also reviewed and compared to transcripts in order to establish consistency among emerging themes. Descriptive statistics were employed for all demographic data.

#### *Parents and Advocates*

Detailed notes, including as much verbatim material as possible, were taken of each interview. Data analysis was initiated after all of the participants were interviewed. A

thorough review of the notes was undertaken to allow the researcher to become familiar with the data. For the interview that was audiotaped, the tape was transcribed and the transcripts compared with written notes to cross-check and verify accuracy. The data were then organized by interview guide question to allow the researcher to look across all participants and their answers in order to identify consistencies and differences.

Participants' comments were coded and responses categorized into emerging themes.

Patterns and connections between categories were identified and summaries were written.

### *Integrated Analysis*

The final analysis of the data then focused on drawing together themes across all the participants (i.e., parents, advocates, focus groups). Key themes that emerge across all the participants were drawn together, highlighting both similarities and differences in participants' experiences and accounts of the needs of parents with FASD.

## CHAPTER FOUR

### RESULTS

This section provides a synthesis of the findings from the data collected. The section begins by describing the demographic characteristics of the participants, as well as the qualitative data addressed within the demographic questionnaire. The information gathered through the demographic questionnaire served to expand on the data gathered from the focus groups and interviews. An integrated data analysis then follows. This section presents the key themes to emerge from the findings (i) the needs for services and support, (ii) desirable services and supports, and (iii) barriers to services and support. Each theme consists of several sub-themes and is illustrated where possible with quotes. The last part of the result section presents detailed analysis of the data with several general categories of parental needs, desirable service, and barriers to service delivery being discussed, in relation to this study and other similar studies.

#### Demographic and Background Data

##### *Service Providers*

The 9 service providers in the study represented a range of organizations involved in providing services to families including those affected with FASD. Among those involved were caseworkers from social service teams such as Project Parent North, Northern Family Health Society and Structured for Success. All the service providers who participated in the study were female. There were 5 participants 38 years of age and over, 2 participants 26 to 31 years, 1 32 to 37 years, and 1 between 20 to 25 years. The majority of the service providers who took part in the focus group had a professional background in social work. All considered themselves to have experience working with families, with years of

experience ranging from 3 to 25. The service providers also considered themselves as having experience, or some sort of background working with parents with FASD. This they substantiated by virtue of some form of workshop, training seminar, or conference on FASD, and their experience of working in social services for some time. All service providers stated that they have parents on their caseload who have, or are suspected to have, FASD.

Data were also collected on what group these organizations target, the various services offered by each organization, and their targeted outcome. From this, it appears that services such as mentoring and guidance, counselling, advocacy, family support, pre and post-natal education, referrals, child protection issues, and home visits are being provided by these organizations; two of the participants stated that their organization provides such services that specifically target individuals with FASD.

When asked what education and training they had received (if any) on supporting parents with FASD in pregnancy and parenthood, it was striking that none of the service providers had formal academic training specific to FASD. Most had acquired their knowledge through workshops, seminars, conferences, and other resource materials on FASD, as well as experience gained while working within their professional capacity.

Despite the lack of formal training, 7 of the 9 service providers indicated they worked with parents affected with FASD most days, 1 worked with the affected parents on a weekly basis, and 1 worked with parents with FASD once a month. The frequency of the different types of activity is presented in Table 3 below.



Table 3

*Frequency of Activities Undertaken by Service Providers*

Activity	Never	Rarely	Sometimes	Often
Advocacy on behalf of the parent			4	5
Assessment of parenting needs		2	2	5
Practical advice and support with developing parenting skills		2	2	5
Assessment of parenting skills		2	3	4
Parenting class or parenting skills training	2	1	2	4
Child protection issues		2	4	3
Vocational and other skills training	1	2	3	3

From these results, it would appear that the three most frequent activities undertaken were advocacy on behalf of parents, practical advice and support with developing parenting skills, and assessment of parenting needs. Child protection and vocational and other skills training were the least frequent. Additional activities undertaken by service providers are counselling, living skills, budgeting, relationship skills, cooking skills, cleaning and time management, priority planning. Service providers were asked to state if they agreed or disagreed with a number of statements concerning working with parents with FASD. The responses are shown below in Table 4.

Table 4

*Working with Parents with FASD*

Statement	Agree	Not sure	Disagree
There is little systematic planning of care for families where the parent is affected with FASD	9		
Professional interventions are usually 'crisis interventions'	9		
Parents with FASD can learn, but need specialized help	9		
Professionals require further training to properly assist parents with FASD	9		
Parents with FASD have low adaptive skills (e.g. home management, money management, time management etc.)	8	1	
Professionals are often unaware of what services are available	7	2	
Parents with FASD fail to anticipate the demands children will make on them	7	2	
Professionals focus on inadequacies of parents with FASD, rather than focusing on ways to help meet their needs	6	1	2

It can be seen that more service providers agreed with the statements than disagreed. The highest level of agreement was: (i) there is little systematic planning of care for families where the parents are affected with FASD, (ii) professional interventions are usually 'crisis interventions', (iii) parents with FASD can learn, but need specialized help, and (iv) professionals require further training to properly assist parents with FASD. Most service providers agreed that parents with FASD have low adaptive skills; professionals are often unaware of what services are available, and parents with FASD fail to anticipate the demands that children will make on them. Disagreement was recorded on only one statement; that is, professionals focus on inadequacies of parents with FASD rather than focusing on ways to help meet their needs.

Service providers believe that parents with FASD need appropriate service and support, believe that many service providers are unaware of what services are available, and require further training to assist parents.

Table 5 presents the service providers' views on the usefulness of specific service development. Special parenting projects for parents with FASD rated highest among service development considered useful. One-to-one support from organizations and agencies such as MCFD and family planning services specifically targeting parents with FASD were also rated as essential. In order to ascertain how organizations work with others to provide useful services for parents with FASD, service providers were asked to state the frequency of various service links. The most frequent service/support link was referrals from other agencies followed by inter-agency exchange of program, information and services. See Table 6 for details.

Table 5

*Usefulness of Specific Service Development*

Service development	No response	Useful	Essential
Special parenting project(s) for parents with FASD		1	8
More one-to-one support from organizations and agencies such as MCFD		2	7
Family planning services specifically targeting parents with FASD	1	1	7
Specialist assessments and referral of parents with FASD		3	6
Parenting skills group(s) for parents with FASD	1	2	6

Table 6

*Frequency of Service/Support Links*

Service links	Often	Occasionally	Never
Parents with FASD are referred to us by other agencies	6	2	
There is inter-agency exchange of program information and services	4	4	
We hold joint client consultation with other agencies	3	5	
We refer parents with FASD to other agencies	2	6	
There is collaboration with health care providers	2	6	

Service providers were asked to identify the strategies they use to provide services to parents with FASD (Table 7). Most participating service providers identify at risk parents and families, provide information and access to birth control, and promote referrals to other services. The small number reporting parent/family support programs is not surprising considering service providers have already noted that there is little systematic planning of care for families where the parent is affected with FASD.

The caseworkers were asked about the accessibility, appropriateness, and relevance of services, support and information provided to parents with FASD. Table 8 shows the responses. All service providers indicated that parents with FASD have problems accessing/using the services and support. Some of the reasons given are lack of understanding on the part of service providers, access protocol, and unrealistic expectations. Seven of the service providers believed that services, information and supports available to parents with FASD were not appropriate, citing that resources and service materials need to be simple, clear, and provided in more than one format to meet the level of parents with FASD. Five stated that the service, information and support given were not relevant.

Table 7

*Strategies Used to Provide Services*

Strategies	Number of service providers
Identify at risk-parents/families	9
Provide information and access to birth control	8
Promote prenatal/postnatal health care	8
Referral to other community services	7
Providing information and education about FASD	7
Home visits/outreach	6
Providing information about child care (e.g. healthy nutrition)	6
Transportation arrangements	6
Provide counselling	6
Accompaniments to appointments	5
Appointment reminders	5
Facilitating access to child care	5
Assist with job search	5
Parent/family support program	4

Table 8

*Information, Service and Support Accessibility, Appropriateness and Relevance*

Question	Response		Example of Reasons for answer	
	<u>Yes</u>	<u>No</u>	<u>YES</u>	<u>No</u>
Do you think that parents with FASD experience problems in accessing/using services and support?	9		<ul style="list-style-type: none"> <li>• Lack of understanding on the part of service providers</li> <li>• Access protocols</li> <li>• Expectation of agencies are unrealistic</li> <li>• Too difficult to access</li> <li>• Too many instructions</li> <li>• Transportation issues</li> <li>• Difficulty generalizing information</li> <li>• They have trouble remembering appointments</li> <li>• Having to make appointments is a barrier to accessing services sometimes</li> </ul>	
Do you think that services, support and information available to parents with FASD are appropriate?	Yes 2	No 7	<ul style="list-style-type: none"> <li>• There are some visual and low literacy information</li> </ul>	<ul style="list-style-type: none"> <li>• Resources and services need to be simple, plain , clear and provides in more than one format</li> <li>• Need more outreach</li> <li>• Need services that extent beyond 9am to 5pm</li> <li>• Too advanced</li> <li>• Few appropriate services...they need in home help with parenting but often families count is not an option because they have an open file with MCFD</li> </ul>
Do you think that service, support, and information available to parents with FASD are relevant?	Yes 3	No 5	<ul style="list-style-type: none"> <li>• The programs that are available are helpful</li> </ul>	<ul style="list-style-type: none"> <li>• Need to be targeted to individual capability and challenges</li> <li>• Not enough education in the community</li> <li>• Not enough access</li> <li>• Most services don't actually meet the needs, but one-on-one support is expensive and rare</li> <li>• Services are not specialized</li> </ul>

*Parents*

From the 3 participating parents, one reported a formal diagnosis of FASD, one of FAE, and the other suspected FASD. The average age of the participants was 24.3 years, with a range from 22 to 28 years. Two of the participants were in common-law relationships, while the other was a single mother. The parents had an average of 3.5 children whose ages ranged from 11 months to 6 years. Two of the participants reported dropping out of school in Grade 9, and the other participant reported having a college diploma. Two were Aboriginal and one Caucasian. Two were bilingual (one parent spoke English and her aboriginal native language and the other spoke English and sign language) and one spoke only English.

*Advocates*

The advocates ranged in age from 27-54 years with a mean age of 43.3 years. One participant was a common-law partner of the parent, one was the adoptive mother of the parent, and the other was an advocate of the parent. Two of the advocates were Caucasian and one Aboriginal. All three advocates had either Grade 12 or university and college level education.

*Analysis and Triangulation of Focus Group and Interview Data*

Parents with FASD, their advocates, and service providers identified three key themes: (1) parenting needs, (2) desirable services and support, and (3) barriers to services and supports. Major sub-themes were identified within each theme. The four sub-themes from parenting needs were: (i) domestic (e.g., housing, transportation & budgeting), (ii) parenting training and childcare, (iii) public and social service needs and (iv) formal and informal support. The three sub-themes from the desirable services and supports theme

were: (i) support network, (ii) public and social service, and (iii) new service model. The study participants identified five barriers to service delivery: (i) system level, (ii) lack of time, funding and personnel, (iii) lack of resources and education, (iv) service providers' skills, attitude and expectation, and (v) limited service, access to service and service coordination.

### *Parental Needs*

#### *Domestic Needs*

Parents with FASD were thought to need help with a number of practical or daily living skills that are pertinent to caring for children. The issues identified by all participants were: (i) housing, (ii) transportation, and (iii) financial support, money management and budgeting.

*Housing.* Across all participants there were reports of parents needing assistance with housing. Parents, in particular, identified the need for affordable housing opportunities. As one parent described it, "it is expensive to pay rent and all other things with just your welfare check...I applied for housing but I am on the waiting list".

Supportive housing appears to be a main concern for advocates and service providers as well. Another striking comment made was that parents with FASD require housing that is close to support services, social and family networks, shops, medical programs, recreation options, bus stops, and amenities that assist people with FASD.



*Transportation.* The prevailing feeling among all participants was that parents with FASD often experience difficulties with transportation. Service providers, parents, and advocates were concerned about those parents' ability to get from one place to the next, particularly to get to appointments. One parent commented that, "sometimes my mum gives me a ride to the grocery store or when I have to take the kids to the doctor; that really helps." Service providers and advocates noted that in most cases a parent's only means of transportation is public transportations otherwise they rely on their family members and friends for transportation. The availability of transportation, may to some extent, determine how accessible services such as health care, employment, and other services and programs are to parents with FASD.

*Financial support, money management and budgeting.* Service providers, advocates and parents all felt that help was needed with money management and budgeting. Parents mentioned not being able to adequately allocate their income efficiently. All parents reported some financial problems in the last year. Problems most frequently expressed were having bills, not being able to get things for their children, and having utilities disconnected for non-payment of bills. Service providers, parents, and advocates expressed the need for financial assistance and resources directed at parents with FASD on how to manage money so that they can develop skills that can help them balance their income and spending habits.

#### *Parenting Training and Childcare*

From the service providers', parents, and advocates' perspectives, parents needed to learn:

- i. How to discipline children, such as how to implement age appropriate discipline and adjust discipline to fit different situations;
- ii. More about child development and how to deal with the children's changing needs over time; and

iii. How to recognize when their children are *at risk*.

Of all the concerns raised, child discipline elicited the most discussion. In particular, parents asked for help to learn strategies to manage discipline (e.g., during play, to control fighting between siblings, to establish some standard in the home) without spanking. One parent said, “it’s getting harder now because the kids are getting older and they don’t listen to me...its frustrating and difficult sometimes.” Service providers were concerned with the ability of parents to use age-appropriate discipline. One service provider gave an example of a mother trying to use ‘timeouts’ for a baby that was only about 6 months old. She went on to explain how the parent expressed frustration because she felt that a ‘timeout’ was not working.

Parents talked about wanting to know more about the way their children developed. They reported needing help to manage and support their children as they grow physically, academically and socially. Their concerns related to their children’s needs both now and later. For example, parents discussed the idea of finding activities for their growing children to let them have fun and meet other children. One parent said, “You know, it would be nice if I had day-care or some kind of children’s group where she could go and play. She is at that age now where I think she needs to meet other kids her age.”

Advocates and service providers emphasized the need for parents to learn how to identify when their children are at risk. They noted that parents are not always attuned to situations that may place their children at risk because they quite often do not pick up on environmental cues. Service providers and parents went on to highlight the fact that parents are sometimes not able to say no to relatives or friends who abuse substances and are likely to expose their children to risk as a result of substance abuse.

One parent wanted to know more about how to raise children with disabilities such as ADHD and FASD. The idea of getting subsidized day care or help with day care was expressed by all participants. Activities for their children were another area perceived by parents and advocates where help was needed. Parents talked about activities for their children and being able to have their children in an area where they can have fun and meet other children. The need for respite so that parents can go out of the house more often and have a break from the children on a regular basis was emphasized by service providers and advocates. Service providers talked about having a foster family for the entire family. Parents also reported that they wanted someone to help them take care of the children. “Taking care of both is hard especially when they are both crying at the same time” one parent said.

#### *Public and Social Service Needs*

Participants discussed the need for a number of public and social services. All expressed the need among parents for employment opportunities, including job training, employment placement and education. All parents expressed interest in finding some form of employment to help themselves. Parents, advocates, and service providers emphasized the need for counselling to help parents through difficult times and other challenges they may encounter. There was also discussion of the need for low-cost access to birth control by service providers and advocates. They felt that parents with FASD had a great need for maternity support and mental health support, including substance abuse treatment, and other health care for themselves and children. The need for literacy was echoed across all participants. Participants felt that parents needed more education and literacy training. One parent describes herself as needing literacy because she is unable to help her child with

school work. “I can’t help my older kid with home work because I have problems with reading.” Service providers and advocates further discussed the need for outreach as well as legal assistance with regard to child protection issues, and regaining custody. They also highlighted the need for appropriate referral sources, such as physicians and nurses, who are familiar with FASD. For instance, service providers talked about the difficulties parents face when they are in the hospital or at the doctor’s office because nurses and doctors do not always understand them and parents, in turn, do not understand what is required from them.

### *Formal and Informal Support*

Developing supportive relationships with other people and especially with other parents was considered very important. One parent commented, “I would like to join some kind of parenting group or something so I can meet people with the same problem.” Another said, “it would be nice if there was a single parents’ group to go to.” Service providers as well as advocates noted that having some sort of support group is critical for parents as they are quite often isolated and have very little support network (i.e., friends or family) to assist them. They talked about needing opportunities to form social networks and allowing parents to be involved in the process of care that is required of them. The need to access mainstream services and to get information about services and support were also identified as major parental needs. Parents talked about needing more information about FASD on one hand and not being aware of the services that are available to them on the other. Further, parents were thought to be in need of advocacy due to some of the challenges they face when dealing with the public and social system. For example, service providers and advocates talked about assisting parents with practical things like filling out

forms, reading reports, making calls and referrals on their behalf, reminding parents of appointments, and driving them to appointments and programs critical to their parenting role.

### *Summary*

Table 9 summarizes the expressed needs for services and support from the whole study sample. Three key themes were identified and sub-themes were drawn from each theme bringing to the spotlight the needs of parents with FASD and how the services ought to be. Parents were thought to need help in a number of areas that included access to affordable housing, transportation, employment, education, information, benefits, recreational activities for the family, child care, respite care for children when parents need to take a break from parenting responsibilities, and support and advocacy for themselves and for their children particularly with the school system.

Table 9

*Needs Matrix*

Participants	Themes	
	Domestic	Parenting training and childcare
Service Providers	<ul style="list-style-type: none"> <li>• Subsidized housing/low-income housing</li> <li>• Home management training (house cleaning, grocery shopping)</li> <li>• Transportation</li> <li>• Money management</li> <li>• Help with budgeting</li> <li>• [Communication (e.g., telephone services)]</li> <li>• <b>Help getting organized</b></li> </ul>	<ul style="list-style-type: none"> <li>• Child management /care</li> <li>• Child developmental stages</li> <li>• Child discipline</li> <li>• [Medical emergency]</li> <li>• Daycare</li> </ul>
Parents	<ul style="list-style-type: none"> <li>• Better housing</li> <li>• Help with managing money &amp; budgeting</li> <li>• Home management skills</li> <li>• Transportation</li> </ul>	<ul style="list-style-type: none"> <li>• Help with childcare &amp; day care</li> <li>• Child development</li> <li>• Child discipline</li> <li>• <b>Help in finding activities for kids</b></li> </ul>
Advocates	<ul style="list-style-type: none"> <li>• Help with cleaning the house</li> <li>• Need help with grocery shopping, laundry etc</li> <li>• Need help with budgeting money</li> <li>• Adequate housing</li> <li>• Food</li> <li>• Transportation</li> <li>• [Time management]</li> <li>• <b>Help getting organized</b></li> </ul>	<ul style="list-style-type: none"> <li>• Help with taking care of kids</li> <li>• Day care</li> <li>• <b>Help in finding activities for kids</b></li> <li>• [Reminder so they don't forget to change kids]</li> <li>• Child discipline</li> <li>• Child development issues</li> </ul>

(table continues)

Table 9 (cont'd)

*Needs Matrix*

Participants	Themes	
	Public and social services needs	Formal and informal support
Service Providers	<ul style="list-style-type: none"> <li>• Literacy and education</li> <li>• [Need material that are easy to understand]</li> <li>• Need information and resources on FASD</li> <li>• Counselling e.g. Substance abuse treatment</li> <li>• [Mental health]</li> <li>• <b>Legal assistance</b></li> <li>• Health care (help with finding a family doctor)</li> <li>• [Information on pregnancy]</li> <li>• [Respite]</li> <li>• Financial support</li> <li>• <b>Outreach</b></li> <li>• Need help finding a job</li> </ul>	<ul style="list-style-type: none"> <li>• Support network (families, friends, peer support)</li> <li>• [Foster family to help the entire family]</li> <li>• [Provide a way for effective dialogue between parents and service providers]</li> <li>• Help finding support within the community &amp; using community resources</li> <li>• <b>Advocacy</b></li> <li>• In home support</li> <li>• <b>Ongoing support</b></li> <li>• <b>Someone to act as an external brain</b></li> <li>• <b>Help getting to and from appointments</b></li> </ul>
Parents	<ul style="list-style-type: none"> <li>• <b>Employment training</b></li> <li>• Information</li> <li>• Literacy and education</li> <li>• Health care</li> <li>• Financial support</li> <li>• Drug and alcohol counselling</li> <li>• Need help finding a job</li> </ul>	<ul style="list-style-type: none"> <li>• Support network (help with making friends)</li> <li>• Help finding activities for children / other resources</li> <li>• In home support</li> <li>• <b>Help getting to appointments</b></li> </ul>
Advocates	<ul style="list-style-type: none"> <li>• <b>Outreach</b></li> <li>• <b>Employment training</b></li> <li>• Information</li> <li>• Literacy and education</li> <li>• Counselling</li> <li>• Help in accessing services e.g. health care</li> <li>• Need help finding a job</li> <li>• <b>Legal assistance</b></li> <li>• Financial support</li> </ul>	<ul style="list-style-type: none"> <li>• Support network (friendship)</li> <li>• <b>Advocacy</b></li> <li>• [Help dealing with issues of poverty, neglect and isolation]</li> <li>• In home support</li> <li>• <b>Ongoing support</b></li> <li>• <b>Someone to act as an external brain</b></li> </ul>

*Note:* Highlighted items were mentioned by only 2 participant groups (e.g. Parents & Advocate, Advocate & Service provider, Service provider & parents). Items in parentheses were identified by only one participant group

### *Desirable Services and Support Needs*

Service providers, parents, and their advocates identified a number of desirable services and information that need to be developed or enhanced. In particular, advocates and service providers noted that a more comprehensive system of care needed to be implemented to help service providers better meet the needs of parents with FASD. They expressed some views that they felt would be a foundation for a good system of care and described the services needed to implement these principles. The three main sub-themes that emerged from the data were: (i) support network, (ii) public and social services, and (iii) new service model.

#### *Support Network*

Availability of support was seen as a highly desirable service that was needed to improve the quality of life and daily living skills of parents with FASD. Participants had a number of helpful suggestions regarding services that could be enhanced, and how organizations and agencies could enhance these services. Suggestions were also made about program and service development that could better meet the needs of parents with FASD. The development of programs that provide an opportunity for parents to build relationships with other people, especially other parents, was considered desirable by all. One advocate described this as follows.

I help her the best way I can but she needs friends who are sober and having a support group would help...I think if she meet with other parents she won't get bored or think she have to look for something to do...you know she doesn't have a lot of 'good friends' so in a way she is isolated. So a support group would really help and it would be good for the children too.

Parents acknowledged some of the positive and negative features of the services and support they are receiving or have received. All the parents described the services they



receive from Northern Family Health Society, Project Parent North, and Employment Action as being useful to them. In particular, the parents expressed satisfaction about the fact that they were able to get groceries at Northern Family Health Society at a lower cost. Another service that one parent felt was useful to her was the fact that transportation was provided at Project Parent North. “You know I did not have to worry about how to get there...they pick me and my child up and then drop me home at the end.” Support such as having “house keeping classes for mums” were suggested by parents as something that would help them greatly.

All parents, their advocates, as well as service providers, felt that having a parenting group would help, as they would be able to meet other parents like them, learn new skills, and make new friends. Service providers and advocates envisioned a social space or some sort of support group that involves activities and socializing with other parents and one that would create a play environment for their children as well. They emphasized the importance of developing more community and family support systems, as well as advocacy for parents to ensure that the parents’ needs are met and rights are well protected. Advocates talked about how parents are often fearful of termination or limitation of their parental rights. Thus, they believe that development of an advocacy network in which parents can receive legal support, advice, help with filling out forms, communicating with social services, general information about government programs, help with financial planning, and dealing with social services expectations would not only help parents, but would enhance the competency of the system of care available to parents.

In addition, participants wanted service providers to acknowledge and recognize the strengths and disabilities of parents with FASD. The community was also seen as needing

to know more about FASD and the abilities of parents with FASD rather than just their disabilities. “They need to teach people more about our abilities....it is really hard when all people see is what you cannot do well.” The need for other practical support was also emphasized. Practical support, they emphasized could be as simple as a phone call to remind them of appointments or to remind and discuss with parents what they need to do for the day so as to establish routine and organization. For example, service providers mentioned that,

The idea of a reminder call will help them keep appointments, but we don’t do that.

Doctors charge money if they miss appointments ...its like we are setting them up for failure because we know they are not able to keep track of time yet we don’t give them reminder calls.

Further, it was suggested that service providers work with other service providers to reduce repetition of information and services and to provide better and more efficient service and support.

We, as service providers, need to come together to work as a team so as to reduce duplication of material and to prevent confusion in material presented to these parents. Things should be standardized so that they are not receiving conflicting information...for example; one caseworker might say to a parent do this that way while another caseworker may ask the parent to do it that way.

### *Public and Social Services*

Service providers, parents, and their advocates reported that parents with FASD needed more access to services. To ensure this happens, service providers and advocates noted that service providers needed to actively follow up on parents, raise their awareness about support and services available to them, refer them to those agencies in the local community where they can get help, and educate them about FASD so that they can have a better understanding of FASD. Education and employment training were also seen as

necessary to help parents upgrade their learning skills in order to better assist their children and find employment. Parents expressed their desire to work. One parent said, “If I had someone to help me with childcare, I would go and look for a job but I have no help with childcare.”

Advocates pointed out that counselling needs to be a major component of the service and support offered to parents. As one advocate put it,

You know we tell them to straighten up their life but we do not provide the kind of services they need at times...they need counselling for drug and alcohol issues...because she does not have sober friends. That's how she lost custody at one point and I would hate to see her mess up again...they need counselling because they deal with a lot like the stress of not working and having limited income, stress of trying to be a good mother.

Another sentiment expressed by advocates and service providers was the need to develop some type of system where they can access benefits. They noted that benefit eligibility criteria and program eligibility requirements tend to limit the service and support that are accessible to parents and often exclude them from receiving benefits. For example, reference was made to <70 IQ criterion which is required to be eligible to receive adult income benefits. Advocates believe that this creates a financial strain, and to some extent impoverishment, for parents whose IQs  $\geq 70$  and are who are trying to provide a safe home for their children. They believe that parents need help with information about programs that offer benefits, how to access those benefits, and how to ensure that those benefits are well implemented to match their needs.

*New Service Model*

Service providers and advocates suggested that parents need support for multiple issues that do not necessarily arise in their encounters with service providers. Service providers and advocates discussed the need for an in-home training for parents. They pointed out that parents were quite often more comfortable talking about their challenges in their home and are better able to apply new skills when they are taught in their home environment where the information is contextualized. “We need funding for outreach programs that will allow workers to spend more time in the home environment with them since they have a hard time transferring material learnt in one environment to other environments.”

Moreover, going to the parents’ home provides the service provider an opportunity to identify any issues relevant to the child’s well being that are unlikely to come up in another setting. There were suggestions about how organizations could tailor services and programs to be more individual-oriented and less isolating and confusing so as to provide maximum service that would match the needs of parents with FASD. Service providers discussed the fact that programs tend to be abstract in nature and quite often parents get lost in the process. All participants agreed that services must respond to individual parents’ needs. More specifically service providers pointed out that individual parent’s needs for services and support are influenced by

- Family background (relationships issues, presence or absence of positive role models, culture)
- Social support network
- Place of residence
- Socio-economic situation (e.g., low-income)
- Child age and the stage of development
- Individual skills and strengths

As such “we have to be careful to do the things that they see they need and not all the things that we see they need...we need to work with them where they are at and not want to change everything...otherwise they see us as interfering in their lives and they don’t see the program as helping so they sort of stay away.”

In addition, parents wanted materials that are easier to understand. There were also suggestions for development of materials that are geared towards all developmental levels. “We need low-literacy brochures and information booklets,” one service provider said. Service providers and advocates stated that each parent’s abilities had to be taken into account, explanations need to be simplified, and tasks need to be broken down into components that parents can comprehend. Service providers added that repetition and reinforcement of material should be provided. For example, as one service provider noted, “you cannot just ask them to do something...you have to explain it at their level, you have to get them to try it, and you have to demonstrate it.”

Ongoing and long-term support or transition and after-program support and services that are pro-active were seen as a desirable and essential service characteristics that needed to be implemented. As one service provider stated,

They may go away for a while and then come back simply because the service or support they received or utilized at the time was probably sufficient to help them with the crisis they were dealing with at the time. However, as their children develop and their needs change overtime, so does the parents’ need for additional and different service.

Another service provider said, “Working with an individual affected with FASD is like going to a library for information, it’s ongoing and they need to know that it’s always there for them to access when there is a breakdown.” As a result, service providers claim the idea that services can be pulled backed once parents are seen as being able to maintain some

stability or the time period has elapsed is unrealistic. The following supports were highlighted as part of their organization's effort to extend some sort of continued service after parents have completed the program.

- We offer a day back so they can come and talk about things
- Call to check on them
- Counselling and referrals
- Cooking club is also available
- There is a store at NFHS...we sell items at a lower price so they often come back to use that service
- Baby shower so that they can meet new people

Service providers also underscored the fact that services need to be more empowering and pro-active. As one participant noted, "If we provide ongoing support, if the parents can be enabled and empowered to care for their children, then we will avoid some of the crisis that normally happen." All participants emphasized that services and support needed to allow greater input from parents. For example, parents talked about wanting to be involved in decision-making, raising community and service providers' awareness about FASD so that people and service providers can concentrate on their abilities rather than their disabilities. Advocates and service providers mentioned the need to have programs and other services that routinely follow up on parents. Program evaluation was seen as an aspect of service that needs to be developed or enhanced. As one service provider explains it, "we need to have more inclusion audits so that they will be able to say what helps them or not". Another said, "we try to make services as appropriate as we can, we think they are relevant, but we never ask them if their services are relevant." For a list of service and support participants perceived needed to be enhanced or developed to better support parents with FASD, see Figure 1.

*Summary*

There was little variation in the perception of the study participants concerning desirable services. Not all participants responded on all areas, but with respect to services and support that needed to be developed and enhanced, there was a strong consensus concerning many issues. Thus, individual-oriented programs, in home programs, advocacy, community support, outreach, counselling, transportation, pregnancy programs, education and FASD support groups were stressed. Figure 1 presents the expressed needs and desirable services and support for the three major categories identified.

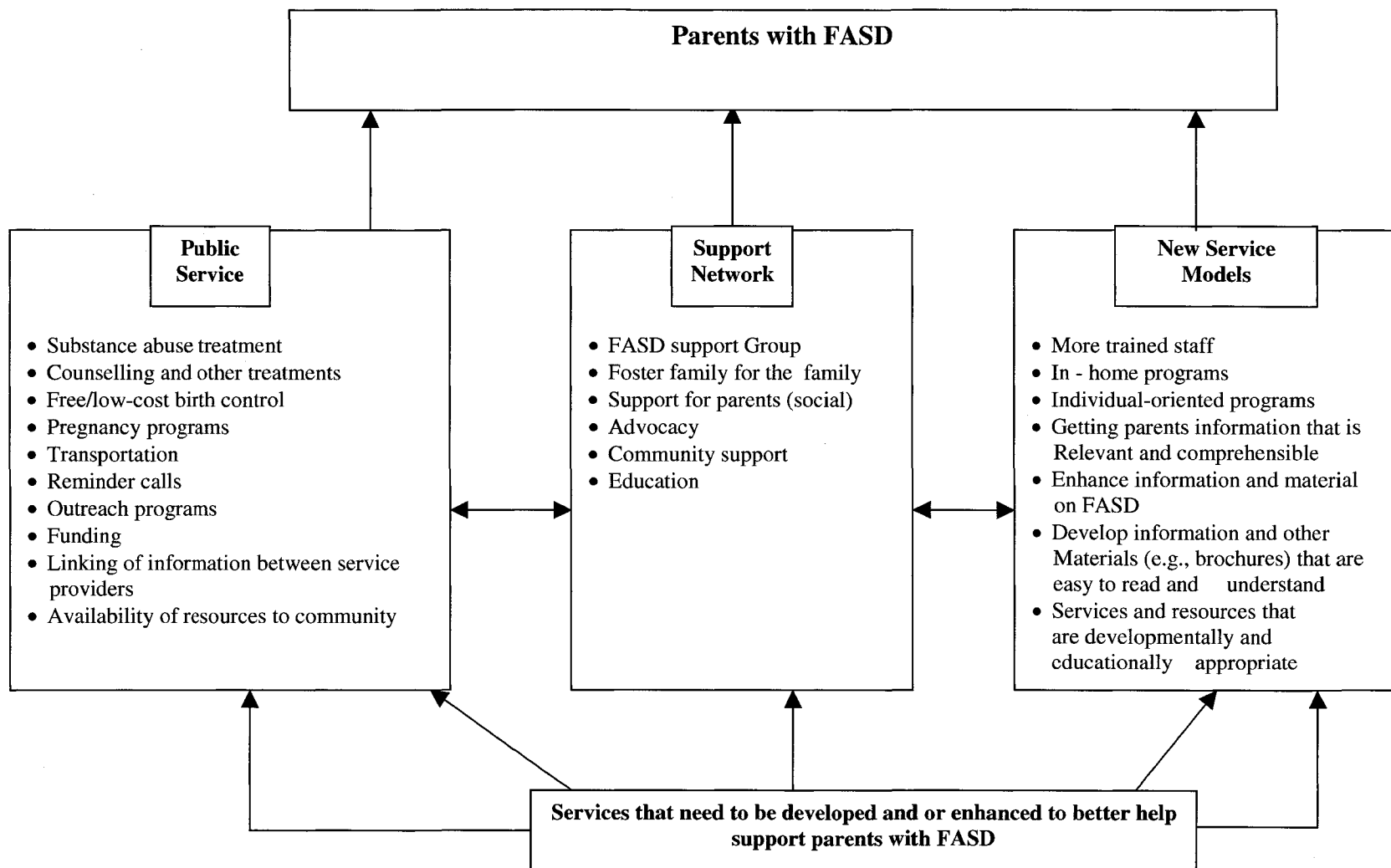


Figure 1

*Desirable Services and Support*



### *Barriers to Services and Support*

Participants spoke at considerable length about what they felt is challenging. Five barriers were identified: (i) system level barriers, (ii) lack of time, funding, and personnel, (iii) lack of resources and education, (iv) service providers' skills, attitude, and expectation, and (v) limited services, access to service, and service coordination.

#### *System-Level Barriers*

Service providers underscored what they felt was a 'restrictive service mandate' by social services and described the focus of most of the mandated programs as being too focused on parents' weaknesses as opposed to their abilities, preferences, and values. Participants talked about the fact that parents quite often had to go through several steps and fill out several forms in order to be excluded from or granted certain benefits or service. Service providers were also concerned with the idea a parent quite often was required to have a 'file' or 'diagnosis' or put in a certain demographic to receive services. One service provider lamented,

If you don't have success for some time you are required to close the file/if they come back you have to start a new file and they are seen as incomplete. They probably need certain things at different time...

We have attendance policy and goal work completion policy ...and now we realize that is not fair.

#### *Lack of Time, Funding, and Personnel*

It was noted that more time was necessary with parents with FASD than with other parents to allow service providers to be able to determine what parents need and to implement necessary services and supports. To achieve this, more funding and trained personnel were deemed necessary. Time was discussed in two contexts. First, service providers believed that the timeline imposed (i.e., duration of programs) by MCFD may be

inappropriate given these parents' strengths and weaknesses. They also felt that standard timelines do not take into account that parents may need ongoing services and support; for example, to coincide with different developmental stages of their children. Assistance, according to the service providers, cannot be time limited as in programs in which service delivery ceases after five months or when parents are perceived to be coping well.

Secondly, most service providers agreed that services should be available 24 hours a day, 7 days a week in order to allow parents to access services and support whenever needed.

Service providers expressed concern about limited funding. This, they felt, forced them to limit the amount of resources and material that can be used for a specific program and as such, they were not able to develop a specific program aimed at parents with FASD. Two service providers mentioned that their agency was now beginning a *wraparound project* geared towards individuals with FASD. The concern expressed about lack of time, funding and staff is illustrated in the following quotes:

They have more parenting goals as children get older...5 months is not enough.

What is enabling for one is support to another ...for example, a 6 weeks program may be all one individual needs and for him/her that is enabling, but for another individual it may not be.

They are doing well and then the ministry decides to withdraw the support and then they crash...so maybe we should change our support not withdraw it.

We need more funding for outreach programs that will allow workers to spend more time in the home environment with them since they have a hard time transferring material

### *Lack of Resources and Education*

Participants were overwhelmingly concerned about the fact that information and materials, for and about adolescents and adults with FASD, are limited and the fact that there are not enough resources to run the kind of parenting program individuals with FASD

need. “I think they just miss out a lot” one participant expressed, “the programs don’t really meet their needs.” Further, the participants also noted that social service workers, other professionals, and teachers should be educated to deal with parents who are affected with FASD. It was recognized that even professionals are often unaware of how to navigate the fragmented social system. Funding was again cited as being an essential component of developing programs that matched the needs of parents and to cover transportation, activities for support groups, workshops, staff training and education of the community at large. Consequently, all participants felt that more information and resources were needed. Parents talked about wanting to know more about FASD and the need to educate people about FASD.

#### *Service Providers’ Skills, Attitudes and Expectations*

A common concern among all the advocates was that service providers needed additional training to work with parents in appropriate ways. Service providers’ level of current training and expectation in dealing with parents with FASD were questioned. For example, one advocate said “sometimes it appears that the social workers take their values and apply them to the parents, they are not always sensitive to the parents’ needs and as a result the parent is sometime reluctant to work with them.” Another advocate mentioned that because some service providers have limited training in working with people with FASD,

They don’t always understand that you don’t necessarily have to move the parents up the next step, because the next step is not always perceived as a concern for the parents and so when you try to move them to the next step it is often seen as the social worker forcing them into something.

Parents and service providers also expressed concern about the expectations of service providers. One parent lamented, “I did not like my social worker she was asking for too much.” Service providers claimed that:

We have too many expectations, if they miss one supervised visit then we then see as not willing/and then they think they fail ...then what's the point

Some services like Project Parent North have transportation so there is a better chance that you can ensure parents attend the program, but most don't offer transportation .....so when we have a program for a set amount of time and we expect them to come in each week without a way of getting there it doesn't always work...so, I think the right thing is, they miss out on services because they are harder to cater for, not that they don't complete....it is just easy to put it this way I think.

Advocates also felt that too often parents get caught in the wishes and expectations of social services and are not involved in decision-making (e.g., being provided options and freedom to choose), their opinions are not sought, and they are not encouraged to speak out thereby creating and maintaining a state of dependency. As such, participants believe by providing training to service providers on how to work with FASD, the system of care to help parents will be greatly enhanced.

#### *Limited Service, Access to Services, and Service Coordination*

Creating opportunities for access to service and support were generally seen as critical to assisting parents. Participants talked about the scarcity of programs that appropriately match the needs of parents' with FASD and the lack of expertise in working with parents with FASD. Lack of coordination between different agencies and professionals providing services for parents was noted as one of the reasons why services were inappropriately matched to parents' needs. Parents reported not knowing all the services that are available. One parent expressed disappointment that more services are not available to help when they need it.

As you can see it really bothered me, you know we were not asking for much...just this one time when we really needed help no one could help...they just let us down....all that walking for nothing.....it's like you are begging them.....it's like you have to lie to get help.

People with FASD use a broad range of services, which are provided by different agencies functioning under different organizational structures and boundaries and with different aims, objectives and philosophies. For services to be effective, good service coordination is needed; however, participants in the study generally felt that service coordination was not optimal despite there being some formal groups and agencies involved in providing and planning services, as well as making referrals. Almost every service provider made some comment about the fact that improper service coordination was a hindrance to providing appropriate service and support to parents. A typical comment was:

We do referrals for prenatal care, for example, one doctor has agreed to take in new patients, but we have no real formal service linkage at the moment, it depends on the individual dealing with the case.

### *Summary*

Service providers, parents and advocates identified major barriers and gaps in the delivery of services, with general agreement. Service providers reported several barriers and gaps that prevented them from providing efficient services while the parents and advocates identified barriers and gaps in accessing appropriate services and support. The most common barrier reported included not having transportation to programs, lack of training of the caseworkers, lack of resources, and insufficient time and funding.

## CHAPTER FIVE

### DISCUSSION

The aim of the present study was to determine the perceived needs of parents with FASD. Parents with FASD, their advocates and service providers provided a great deal of information about the needs of parents with FASD. The findings held important implications for service delivery and program implementation for parents with FASD.

First, the demographic data demonstrated that service providers had strong concerns about the quality of services and support being provided to parents with FASD. All service providers felt that there is little systematic planning of care for families where a parent is affected with FASD. They also intimated that professional interventions are crisis interventions and professionals require further training to properly assist parents with FASD.

The qualitative findings regarding the usefulness of 'specific service development' also indicate that service providers recognize the need to enhance and develop need-led services. Overall the service providers rated almost all the service development as essential (see Table 5). The notable findings are, the identified need for special parenting project(s) for parents with FASD, increase one-to-one support from organizations and agencies, and family planning services targeting parents with FASD are crucial. This finding is troubling because, at the very least, there should be programs in place specific to the needs of parents with FASD. The fact that all service providers in the study reported little systematic planning of care indicates that parents with FASD represent an invisible and underserved population.

Second, it was identified that parents with FASD have multiple needs. Parental needs were identified along four domains. These were: (i) domestic, (ii) parent training and childcare, (iii) public and social services, and (iv) formal and informal support. Furthermore, service providers, parents and their advocates identified a number of desirable services and support that they felt needed to be developed or enhanced in order to better meet the needs of parents with FASD. Three sub-themes also came out of the desirable service category. They were: (i) support network, (ii) public and social service, and (iii) new service model. Moreover, the participants identified several barriers that prohibited effective, and appropriate service delivery. Five sub-themes emanated from this; (i) system level, (ii) lack of time, funding, and personnel, (iii) lack of resources and education, (iv) service providers' skills, attitudes and expectations, and (v) limited services, access to services, and service coordination.

The domestic needs most identified by participants of this study are (i) housing, (ii) transportation, and (iii) financial support, money management, and budgeting. Given the fundamental importance of housing, transportation, and income to family welfare, the expressed need for adequate and subsidized housing, transportation assistance, and financial support are perhaps, some of the most gripping needs to emerge from this study. Low income, and living in substandard housing have been identified as characteristics associated with perpetrators of child maltreatment (Feldman et al, 1992). Further, research has indicated that financial pressure creates an undue level of preoccupation with budgetary management and other daily living issues, resulting in frustration, depression, inconsistent discipline practices, and poor family outcomes that are likely to occur. Thus, access and availability of affordable housing and accessibility of housing to transportation, shops,

recreation and programs are important. A practical and workable living arrangement will provide a foundation for parents with FASD to remain somewhat secure and stable, allowing them to provide a somewhat stable environment for themselves and their children. Moreover, housing generally occupies the greatest share of a household's budget and defines a thin line between a stable or homeless state. Health and safety of children, employability, and access to work and services all depend largely on safe affordable housing (Skagit County Community Action Agency, 2001).

Child development outcomes rank as the primary scientific concern for parental adequacy by parents with developmental disabilities (Keltner, 1993). Results from this study indicated that parents with FASD needed to learn more about child development and how to deal with children's changing needs overtime. Parents talked about wanting to know more about the way their children develop and needing help to manage and support their children as they grow. This suggests that some parents with FASD are unable to adapt to rapid developmental progress in their children. It also hints that there is a likelihood for developmental delays in children of parents with FASD as rapid developmental changes in children may strain the parenting skills of some parents with FASD.

In this study, parents reported difficulty managing their children's behaviour. Service providers and advocates expressed similar views. Parents were thought to need help with how to discipline children; for example, how to implement age appropriate discipline and adjust discipline to different situations. Appropriate services and support are, therefore, needed to aid parents to learn simple strategies for coping with growing children.

Many of the sub-themes described by the participants are echoed in the literature on parents with intellectual disabilities and parents with mental illness. Feldman et al. (1985,



1992), for example, noted that the failure to adjust parenting styles to child development and inconsistent use of child discipline put children at risk for neglect, maltreatment, environmentally-related developmental delays and behavioural problems.

It is not surprising that, service providers, parents, and advocates place emphasis on child development, and discipline. Parenting is most frequently operationalized in terms of these childcare skills and deficits in these areas give rise to concerns of neglect and child abuse (Hayman, 1990). These findings are comparable with results from studies such as Kroese, Hussein, Clifford, and Ahmed (2002) that looked at the perceived benefits and burden of parenting by parents with intellectual disabilities. They are also consistent with, and support, the assertion made in studies (e.g., Hashima & Amato, 1994) that suggest help with childcare was a strong predictor of positive parenting. Based on this framework, childcare may be considered one of the most important support services provided to parents with FASD.

Koeske and Koeske (1990) found that educational input can provide a buffer against stress caused by the changing needs of children. For parents with FASD, this stress may become pronounced, without support, as their understanding of their child's needs may not advance fast enough to keep up with the child's development. The strain that this perceived lack of understanding causes is illustrated by the comment of one parent who felt that as her children were growing older they were becoming less responsive to her counsel.

Furthermore, the fact that parents need literacy and education seems to espouse Feldman and Walton's (cited in Feldman, 1994) idea that lack of education may lead to insufficient knowledge concerning developmental expectations and effective child management, which according to Feldman, increases the risk for child abuse and social

maladjustment. These findings also echo suggestions from Tymchuk and Andron (1990) that provision of safe and adequate childcare requires a minimum level of intellectual capacity. Moreover, the findings lend support to the idea that parents who have more educational experiences have several tangible (more income, know more about resources that they can use) and intangible (coping skills, self-efficacy) benefits that help them in their day-to-day living (Dill, 1998).

The need for other public and social services such as information and resources on FASD, counselling, and health care were also underscored by all participants. Legal assistance, employment training, and outreach were also noted by service providers and advocates.

Although parents identified the support of family, partner, and friends as generally positive; parents also reported needing more help than they were currently receiving in the area of social and community support. Service providers and parents also commented on the fact that mainstream parenting support is very limited. In this study and in that of Walton-Allen and Feldman (1991) and Llewellyn (1995), participants identified the need for social and community services and support. Furthermore, parents reported needing help in finding support groups, children's activities, and accessing other community resources. Parents also underscored wanting help with meeting people and making friends.

These informal and formal support needs identified, seem to support the adoption of a social and ecological model that explains the maltreatment of children and other negative outcomes. Viewed from the context of the research findings, it appears that a formal support network is vital to effectively carrying out parenting responsibilities. This has important implications for service delivery. That is, in addition to family and

professional support, support groups and other initiatives, which allow parents with FASD to improve their social network, must be considered essential features of a successful, parenting program. Moreover, these networks could form the basis for developing resiliency in both parents and children, as well as become a critical determinant of the efficiency of their learning environment.

This conceptualization of a support-network influence on parental adequacy and competence and the consequent child outcome, assumes that the types of needs identified in this study are factors that are critical to overcome barriers to employment, poverty, education, and access to resources. The question is, how can health, education, social, and family support services implement programs and establish more effective partnerships that will enable them to work in a supportive fashion with each other and at the same time in partnership with voluntary organizations and community support to provide the kind of support parents with FASD need?

In examining the differences within categories of parental needs between service providers, advocates, and parents, a few unrecognized needs were noted; (i.e., those needs that are not expressed by parents). Service providers and advocates perceived needs in areas such as legal assistance, time management, help with getting organized, advocacy, outreach, obtaining telephone services, needing a foster family for the family, and needing someone to act as an *external brain*. These perceived needs differed from the parents because of the different role which service providers and advocates were fulfilling and because their evaluation of current services and support may have been more complex and detailed than that of the parents. For example, the parents, advocates, and service providers discussed parents needing help with home management (e.g., cleaning, and grocery

shopping), however, service providers and advocates were also concerned about the parents' ability to manage time and get their day organized. Many of the service providers' and advocates' more critical accounts relate to helping parents recognize when they need help, particularly in relation to child protection, how to advocate for themselves and their children.

Desirable services such as ongoing support, in-home support, educationally appropriate level material, and individually-oriented programs reflect, and are similar to the components in-home program, educational level program, feedback and reinforcement techniques that Feldman (1994) described. They can also be used as principles to guide service provision to parents with FASD. The most glaring call was for services to be tailored to each parent's individual needs. This was seen as seminal because participants, specifically service providers and advocates, recognized that each parent's ability was different; therefore, it needed to be taken into account so that materials could be simplified or broken into components that are understandable to each individual. Service providers, by their own admission, stated that programs and services are quite often too abstract, 'standardized' and 'structured'. While they recognize that 'structure' is a core factor when working with parents with FASD, they felt that programs lack flexibility to allow them to adjust or adapt the curriculum and modules to meet individual needs. Accordingly, many services that parents with FASD access focus primarily on childcare skills, child protection issues, and parents' deficits so these skills are likely to become foremost in the mind of service providers when working with parents. One possible reason for this 'narrowed' focus may be restrictive program guidelines and funding restraints but it may also result from gaps in expertise of service workers. Parents experience needs across a wide range or

continuum. Therefore, to meet their ever-changing needs, service providers must be competent to work with those affected with FASD because this will reflect the way knowledge is integrated and attitudes and expectations are modified to meet the parents' needs. Information about the circumstances of parents with FASD is important in informing need-led (rather than service-led) provision, which takes a holistic approach to the whole family's needs.

The second key aspect of the themes identified is for services to be home-based. In-home support was considered vital to the system of care provided to parents with FASD. Parents were thought to feel more comfortable in their natural environment where they would be able to learn and apply new skills that were taught.

The third principle is for service to take into account the learning needs of parents when designing and implementing programs. Parents with FASD need opportunities to learn on their own time and in a way that is effective and understandable to them. The latter includes providing opportunities for demonstration and for learning to take place in the home setting. It also requires teaching resources to be suitable and at an understandable educational level, particularly for parents with limited literacy skills. Moreover, services need to incorporate procedures into their planning which would involve parents input into selecting and setting personal parenting objectives. Parents will demonstrate less resistance and will learn best when their views about what they need are heard and taken into account.

The fourth principle is for services to provide ongoing support or sustained support to parents as their needs change and the needs of their children change. Ongoing support provides benefits to parents, service providers, and advocates; e.g., increased opportunities for intervention and prevention and a more comprehensive approach to support, rather than

a crisis orientation. These findings support the general concern with continuity of care for parents with developmental disabilities (Cohen, 2002). More resources, specifically allocated to parents with FASD, will assist service providers to incorporate a pro-active and empowering focus in their service delivery thus, forestalling the usual revolving door/cyclical patterns that parents often display.

Advocacy for parents and assisting parents to become advocates for themselves and their children were identified as significant in this study. The advocacy role of service providers was identified as a desirable service. Service providers acknowledge that more could be done, but due to time constraints, staff, and funding they are quite often limited in their capacity. For advocacy to be effective and appropriate, a good knowledge of community resources is required to ensure that parents' needs are met. Advocacy also requires that service providers become knowledgeable about the roles, services, mandates and contributions of other agencies. Many parents are involved with multiple agencies and this can be confusing, not only to parents, but also to service providers who are often unable to navigate through the fragmented service system.

The service providers in the study were faced with considerable constraints. Of these, restrictive service mandate, lack of time, funding, and personnel, inadequate staff training, lack of resources and education, limited services, poor service coordination, and services providers' attitudes, and expectations were noted. Clearly, to provide effective and appropriate services to these parents, such service constraints must be eliminated.

The research findings demonstrate that although a large proportion of the service providers had some experience working with families and had undertaken some basic training/education (e.g., training seminars, conferences on FASD), all the service providers

felt they needed more education and training to help them better support parents with FASD.

There is a clear need to enhance inter-agency collaboration as an essential element in providing support and services to parents with FASD. Service providers identified inter-agency collaboration as vital to reduce repetition of services and decrease the potential for parents to receive contradictory and confusing advice. This is especially noteworthy because, according to Cross and Marks (1996), the confusion that results when there is a lack of service co-ordination between the roles and boundaries of different professionals and agencies often leads either to poor uptake when help is requested or to a plethora of professionals and programmes.

It appears that the greatest areas of unmet needs were in social and community support, childcare, and parenting services, health and social services. Parents were thought to need help in creating a support network (making friends, meeting other parents with FASD, and getting activities for their children), transportation, and accessing resources and services (e.g., knowing what services are available and how to get them). On the whole, service providers and advocates thought that parents needed more access to counselling, to help alleviate any stress, emergencies or issues (e.g., pregnancy and birth control issues, financial, and social issues) that arise. They also thought that schools should better accommodate the difficulties these parents face. Parents with FASD are quite often vulnerable because of their socio-economic situation and their inability to confront and understand the complexities of the service system with which they are involved. This has a direct implication for service provision and suggests that to continue to overlook the needs of parents with FASD could place them at a further disadvantage.

Providing services and support for parents with FASD to meet their needs is not a short-term exercise. Children's needs change. Parents' needs also change over time and all parents will have differing needs. Some parents will need services and support to become independent; others will need services and supports to continue their parenting. Whatever the case, it appears that meeting parents' identified needs presents a challenge to those agencies providing services to people with FASD. The current constraints on long-term, ongoing, and preventative work with parents with FASD militate against supporting these parents. Developing services based on the suggestions given would help to ensure that parents with FASD receive the support and services they need.

#### *Limitations*

Of course all studies have limitations and this one was no exception. Most obviously, individual interviews with more parents and advocates would have been valuable. The small sample in this study does not provide the degree of representativeness of a larger population.

More generally, it would have been desirable to extend the needs assessment to include more service providers, such as MCFD social workers, doctors, mental health workers, drug and alcohol specialists, and maternity care nurses. Indeed, an even more comprehensive assessment would have involved a comprehensive assessment of parents' adaptive and functional skills as well as observing service providers in their provision of service. As is often the case, this more comprehensive approach was precluded by time constraints and other contingencies.

To the researcher's knowledge this study was, however, one of the first of its kind in BC to investigate the needs of parents with FASD. Despite the above reservations, the data



gained from this study provide insights that may be generalized to other parents with FASD comparable to those in this study. The researcher recognizes parallels, at a contextual level, between the parents in the study and parents living in other contexts which may differ in terms of social and ecological factors. Plus, there is variability in the presentation of FASD which would affect parenting. However, it appears that parents with FASD have some characteristics in common that affect parenting, in particular cognitive impairments and problems in adaptive functioning. Thus, the researcher believes that generalization from this study is appropriate while acknowledging the limitations identified above. The results should provide a useful basis for developing, implementing, planning, training, funding, and providing and support services. Moreover, service providers in the BC in general and northern BC in particular may be able to use the results of this study to investigate gaps in their service.

### *Conclusions*

This study sets out to investigate the needs of parents with FASD. A significant amount of data has been collected and a number of practical improvements identified. The key findings relate to practical support and system-level barriers of the current provision. Problems related to access to housing and childcare are highlighted. Slight differences in identified need between parents, advocates, and service providers were apparent in some areas such as legal assistance, pregnancy counselling, and low-cost birth control. The research findings demonstrated that the training needs of professionals were paramount to assist these parents. It is clear from the comments received from the service providers' focus groups and parents, as well as advocates' interviews, that staff training is important. There is an urgent need to develop a more integrated and accessible service. Such a service

may have development cost implications. However, these should be weighed against the human and financial cost of preventing children and their families from potentially devastating outcomes.

In summary, the findings are potentially important as they identify core needs from the perspective of parents, advocates, and service providers. They also provide clear recommendations to improve and develop services. These recommendations target policy and programs that will provide pro-active service and empower parents. But more importantly, services and support that are need-led rather than service-led ultimately should lead to more resilient parents with more adaptive skills and thereby reduce the likelihood of children being at risk or parents losing custody of their children.

## CHAPTER SIX

### RECOMMENDATIONS

Implementing the following would greatly improve social service effectiveness in providing adequate services and support to parents with FASD.

#### *Support Services*

- 1) A particular kind of support could be the development of a peer helper support network, advocacy service to help parents during special 'events' in their life and the changes that these brings.
- 2) Social services in conjunction with outreach and addiction service providers should implement aftercare services including fostering increased communication among service providers, and effective follow-up services to connect parents with positive supports in their homes.
- 3) There should be a case-coordinator to ensure that the families' need for information, advice, and help are identified and addressed. Particular areas covered should include financial support – help with claiming benefits, housing, and support for all family members' needs.
- 4) There is need for strengths-based versus a deficit focus approach to parenting support.
- 5) Home care and support services should provide reliable help with day-to-day living activities;

Support can include:

- Maintenance support
- Social and peer support

- Psychosocial interventions
  - Education and employment
  - Human services (see figure 2)
- Teaching skills in the home to increase the independence of parents with FASD.
  - Offering drop-in services on a routine basis, in and out of office hours and at times of stress and pressing need.

### *Training*

- 1) Training needs to be provided to staff from all sectors so that everyone who has specific contact with parents can work effectively. The training should cover how to identify parents with FASD and how to refer to the appropriate agency early, then deal with assessments of parenting needs which should consider establishing what services and support each parent requires and how best to provide the support that has been identified.
- 2) Staff working with parents with FASD should continue to have regular in-service training so that they can both increase their knowledge of this population and receive up-to-date information about relevant skills and techniques. This should also be supplemented by external training courses, seminars, and workshops as necessary.
- 3) The training should provide professionals with knowledge of the range of services which are available to meet the needs of this group.

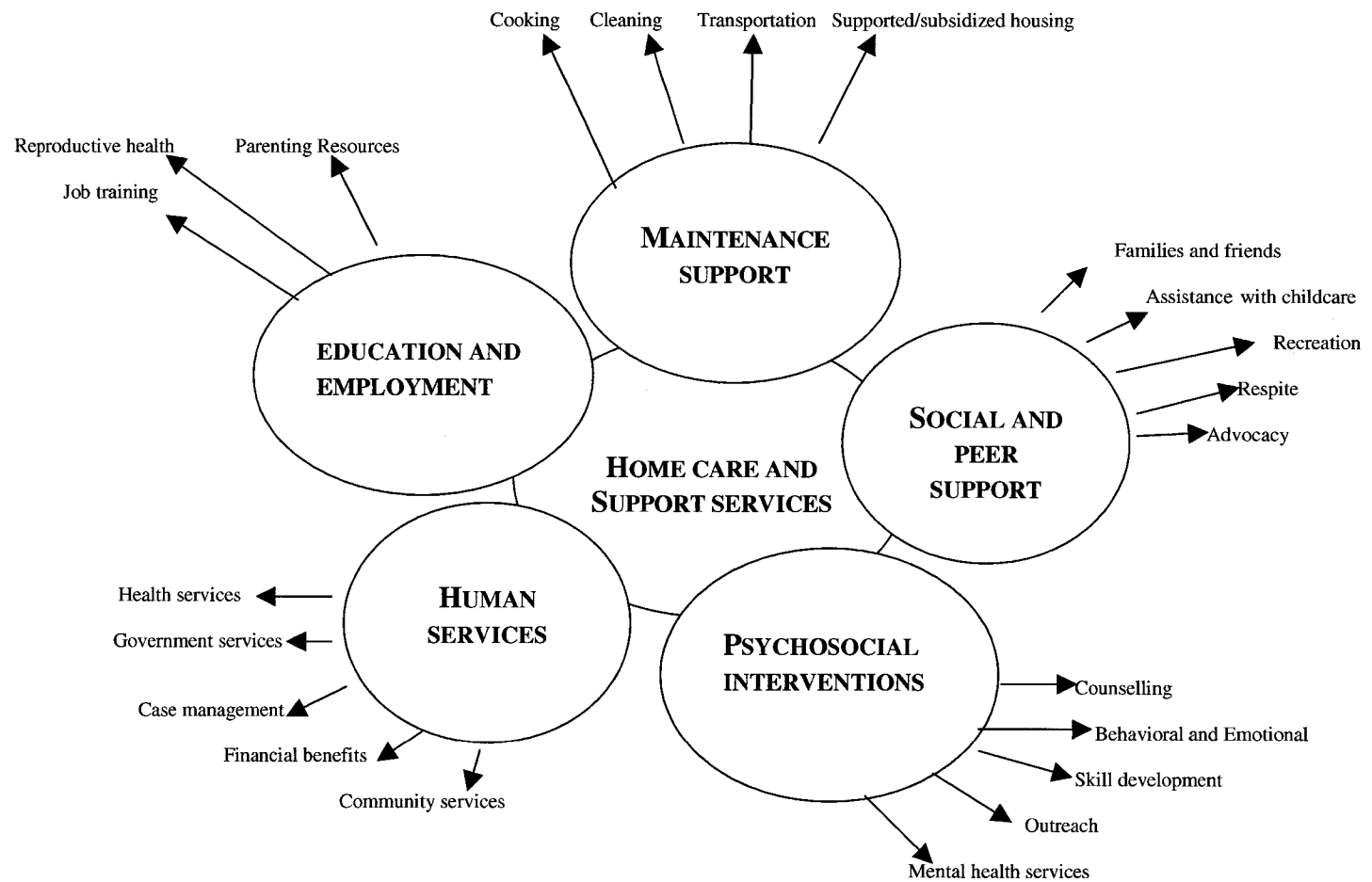


Figure 2. Framework of home and support services (based on the recommendations listed in this study).

- 4) Training of professionals also needs to encompass an understanding of how best to communicate with parents with FASD so that their needs can be correctly identified and provided support can be given in a pro-active and empowering manner.
- 5) Alongside the training of the professionals already in practice, it is recommended that specific training on working with parents with FASD should be included in the training programs for those aspiring social workers, outreach workers, nurses, teachers, and other health care professionals who are likely to work with affected families.

#### *Service Coordination/Linkage or Case Management*

There is a need to better understand how to coordinate essential community, social, health, and support services. These services should provide linkage and referral as well as assistance to families which ensures accessibility to and relevance of support. It should focus on activities that establish and monitor life-long services as well as provide accountability and continuity of service.

- 1) Major responsibility of a case manager should be:
  - I. Assessments
  - II. Advocacy
  - III. Parental empowerment
  - IV. Service planning
  - V. Linkage and referral
  - VI. Monitoring quality of life
  - VII. Crisis response planning
- 2) In order to reduce the duplication or omission of support services and to avoid the possibility of providing conflicting advice to parents, a contact sheet should be developed. This should be inserted in the parent's record for the

professionals/volunteers to see and record the date, purpose of visits and its outcomes, and names, and contact information.

- 3) Facilitate the development of interagency co-operation and collaboration, to ensure the needs of parents with FASD are identified and receive a response that is both planned and flexible to their changing needs.
- 4) Establishing a multi-agency steering group to develop care coordination is the first step. Service should be planned on an individual basis. Currently people with FASD are not served as individuals with very personal needs and preferences. Rather, they have been offered pre-determined sets of services based on the notion of what they need. The individuality of parents with FASD should be recognized and the aim in future should be to arrange services on an increasingly individual basis taking into account personal preference, education level, age, strengths, weaknesses, race, and needs. Where necessary, individuals should be helped to express their views and preferences either through the development of self-advocacy skills or through an independent advocate.
- 5) Case conferences should include all those involved in providing service to a parent, the parents themselves, their spouses, their advocates and where applicable their children.

### *Information*

Information on resources needs to be made available in different formats, i.e. pictorial, easy to read and understandable leaflets, visual aids information and accessible videos to assist parents in caring for themselves and their children.

*Continuity of Service Provision*

- 1) Many parents with FASD will need ongoing support throughout the years. The nature of that support and service needs regular appraisal so that the changing circumstances and needs can be identified and responded to.
- 2) Providing continuity on case management will enhance the provision of a full spectrum of information about resources and services.

*Review*

- 1) Any parenting program that may be developed requires evaluation and should include parents' input.
- 2) Regular review is important in any need-led service provision. It is only by reviewing the parent's progress and judging the effectiveness of the program in meeting his/her changing needs that responsible decisions can be made about the adequacy of current activities. It is important to carry out regular reviews. They should involve the parent, his/her advocate, family and other service providers. This process will enable monitoring not only of the progress of the individual but of particular elements of service delivery in terms of continued value for the individual and service as a whole.

*Funding*

- 1) More funding should be allocated to FASD research and for developing programs that specifically target parents with FASD.
- 2) More funding should be given to acquire and train staff to work efficiently and improve competencies.



*Assessment*

- 1) Assessments of FASD in adolescents and adults have proven to be problematic. It is recommended that a simple short assessment tool be used when someone begins a program so as to evaluate his/her needs. The foundation of service should therefore be an assessment of adaptive functioning with regular re-assessment, to cover strengths and needs, abilities and deficits, health considerations, particular needs due to race and gender, and the wishes of the individual and his/her family or advocate. This should not involve simply administering tests of schedules, but careful observation, discussion, and perceptious sharing between staff of all disciplines, family, and the individual. Such assessments should be recorded so that the information is available both for use in devising a program and for later cross reference.
- 2) Following identification and assessment, when it is apparent that additional help or different help and support is required, a program of care that meets the needs of the family should be developed.
- 3) It is likely that this service would require ongoing assessment and review as the needs of the child and the family change. It is recommended that some pilot scheme be set up in conjunction with PPN or NFHS to develop parenting programs on an individual basis or in a group setting to meet the needs of these families by providing practical guidance and support.

More generally, if the recommendations are conceptualized as a hierarchy of needs, we should first take care of the system so as to eliminate all the system-level barriers so the

system can better assist the parents and the parents can take care of their children. See Figure 3.

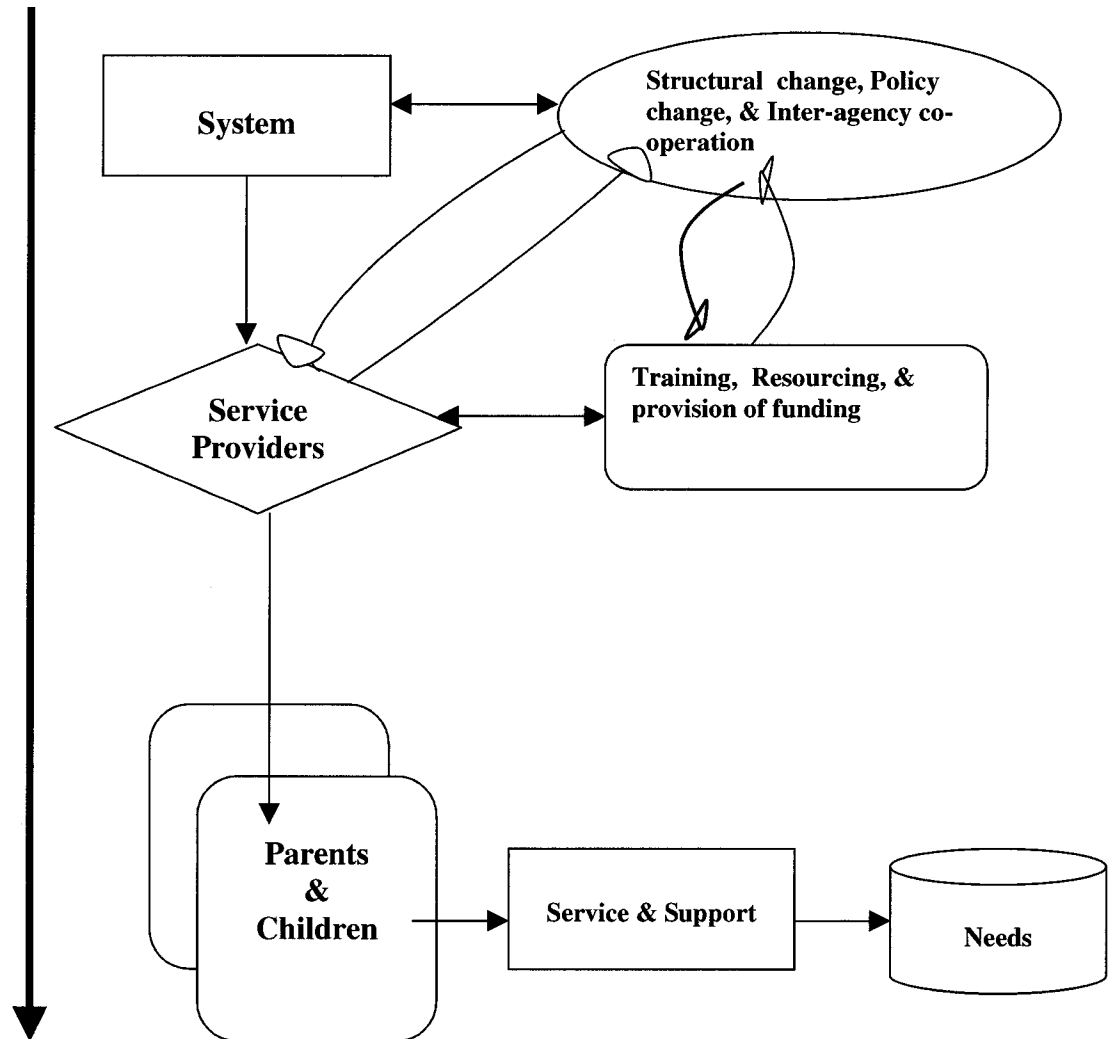


Figure 3. A conceptualized hierarchy of needs.

## REFERENCES

- Abkarian, G.G. (1992) Communication effects of prenatal alcohol exposure. *Journal of Communication Disorders*, 25, 221-240.
- Abramson, L., Metalsky, G., & Alloy, L. (1989). Hopelessness theory of depression: A theory-based subtype of depression. *Psychological Review*, 9, 358-372.
- Ainsworth, M., Blehar, M.C., Waters, E. & Wall, S. (1978). *Patterns of attachment: A psychological study of the strange situation*. Hillsdale, NJ: Erlbaum.
- Ainsworth, M. & Bowlby, J. (1991). An ethological approach to personality development. *American Psychologist*, 46, 333-341.
- Alpern, L., & Lyons-Ruth, K. (1993). Preschool children at social risk: Chronicity and timing of maternal depressive symptoms and child behaviour problems at school and at home. *Development and Psychopathology*, 5, 371-387.
- Archibald, S.L., Fennema-Notestine, C., Gamst, A., Riley, E.P., Mattson, S.N., & Jernigan, T.L. (2001) Brain dymorphology in individuals with severe prenatal alcohol exposure. *Developmental Medicine and Child Neurology*, 43 (3), 148-154.
- Arendell, T. (1997). A social constructionist approach to parenting. In T. Arendell (Ed.), *Contemporary parenting: Challenges and issues*. Thousand Oak, CA: Sage.
- Astley, S.J. (2004). *Diagnostic guide for fetal alcohol spectrum disorder: The 4-digit diagnostic code*. Seattle, WA: FAS Diagnostic & Prevention Network, University of Washington Press.
- Astley, S.J. & Clarren, S.K., (2000). Diagnosing the full spectrum of fetal alcohol exposed individuals: Introducing the 4-Digit Diagnostic Code. *Alcohol & Alcoholism*, 35 (4), 400-410.

- Avis, M., Bond, M. & Arthur, A. (1997). Questioning patient satisfaction: An empirical investigation in two out patient clinics. *Social Science and Medicine*, 44, 85-92.
- Azar, S.T. & Benjet, C.L. (1994). A cognitive perspective on ethnicity, race, and termination of parental rights. *Law and Human Behaviour*, 18, 249-268.
- Azar, S.T., Lauretti, A.F., & Loding, B.V. (1998). The evaluation of parental fitness in termination of parental rights cases: functional-contextual perspective. *Clinical Child and Family psychology Review*, 1(2), 77-100.
- BC FAS Resource Society. (1998). *Community action guide: Working together for the prevention of fetal alcohol syndrome*. Ministry for Children and Families. Retrieved August 12, 2004 from, <http://www.mcf.gov.bc.ca/fasd>.
- Beck, A.T. (1967). *Depression: Clinical, experimental, and theoretical aspects*. New York: Harper & Row.
- Becker, H.C., Randall, C.L., Salo, A.L., Saulnier, J.L., & Weathersby, R.T. (1994). Charting the course of FAS. *Alcohol Health and Research World*, 18 (1).
- Belsky, J. (1984). The determinants of parenting: A process model. *Child Development*, 55, 83-96.
- Belsky, J., Crnic, K., & Gable, S. (1995). The determinants of coparenting in families with toddler boys: Spousal differences and daily hassles. *Child Development*, 66, 629-642.
- Belsky, J. & Isabella, R.A. (1985). Marital and parent-child relationships in the family of origin and marital change following the birth of a baby: A retrospective analysis. *Child Development*, 56, 342-349.

- Boland, F.J., Burill, R., Duwyn, M., & Karp, J. (1998). Fetal alcohol Syndrome: implications for correctional Services. Correctional service of Canada. Retrieved August 14, 2003 from, <http://www.csc-scc.gc.ca/text/rsrch/reports/>.
- Bolton, F.G., Jr., Laner, R.H., & Kane, S.P. (1980). Child maltreatment risk among adolescent mothers: A study of reported cases. *American Journal of Orthopsychiatry*, 50, 489-504.
- Bookstein, F.L., Streissguth, A.P., Sampson, P.D., Connor, P.D., & Barr, H.M. (2002). corpus callosum shape and neuropsychological deficits in adults males with heavy fetal alcohol exposure. *NeuroImage*, 15, 233-251.
- Booth, T., & Booth, W. (1993). Parenting with learning difficulties: Lessons for practitioners. *British Journal of Social Work*, 23, 459-480.
- Booth, T. & Booth, W. (1994). Parenting under pressure. Mothers and fathers with learning difficulties. Buckingham, UK: Open University Press.
- Bornstein, M. H. (1991). *Cultural approaches to parenting*. Mahwah, NJ: Erlbaum
- Bornstein, M.H. (Eds). (1995). *Handbook of parenting (Vols. 1-4)*. Mahwah, NJ: Erlbaum.
- Bowes, J.M. & Haynes, A. (Eds). (1999). *Children, Families, and Communities: Contexts and consequences*. Melbourne, Oxford University Press.
- Bradshaw, J. (1972). The concept of social need. *New Society*, 640-643.
- Brandon M. (1957). The intellectual and social status of children of mental defectives. *Journal of Mental Science*, 103, 710-738.
- Bray, D. L. & Anderson, P.D. (1989). Appraisal of the epidemiology of fetal alcohol syndrome among Canadian Native people. *Canadian Journal of Public Health*, 80, 42-45.

- Budd, K.W., Ross-Alamolki, K., & Zeller, R.A. (2000). Two prenatal alcohol use instruments compared with a physiological measure. *Journal of obstetrical, gynecological, and Neonatal Nursing*, 29, 129-136.
- Bugental, D., & Cortez, V. (1988). Physiological reactivity to responsive and unresponsive children as modified by perceived control. *Child development*, 59, 686-693.
- Burr, W.R. (1976). *Successful marriage: A principle approach*. Homewood, Illinois: The Dorsey Press.
- California Fetal Alcohol Spectrum Organization. (2004, April). FASD News: *Fetal alcohol Syndrome and Alcohol Related Disorders*, 1 (10). Retrieved August 10, 2004, from <http://www.calfas.org>.
- Callery, P. & Luker, K. (1996). The use of qualitative methods in a study of patients' experiences of care on a children's surgical ward. *Journal of Advancing Nursing*, 23, 338-345.
- Canadian Pediatric Society. (2002). Fetal Alcohol Syndrome. *Pediatric Child Health*, 7 (3), 161-174.
- Carlson, M., & McLanahan, S. (2001). Shared parenting in fragile families. Center for Research on Child Wellbeing Working Paper #01-16-FF. Princeton University.
- Chudley, A.E., Conry, J., Cook, J.L., Lock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172 (5).
- Cicchetti, D., Rogosch, F.A., Toth, S.L., & Spagnola, M. (1997). Affect, cognition, and the emergence of self-knowledge in toddlers offspring of depressed mothers. *Journal of Experimental Child Psychology*, 67, 338-362.

- Clark, E, Lutke, J, Minnes, P. & Ouellette-Kuntz. (2004). Secondary Disabilities among Adults with Fetal Alcohol Spectrum Disorder in British Columbia. *Journal of Fetal Alcohol Syndrome International*, 2 (13).
- Clarke, C.E. (2003). Community integration and independence among adults with fetal alcohol spectrum Disorder in British Columbia. Unpublished master's thesis, Queen's University, Kingston, Ontario, Canada. Retrieved August 2, 2004, from <http://www.fasdconnections.ca>.
- Clarke, M., & Tough, S. (2003). Health Canada Preliminary Results/Final Report. A National Survey Regarding Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome. Retrieved May 5, 2004 from, <http://www.fasdconnections.ca>.
- Clarren, S.K. (1986). Neuropathology in fetal alcohol syndrome. In J. R. West (Ed), *Alcohol and Brain Development*. New York: Oxford University Press.
- Clarren, S.K., Astley, S.J., & Bowden, D.M. (1988). Physical anomalies and developmental delays in nonhuman primate infants exposed to weekly doses of ethanol during gestation. *Teratology*, 37 (6), 561-569.
- Clarren, S.K., & Smith D.W. (1978). The Fetal alcohol syndrome. *New England Journal of Medicine*, 298 (19), 1063-1067.
- Cohen, B.J. (2002). Alternative organizing principles for the design of service delivery system. *Administration in Social Work*, 26, 17-38.
- Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In R. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48-17). New York: Oxford University Press.

- Connor, P.D., Sampson, P.D., Bookstein, F.L., & Streissguth, A.P. (2000). Direct and indirect effect of prenatal alcohol damage on executive functions. *Developmental Neuropsychology*, 18 (3), 331-354.
- Connor, P. D., Streissguth, A. P. (1996). Effect of prenatal alcohol exposure across The Life Span. *Alcohol Health & Research World*, 20 (3), 170.
- Connor, P.D., Streissguth, A.P., Sampson, P.D., Bookstein, F.L., & Barr, H.M. (1999). Individual differences in auditory and visual attention among alcohol-affected adults. *Alcohol Clinical Experimental Research*, 23 (8), 1395-1402.
- Cook, C. S., Nowotny, A. Z., & Sulik, K. K. (1987). Fetal alcohol syndrome. Eye malformations in a mouse model. *Archive of Ophthalmology*, 105 (11), 1576-1581.
- Cramer, B. (1987). Objective and subjective aspects of parent-infant relations: An attempt at correlation between infant studies and clinical work. In J.D. Osofsky, (Ed.), *Handbook of Infant development* (pp.1037-1058). New York: Wiley.
- Cross, G. & Marks, B. (1996). Special families, special needs. *Nursing Times*, 92 (13), 38-40.
- Cunningham, C., Benness, B., & Siegel, L. (1988). Family functioning, time, allocation, and parental depression in families of normal and ADDH children. *Journal of Clinical Child Psychology*, 17, 169-177.
- Davies, A. (1999). Parent-held child health records: An evaluation of parental attitudes. *British Journal of Community Nursing*, 4 (5), 242-249.
- DeMulder, E., & Radke-Yarrow, M. (1991). Attachment with effectively ill and well mothers: Concurrent behavioural correlates. *Developmental and Psychopathology*, 3, 1



- Denzin, N. (1978). *The research act* (2<sup>nd</sup> ed.) New York: McGraw-Hill.
- Dill, B.T. (1998). A better life for me and my daughter: Low-income single mother's struggle for self-sufficiency in rural South. *Journal of Comparative Family Studies*, 29, 419-428.
- Dorris, M. (1989). *The broken cord*. New York: Harper & Row.
- Dowdney, L., & Skuse, D. (1993). Parenting provided by adults with mental retardation. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 34, 25-47.
- Famy, C., Streissguth, A.P., & Unis, A.S. (1998). Mental illness in adults with Fetal alcohol Syndrome or Fetal Alcohol Effects. *American Journal of Psychiatry*, 155 (4), 552.
- Fauber, R., Forehand, R., Thomas, A., & Wierson, M. (1990). A mediational model of the impact of marital conflict on adolescent adjustment in intact and divorced families: The role of disrupted parenting. *Child Development*, 61 (4), 1112.
- Feldman M. (1986) Research on parenting by mentally retarded persons. *Psychiatric Clinics of North America*, 9 (4), 777-796.
- Feldman, M. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies, *Research in Developmental Disabilities*, 15 (4), 299-332.
- Feldman, M. (1998). Parent with intellectual disabilities: Implications and interventions. In J.R. Lutzker (Ed.) *Handbook of child abuse and neglect research*. (pp.401-419). New York: Plenum.
- Feldman, M. A., Case, L., Garrick, M., MacIntyre-Grande, W., Carnwell, J., & Sparks, B. (1992). Teaching child-care skills to parents with developmental disabilities. *Journal of Applied Behavior Analysis*, 25, 205-215.

- Feldman, M. A., Case, L., & Sparks, B. (1992). Effectiveness of a child-care training program for parents at-risk for child neglect. *Canadian Journal of Behavioral Science*, 24, 14-28.
- Feldman, M.A., Case, L., Towns, F., Betel, J. (1985). Parent education project I: Development and nurturance of children of mentally retarded parents, *American Journal of Mental Deficiency*, 90, 253-258.
- Feldman, M., & Walton-Allen, N. (1993). Intellectual, academic and behavioural status of school-age children: maternal mental retardation and poverty. In M. Feldman. Parenting education for parents with intellectual disabilities: A review outcome studies. *Research in developmental disabilities*, 15(4), 299-332.
- Fendrich, M., Warner, V., & Weissman, M. (1990). Family risk factors, parental depression, and psychopathology in offspring. *Developmental Psychology*, 26, 40-50.
- Ford, D.L., & Lerner, R.M. (1992). *Developmental systems theory: An integrative approach*. Newbury Park, California: Sage.
- Friedler, G. (1988). Effect on future generations of paternal exposure to alcohol and other drugs. *Alcohol, Health and Research World*, 126-129.
- Gath, A. (1988). Mentally handicapped people as parents. Is mental retardation a bar to adequate parenting? *Journal of Child Psychology and Psychiatry* 29 (6), 739-744.
- Gelfand, D. & Teti, D. (1990). The effects of maternal depression on children. *Clinical Psychology Review*, 10, 329-353.
- Gillberg, C., & Geijer-Karlsson, M. (1983). Children born to mentally retarded women: A 1-21 year follow-up study of 41 cases. *Psychological Medicine*, 13, 891-894.

- Glaun, D., & Brown, P. (1999). Motherhood, intellectual disability and child protection: Characteristics of a Court Sample. *Journal of Intellectual and Developmental Disability, 24* (1), 95.
- Goodlett, C. R. & Horn, K. H. (2001). Mechanism of alcohol induced damage to the developing nervous System. *Alcohol Research & Health, 25* (3, 175).
- Greenbaum, R. & Koren, G. (2002). Fetal alcohol spectrum disorder – New diagnostic initiatives. *Paediatrics & Child Health, 7* (3), 139-141. Retrieved August 06, 2004, from <http://www.pulsus.com/Paeds/>.
- Hashima, P.Y., & Amato, P.R. (1994). Poverty, social support, parental behaviour. *Child Development, 65*, 394-403.
- Hayman, R.L. (1990). Presumptions of justice: Law. Politics and the mentally retarded parents. *Harvard Law Review, 103*, 1201-171.
- Health Canada. (1996). *Joint statement: Prevention of fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) in Canada*. Ottawa.
- Health Canada. (1998). *Alcohol and pregnancy. Canadian Perinatal Surveillance System*. Retrieved July 20, 2004, from <http://www.hc-sc.gc.ca>.
- Health Canada. (2000, May). fetal alcohol syndrome/ fetal Alcohol Effects. [News release]. Retrieved June 09, 2004, from <http://www.hc-sc.gc.ca>.
- Hertz R. (1979) Retarded parents in neglect proceedings: The erroneous assumption of parental inadequacy. *Stanford Law Review 31*, 785–805.
- Hinde, R. (1989). Ethological relationships and approaches. In R. Vasta (Ed), *Annals of Child Development* (Vol. 6, pp. 251-285). Greenwich, CT: JAI Press.

- Hoyme, H.E., May, P.A., Kalberg, W.O., Kodituwakku, P., Gossage, J.P., Trujillo, P.M., Buckley, D.G., Miller, J.H., Aragon, A. S., Khaole, N., Viljoen, D.L., Jones, K.L., & Robinson, L.K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorder: Clarification of the 1996 Institute of Medicine Criteria. *Pediatrics*, 115 (1), 39-47.
- Hurley, D.J., Chiodo, M.A., Leschied, A., & Whitehead, P. (2003). Correlates of a measure of parenting capacity with parents and child characteristics in child welfare sample. London, Ontario: King's College, The University of Western Ontario. Retrieved March 10, 2005, from <http://www.edu.uwo.ca/CAS>.
- Jones, K.L. & Smith, D.W., (1973). Recognition of the fetal alcohol syndrome in early infancy. *Lancet*, 2 (836), 999-1001.
- Kaatz J. (1992). Enhancing the parenting skills of developmentally disabled parents: A nursing perspective. *Journal of Community Health Nursin*, 9 (4), 209–219.
- Kendziora, K.T., & O'Leary, S.G. (1993). Dysfunctional parenting as a focus for prevention and treatment. In T.H. Ollendick, & R.J. Prinz (Eds.), *Advances in Clinical Child Psychology*, 5,
- Keltner, B. (1993). *Mothers with intellectual limitations*. Final report of a project supported by, (Grant No. 1B15NR02578-01), National Institute of Nursing Research, National Institute of Health. Retrieved April 8, 2005, from <http://ninr.nih.gov/ninr/news-info/publications.html>.
- Kerns, J., Don, A., Mateer, C.A., & Streissguth, A.P. (1997). Cognitive deficits in nonretarded adults with fetal alcohol syndrome. *Journal of Learning Disabilities*, 30 (6), 685-693.

- Kinard, E., & Klerman, L.V. (1980). Teenage parenting and child abuse: Are they related? *American Journal of Orthopsychiatry*, 50, 481-488.
- Kleinfeld, J., Morse, B., & Wescott, S. (Eds). (2000). *Fantastic Antoine grows up. Adolescents and Adults with Fetal alcohol Syndrome*. Fairbanks: University of Alaska Press.
- Knowledge Network, FAS Community Resource Center, (2002). *FAS: When the children grow up*. Retrieved October 10, 2003 from, [http://www.knowledgenetwork.ca/know\\_tool/fas/resources/documentary/index.html](http://www.knowledgenetwork.ca/know_tool/fas/resources/documentary/index.html).
- Kochanska, G., Kuczynski, L., Radke-Yarrow, M., & Welsh, J. (1987). Resolution of control episodes between well and affectively ill mothers and their young child. *Journal of Abnormal Child Psychology*, 15, 441-456.
- Kodituwakku, P.W.; Handmaker, N.S.; Cutler, S.K.; Weathersby, E.K., & Handmaker, S.D. (1995) Specific impairments in self-regulation in children exposed to alcohol prenatally. *Alcoholism: Clinical and Experimental Research*, 19 (6), 1558-1564.
- Koeske, G.F., & Koeske, R.D. (1990). The buffering effect of social support on parental stress. *American Journal of Orthopsychiatry*, 60 (3), 440-451.
- Kroese, B.S., Hussein, H., Clifford, C. and Ahmed, N. (2002). Social support network and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual disabilities*, 15 (4), 324-340.
- Ladue, R.A., Schacht, R.M., Tanner-Halverson, P., & McGowan, M. (1999). Fetal Alcohol Syndrome: A training manual to aid in vocational rehabilitation and other non-medical services. Retrieved July 10, 2004, from <http://www.fasdconnections.ca>.

- Ladue, R.A, Streissguth, A.P, & Randels, S.P., (1992). Clinical considerations pertaining to adolescents and adults with fetal alcohol syndrome. In T.B., Sondregger, (Ed.). *Perinatal substance abuse: Research findings and clinical implications* (pp. 104-131). Baltimore: John Hopkins University Press.
- Leach, M.S., & Braithwaite, D.O. (1996). A binding tie: Supportive communication of family kinkeepers. *Journal of Applied Communication Research*, 24 (3), 200-216.
- Llewellyn, G. (1994). Generic family support services: Are parents with learning disability catered for? *Mental Handicap Research*, 7, 1-14.
- Llewellyn, G. (1995). Relationships and social support: Views of parents with mental retardation. *Mental Retardation*, 33, 349-363.
- Lutke, J. (2004a). *Adults with fetal alcohol spectrum disorder: Swimming upstream- A reality check*. Opening Remarks at the First National Conference on Adults Conference. Retrieved July, 08, 2004, from [www.fasdconnections.ca](http://www.fasdconnections.ca).
- Lutke, J. (2004b). *The Multiple "A" System of Service Delivery for Adolescents and Adults with FASD*. Retrieved July, 08, 2004, from [www.fasdconnections.ca](http://www.fasdconnections.ca).
- Lutke, J & Antrobus, T (2004). FASD and 'the system': Adolescents, adults and their families and the state of affairs. Retrieved December 10<sup>th</sup>, 2004, from [www.fasdconnections.ca](http://www.fasdconnections.ca).
- Lyons-Ruth. K., Easterbrooks, M.A., & Cibelli, C.D. (1997). Infant attachment strategies, infant mental lag, and maternal depressive symptoms: Predictors of internalizing and externalizing problems at age 7. *Developmental Psychology*, 33, 681-692.

- Lyons-Ruth, K., Zoll, D., Connell, D., & Grunebaum, H.U. (1986). The depressed mother and her one-year-old infant: Environment, interaction, attachment, and infant development. *Child Development*, 34, 61-82.
- Mattson, S.N.; Riley, E.P.; Jernigan, T.L.; Garcia, A.; Kaneko, W.M.; Ehlers, C.L. & Jones, K.L. (1994). A decrease in the size of the basal ganglia following prenatal alcohol exposure: A preliminary report. *Neurotoxicology and Teratology*, 16 (3), 283-289.
- Mattson, S. N., Jernigan, T. L., & Riley, E. P. (1994). MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research*, 18(1), 49-52.
- Mattson, S. N., & Riley, E. P. (1995). Prenatal exposure to alcohol: What the images reveal. *Alcohol Health & Research World*, 19 (4), 273-278.
- Mattson, S. N., Schoenfeld, A. M., Riley, E. P. (2001). Teratogenic effect of alcohol on brain and behavior. *Alcohol Research & Health*, 25 (3), 185.
- Michaelis, E. K., and Michaelis, M. L. (1994). Cellular and molecular bases of alcohol's teratogenic effects. *Alcohol Health & Research World*, 18 (1), 7-21.
- Mickelson, P. (1947) The feeble-minded parent: A study of 90 family cases. *American Journal of Mental Deficiency*, 51(4), 644-653.
- Miller, M.W. (1992). *Development of the central nervous system: Effects of alcohol and opiates*. New York, USA: Wiley-Liss, Inc.
- Milner, J.S. & Chilamkurti, C. (1991). Physical child abuse perpetrator characteristics: A review of the literature. *Journal of Interpersonal Violence*, 6, 345-366.
- Miner, S. & Uhlenberg, P. (1997). Intergeneration proximity and the social role of sibling neighbours after midlife. *Family Relations*, 46, 45-153.

- Ministry of Children and Family Development. (2004). Community living services for adults. Retrieved July 10, 2004, from <http://www.mcf.gov.bc.ca>.
- Morgan, D.L. (1998). *Planning focus groups*. California: Sage Publication, Inc.
- Murray, L. (1992). The impact of postnatal depression on infant development. *Journal of Child Psychology & Psychiatry*, 33 (3), 543-561.
- Nanson, J.L., Bolaria, R., Snyder, R. E., Morse, B.A. & Weiner, L.W. (1995). *Canadian Medical Association Journal*, 152, 1071-1076.
- Nolen-Koeksema, S., Wolfson, A., Mumme, D., & Guskin, K. (1995). Helplessness in children of depressed and nondepressed mothers. Special Section: Parental depression and distress: Implications for development in infancy, childhood and adolescence. *Developmental Psychology*, 31, 377-387.
- Novick, N.J. & Streissguth, A.P. (1996). Thoughts and treatments of adults and adolescents impaired by fetal alcohol exposure. *Treatment Today*, 7 (4), 20-21.
- Nunley, K.W. (2001). *Behavioral changes in adult C57BL/6J mice following prenatal exposure to ethanol*. Unpublished manuscript, East Tennessee State University. Retrieved July, 20, 2004, from <http://www.fasdconnections.ca>.
- Osborne, J. (1990). Some basic existential-phenomenological research methodology for counsellors. *Canadian Journal of Counselling*, 24, 79-91.
- Page, K. (2002). The invisible havoc of prenatal alcohol damage. *Journal of the Center for families, Children & the Court*. Retrieved July, 20, 2004, from <http://www.fasdconnections.ca>.



- Pennington, B.F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of Child Psychology & psychiatry & allied Disciplines*, 37 (1), 51.
- Pope, C., Ziebland, S. & Mays, N. (1999). *Qualitative Research in Health Care*. London: BMJ Publishing Group
- Radke-Yarrow, M., Cummings, E.M., Kuczynski, L., & Chapman, M. (1985). Patterns of attachment in two and three year olds in normal families and in families with parents depression. *Child Development*, 56, 884-893.
- Randall, C.L. & Taylor, W.J. (1979). Prenatal ethanol exposure in mice: Teratogenic effects. *Teratology*, 19 (3), 305-311.
- Ray, N. K., Rubenstein, H., & Russo, N. J. (1994). Understanding the parents who are mentally retarded: Guidelines for family preservation programs. *Child Welfare*, 23 (6), 725-743.
- Reder, P. & Lucey, C. (1995). *Assessment of parenting-psychiatric and psychological contributions*. London: Routledge.
- Richardson, D. (1993). *Women, motherhood and childrearing*. London: The MacMillan Press Ltd.
- Riley, E.P., Mattson, S.N., Sowell, E.R., Jernigan, T.L., Sobel, D.F., & Jones, K.L. (1995). Abnormalities of the corpus callosum in children prenatally exposed to alcohol. *Alcoholism: Clinical and Experimental Research*, 19 (5), 1198-1202.
- Roberts, G. & Nanson J. (2000). Best Practices: fetal alcohol syndrome/fetal alcohol effects and the effects of other substance use during pregnancy. Canada's Drug Strategy Division, Health Canada.

- Roebuck, T. M., Mattson, S. N., & Riley, E. P. (1998). A review of the neuroanatomical findings in children with fetal alcohol syndrome or prenatal exposure to alcohol. *Alcoholism: Clinical and Experimental Research*, 22 (2), 339-344.
- Russell, A. (2002). *Report on the Yukon 2002 paired northern conference fetal alcohol syndrome and fetal alcohol spectrum disorder in Australia*. National organization for foetal alcohol syndrome and related disorders.
- Rutman, D., LaBerge, C., & Whewey, D. (2002). *Adults living with FAS/E: Experiences and support issues in British Columbia*. FAS/E Support Network of B.C., and University of Victoria School of Social Work.
- Sampson, P., Kerr, B., Carmichael, O. H., Streissguth, A.P., Hunt, E., Barr, H., Bookstein, F., & Thiede, K. (1997). The effects of prenatal alcohol exposure on adolescent cognitive processing: A speed-accuracy tradeoff. *Intelligence*, 24, 329-353.
- Sampson, P.D., Streissguth, A.P. & Bookstein, F.L. (1989). Neurobehavioural effects of prenatal alcohol: Part II. Partial least squares analysis. *Neurotoxicology and Teratology*, 11, 477-491.
- Sandor, S., Smith, D., MacLeod, P., Tredwell, S., Wood, B., & Newman, D. (1981). Intrinsic defects in fetal alcohol syndrome: studies of 76 cases from BC and the Yukon. *Neurobehavioural Toxicology and Teratology*, 3, 145-152.
- Sinclair, D. & Murray, L. (1998). Effects of postnatal depression on children's adjustment to school. Teacher's reports. *British Journal of Psychiatry*, 172, 58-63.
- Skagit County Community Action Agency. (2001). *Low-income needs assessment report*. Retrieved June, 02, 2005, from <http://www.skagitcap.org>.

- Spohr, H.L. & Steinhausen, H.C. (1987). Follow-up studies of children with fetal alcohol syndrome. *Neuropediatrics*, 18 (1), 13-17.
- Spohr, H.L., Willms, J. & Steinhausen, H.C. (1993). Prenatal alcohol exposure and longterm developmental consequences. *Lancet* 341 (8850), 1.
- Stade, B., Clark, K. & D'Agostino, D. (2004). *Fetal alcohol spectrum disorder and homelessness training manual*. Human Resources Development Canada. Retrieved August 10, 2004, from <http://www.fasdconnections.ca>.
- Stein, A., Gath, D.H., Bucher, J., Bond, A., Day, A. & Cooper, P.J. (1991). The relationship between post-natal depression and mother-child interaction. *British Journal of Psychiatry*, 158, 46-52.
- Steinhausen, H.C., Willms, J. & Spohr, H.L. (1993). Longterm psychopathological and cognitive outcomes of children with fetal alcohol syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32 (5), 990-994.
- Stratton, K., Howe, C. & Battaglia, F. (Eds), (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine, Washington, D.C: National Academic Press.
- Stewart, D.W. & Shamdasani, P.N. (1990). *Focus Groups: Theory and Practice*. California: Sage Publication, Inc.
- Streissguth, A.P. (1986). The behavioural teratology of alcohol: Performance, behavioural and intellectual deficits in prenatally exposed children. In J. West, (Ed.) *Alcohol and Brain development* (p.344). New York: Oxford University Press,.
- Streissguth, A.P. (1994). A long-term perspective of FAS. *Alcohol Health & Research World*, 18 (1), 74.

Streissguth, A.P.; Aase, J.M.; Clarren, S.K.; Randels, S.P.; Ladue, R.A. & Smith, D.F.

(1991). Fetal alcohol syndrome in adolescents and adults. *Journal of the American Medical Association* 265 (15), 1961-1967.

Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F.L. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE). Final report to the Center for Disease Control and Prevention, (Grant No. R04/ccR008515)*. Seattle, Washington: University of Washington School of Medicine, Department of Psychiatry and Behavioural Science.

Streissguth, A.P. & Kante, J. (1997). *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities*. Seattle: University of Washington Press.

Streissguth, A.P., Ladue, R.A. & Randels S.P. (1988). *A manual on adolescent and adults with fetal alcohol syndrome with special reference to American Indians*. Seattle: University of Washington.

Streissguth, A.P. & O'Malley, K. (2000). Neuropsychiatric implications and long term consequences of fetal alcohol spectrum disorders. *Seminars in Clinical Neuropsychiatry*, 5, 177-190.

Swayze II, V.W., Johnson, V. P., Hanson, J. W., Piven, J., Sato, Y., Giedd, J. N., Mosnik, D. & Andreasen, N.C. (1997). Magnetic resonance imaging of brain anomalies in fetal alcohol syndrome. *Pediatrics*, 99, 232-240.

Taylor, C. G., Norman, D. K., Murphy, J. M., Jellinek, M., Quinn, D., Poitras, F. G. & Goshko, M. (1991). Diagnosed intellectual and emotional impairment among parents

who seriously mistreat their children: Prevalence, type, and outcome in a court sample.

*Child Abuse and Neglect*, 15, 389-401.

Teti, D.M., Gelfand, D.M., Messinger, D.S. & Isabella, R. (1995). Maternal depression and the quality of early attachment: An examination of infants, preschoolers, and their mothers. *Developmental psychology*, 31, 364-376.

Turner, J.S. & Helms, D.B. (1979). *Contemporary adulthood*. Washington: W.B. Saunders Company.

Tymchuk, A. J. & Andron, L. (1990). Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect*, 14, 313-323.

Tymchuk A., Andron L. & Rahbar B. (1988). Effective decision-making/problem-solving training with mothers who have mental retardation. *American Journal on Mental Retardation*, 92 (6), 510-516.

Wald, M. (1975). State intervention on behalf of neglected children: A search for realistic standards. *Stanford Law Review*, 27, 985-1040.

Walton-Allen, N. G., & Feldman, M. A. (1991). Perception of service needs by parents with mental retardation and their workers. *Comprehensive Mental Health Care*, 1, 137-147.

Westbrook, M.T. & Chinnery, D.L. (1990). Negative attitudes toward physically disabled women having children: An additional handicap. *Australian Social Work*, 43 (4), 17-22.

World Health Organization. (1997). *Fetal alcohol syndrome*. Retrieved October 10, 2003 from <http://www.who.int/msc/mnh/mnd/prev.htm>.

- Zahn-Waxler, C., McKnew, D. H., Cummings, E. M., Davenport, Y.B. & Radke-Yarrow, M. (1984). Problem behaviours and peer interactions of young children with a manic-depressive parents. *American Journal of Psychiatry*, 141, 236-240.
- Zahn-Waxler, C., Iannotti, S., Cummings, E. & Denham, S. (1990). Antecedants of problem behaviours in children of depressed mothers. *Development and Psychopathology*, 2, 271-291.
- Zuravin, S.J. (1988). Child maltreatment and teenage first births: A relationship mediated by chronic sociodemographic stress? *American Journal of Orthopsychiatry*, 58, 91-103.

## APPENDIX A

### Focus Group Measures

Family Case Workers  
Focus group interview guide

1. Welcome and introductions
2. Introduction of topic for discussion
3. Brief description and purpose of the study
4. Discuss informed consent form with regards to issues of confidentiality, reassurance of anonymity, of value of opinion and voluntary nature of participation, as well as use of audio recording procedure. Obtain informed consent.
5. Outline ground rules for the session
  - I. Refrain from mentioning any names during the session so as to ensure anonymity and privacy of each individual taking part in the session
  - II. Explain the importance of allowing each person to express his/her opinion, and being mindful of dominating the discussion
  - III. All stated opinions are confidential and should not be repeated outside this room.
6. **Ask the participants the following questions:**
  - I. What type of service(s) does your organization, agency, or department provide (e.g., outreach, addiction treatment etc.)?
  - II. What group does your agency, organization or department target?
  - III. Do you have any parents in your case load who have FASD or are suspected to have FASD?  
 [probe:] *How do you identify them?*
  - IV. From your observations and experience of working with families what are the needs of parents with FASD?  
 [probes :]
    - *What reason would you give to explain the needs you have identified?*
    - *How do you see those needs impacting the parent's ability to effectively carry out his/her role as a parent?*



- V. What are some of the needs that have been expressed to you by parents affected with FASD?
- VI. In your experience what would help these parents
- (a) that is currently available?
  - (b) that needs to be develop?
- VII. What, if any, are the barriers that exist for your agency or organization in providing services for parents with FASD?
- VIII. Does your agency have one or more specific programs aimed towards parents with FASD?
- YES:** Name the programs and the services provided by them (e.g. day care, counselling, and outreach)
- NO:** Within your current program structure do you provide services (e.g., counselling, referrals) within more general programming (e.g., nutrition program, head start) for FASD parents.
- IX. What sort of information service, or support have you found useful in assisting parents with FASD?
- X. Within the framework of the services you offer to parents with FASD what are the target outcomes that these services aim for?
- XI. What are the service links, both formal (e.g., treatment referral) and informal, that you as a service provider have with other service providers or agencies that address the needs of parents with FASD? **Do these service links break down?**
- Transitional statement:*** let's talk about services, support and other needs of parents with FASD
- XII. Approximately what percentages of parents who enter the program complete it?
- XIII. What type of support does your organization offer to parents with FASD who have completed your program? (e.g., support group, counselling service, aftercare treatment)

- XIV. As a service provider what do you think are the main reasons why a parent with FASD or parent suspected to be affected with FASD is, or is not, successful in completing the program?
- XV. When parents drop out of the program before completion, what avenues, if any, do you have to reconnect with these parents?
- XVI. Do you notice any patterns or cycles happening in which parents repeats the program at least two or three times? **If yes**
- XVII. What do you think are the reasons why they repeat the program?
- XVIII. As a service provider, what services (either existing or new) would you like to see developed or enhanced to help you better support parents with FASD?
- XIX. Do you have any suggestions and comments about improving services and support for parents affected with FASD?
- XX. Is there anything else you would like to say?

**Thank you for your participation.**

If you have questions regarding the service provider question or this study in general please call Velma Abraham at **960-6061** or email: **[abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)**.

Service providers

Demographic Information

Date and time: \_\_\_\_\_

Group code: \_\_\_\_\_

Please tick the appropriate box

Section 1: About you

Age:

- ☐ 20 – 25
- ☐ 26 – 31
- ☐ 32 - 37
- ☐ 38 and over

Gender \_\_\_\_\_

1. Which organization, social service department (or other) do you work for?  
\_\_\_\_\_
2. Please describe your professional background (e.g. social work, mental health etc)  
\_\_\_\_\_  
\_\_\_\_\_
3. How many years of experience do have you working with families? \_\_\_\_\_
4. Have you ever worked with parents who are affected with FASD? **\_\_YES\_\_ NO**
5. Please describe the education and training you have received (if any) on supporting parents with FASD in pregnancy and parenthood.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Section 2: Working with parents who have FASD**

6. How often do you work with parents who have FASD?

Most days ☐

Once a week ☐

Once a month ☐

Rarely ☐

Never ☐

Other (please specify) .....

7. When working with a parent who is affected with FASD or is suspected to be affected with FASD, which of the following activities are you involved in?

*Please indicate how often you engage in these activities by ticking the box that most closely reflect your experience.*

Activity	Never	Rarely	Sometimes	Often
Assessment of parenting skills				
Child protection issues				
Practical advice and support with developing parenting skills				
Advocacy on behalf of the parent				
Parenting class or parenting skills training				
Vocational and other skills training				
Assessment of parenting needs				

Other activities (please specify): \_\_\_\_\_

8. Published literature suggests that some difficulties may arise in working with this client group.

*From your experience of working with parents who are affected with FASD. Please indicate which statement you agree with or disagree with by ticking the appropriate box.*

Statement	Agree	Not Sure	Disagree
Parents with FASD fail to anticipate the demands children will make on them			
There is little systematic planning of care for families where the parent(s) are affected with FASD			
Professionals are often unaware of what services are available			
Professional intervention are usually 'crisis interventions'			
Parents with FASD can do and learn , but need specialized help			
Professionals require further training to properly assist parents with FASD			
Professionals focus on inadequacies of parents with FASD, rather than focusing on ways to help meet their needs			
Parents with FASD have low adaptive skills (e.g. home management, money management, time management etc)			

9. Which of the following service developments (if any) would be useful for parents with FASD?

*Please indicate your views by ticking the appropriate box in the table below.*

Service Development	Unnecessary	Useful	Essential
Special parenting project(s) for parents with FASD			
More one-to-one support from organizations and agencies such as MCFD			
Parenting skills group(s) for parents with FASD			
Family planning services specifically targeting parents with FASD			
Specialist assessments and referral of parents with FASD			

### Section 3: Provision of services and supports for parents with FASD

Please indicate how your agency, organization or department works with others to provide services to parents with FASD.

*Please indicate your views by ticking the appropriate box in the table below*

Service links	Often	Occasionally	Never
We do referral of parents with FASD to other agencies			
Parents with FASD are referred to us by other agencies, etc.			
We hold joint client consultation with other agencies			
There is inter-agency exchange of program information and services			
There is collaboration with health care providers			

What strategies does your agency, organization or department use to provide services to parents with FASD? *(Please tick all those that are applicable)*

Providing information and education about FASD	
Providing information about child care (e.g. healthy nutrition)	
Promoting prenatal/postnatal health care	
Referral to other community services	
Facilitating access to child care	
Home visits/ outreach	
Parent/family support program	
Accompaniments to appointments	
Appointment reminders	
Transportation arrangements	
Identify at risk-parents/families	
Provide information and access to birth control	
Provide counselling	
Assist with job search	

Other \_\_\_\_\_

*Please circle the appropriate answer and provide a short reason in point form for your response*

<b>Question</b>	<b>Response</b>	<b>Reason for answer</b>
Do you think that parents with FASD experience problems in accessing/using services and support?	Yes / No	
Do you think that services, support and information available to parents with FASD are appropriate?	Yes / No	
Do you think that service, support, and information available to parents with FASD are relevant?	Yes / No	

Does your organization receive any special funding to provide services that specifically target parents with FASD?

Yes \_\_\_\_ No \_\_\_\_

***Thank you for your participation.***

*If you have questions regarding the service provider question or this study in general please call Velma Abraham at 960-6061 or email: [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca).*

**Service providers****Post-Discussion Comment Sheet**

We greatly appreciate your participation in this discussion. Please take the last few minutes to complete this form and turn it into the meeting facilitator ***before*** you leave. Your opinions and feelings provide us with important information about this discussion and will help us in the future. Thank you.

- 1) Are there any feelings or opinions you have that you didn't share during the discussion that we should know? Please describe in as much detail as possible.

- 2) Any comments about the discussion itself and/or the moderator?

---

**For researcher's use only:**

**Date of focus group** \_\_\_\_\_

**Location** \_\_\_\_\_

**Group Code** \_\_\_\_\_



## APPENDIX B

### Parents' Interview Guide

## Interview Guide for parental need assessment

1. Introductions
2. Brief description and purpose of the study
3. Discuss consent form in details, as it relates to the use of audio recording procedure, as well issues of confidentiality, reassurance of anonymity, of value of opinion and voluntary nature of participation. Obtain consent to take participate in the study.
4. Obtain demographics

**Date:** \_\_\_\_\_

**Initials of individual conducting the interview:** \_\_\_\_\_

**Location of where survey was filled out:**

\_\_\_\_\_

Age \_\_\_\_\_ Gender \_\_\_\_\_

I. Number of children in each age category:

- a) 0-11 months \_\_\_\_\_
- b) 1 year \_\_\_\_\_
- c) 2 years \_\_\_\_\_
- d) 3 years \_\_\_\_\_
- e) 4 years \_\_\_\_\_
- f) 5 years \_\_\_\_\_
- g) Other \_\_\_\_\_

II. Please indicate your ethnicity (For example: Asian, African Canadian, Caucasian, Aboriginal, other) please specify \_\_\_\_\_

III. Are you a

- a) single parent \_\_\_\_\_
- b) married \_\_\_\_\_
- c) common law \_\_\_\_\_
- d) divorced \_\_\_\_\_
- e) other \_\_\_\_\_

IV. Education

- a) Grade 8 or less
- b) Grade 9 - 11

- c) Grade 12
- d) Some College
- e) College diploma
- f) Some university
- g) University degree

V. What is the primary language spoken by adults in the home? (Check one)

- a) English
- b) French
- c) Other (Please specify): \_\_\_\_\_

VI. Do (es) your child(ren) currently attend school, or any childcare program?

- a) Yes
- b) No

VII. If yes, please specify which type of program or school he/she/they attend?

<i>Number of Child(ren)</i>	<i>Age</i>	<i>Gender</i>	<i>School</i>

5. Ask the participants the following questions:

I. What is it like being a parent?

***Probes:***

- What has helped you to be a good parent?
- Do you have any challenges regarding your role as a parent? What are they?
- What is it you need to help you feel more confident in your ability as a parent?

***Transitional statement: Lets talk about the support your receive***

II. Who do you receive help with parenting from?

*Husband*                      *Wife*                      *Mother*                      *Father*                      *Friends*  
*Relatives*                      *community health / social worker*

III. Who has been most helpful to you? \_\_\_\_\_

- What kind of support do you receive from your advocate, partner, family, and friend?
- How does that affect your parenting role?

IV. Are there any organizations or community groups that you get support from?

Which one? \_\_\_\_\_

V. Where do you go when you and your child(ren) have problems?

VI. Whom do you call when you have an emergency or some difficulties arise?

***Transitional statement: lets talk about services***

VII. What kinds of services are you currently using or have used in the past? From whom?

**Using a rating scale of (1) for Very helpful (2) for sometimes helpful (3) not**

**helpful**

Can you rate the services you have received or are currently receiving?

<i>Type of services</i>	<i>Ratings</i>

- What kind of services you find most helpful to you?

- Are you satisfied with the services you are currently receiving? Why
- Do you have access to services you need?
- What is the most important service you need?

***Transitional statement: Lets talk about parenting information***

VIII. Do you have access to parenting information you think is useful to you?

- What is it?
- Where did / or are you getting it from?

IX. What is the most important information you need?

X. What would you like of information would you like to know more?

XI. How would you like to get that information?

***Transitional statement: lets talk about your expectations***

XII. What were your expectations about parenting?

XIII. How have current services and support helped to achieve your expectation?

XIV. Are there any expected services or support you did not get?

XV. Do you have any suggestions that would help support services better meet your needs?

***Transitional statement: let's talk about the things that you need and do not have***

Which *early care and education* services do you **NEED** and **DO NOT** have

---



---



---



---

Which *health and social services* do you **NEED** and **DO NOT** have?

---



---

Which *parenting and family support* services do you **NEED** and **DO NOT** have?

---

---

---

Financial situation

- a) No income assistance
- b) Dependent on others, whom? \_\_\_\_\_
- c) Income assistance
- Others \_\_\_\_\_

## APPENDIX C

### Advocates' Interview Guide

## Interview Guide for Advocates

- 1) Introductions
- 2) Brief description and purpose of the study
- 3) Discuss consent form in details, as it relates to the use of audio recording procedure, as well issues of confidentiality, reassurance of anonymity, of value of opinion and voluntary nature of participation. Obtain consent to take participate in the study.
- 4) Obtain demographics

**Date and time:** \_\_\_\_\_ **participant's ID:** \_\_\_\_\_  
**Initials of individual conducting the interview:** \_\_\_\_\_  
**Location of where survey was completed:** \_\_\_\_\_

Age \_\_\_\_\_ Gender \_\_\_\_\_

VIII. Please indicate your ethnicity (For example: Asian, African Canadian, Caucasian, Aboriginal, other) please specify \_\_\_\_\_

- IX. Education
- h) Grade 8 or less
  - i) Grade 9 - 11
  - j) Grade 12
  - k) Some College
  - l) College diploma
  - m) Some university
  - n) University degree

I. What is your relationship to the parent?

**Parent   Sibling   Grandparent   Social worker   other** \_\_\_\_\_

II. Approximately how many hours per week would you spend with \_\_\_\_\_

III. In your opinion what are the most difficult challenges facing \_\_\_\_\_?

IV. What are his/her immediate needs?



V. Do you think that he /she has adequate access to service and support?

- What are the services most required?
  - What are the current service needs that are not being met?
  - Have you or anyone else applied for supported living services for \_\_\_\_
- Yes                      No                      Don't Know**

VI. If no, why not? \_\_\_\_\_

VII. If yes, what are the supported living services applied for \_\_\_\_\_

VIII. Was \_\_\_\_\_ found eligible for supported living services? **Yes      No**

IX. If the person was not found eligible, why not?

X. What kind of supports are in place to assist \_\_\_\_\_ in parenting?

XI. From your experience of being with and assisting \_\_\_\_\_ what additional supports and services should be in place to help meet the needs of parents with FASD?

XII. Which statement do you think best describes \_\_\_\_\_ involvement with his/her child

- a. Raising the child with little or no help from others
- b. Raising the child with help from others
- c. Child was removed by child protection services
- d. Gave up raising the child

XIII. Is there anything else you would like to tell me?

Thank participants for taking part in the study. Debrief participants by reminding them of the aim and significance of the study and what the data will be used for. Inquire whether participants would like to schedule a second interview. Discuss where the second meeting will take place.

### Advocates form for assessing daily living skills

For the following table please tick what in your opinion best describes \_\_\_\_\_ daily living skills.

Daily Living Skills	Very Good	Good	Inconsistent/ Require some assistance	Poor/Require full assistance/ Supervision
Time management (e.g. meet deadlines, understands concepts)				
Ability to communicate (e.g. express and understand information)				
Ability to use public transportation safely				
Kitchen skills (e.g. cooking meal, remembering to turn off stove or other appliances)				
Grocery shopping				
Ability to make decisions				
Money management				
Interpersonal skills (e.g. ability to develop and maintain relationships)				
Domestic skills (e.g. house management, keeping place tidy, environment conducive for child(ren))				
Ability to solve problems				
Ability to get medical care or social services				

## APPENDIX D

### Service Providers' Information Letter and Poster

## **Study Information Letter – for focus group with service providers**

### **Psychology Program**

**Researcher's Name:** Velma Abraham

**Address:** 3333 University Way, Prince George, B.C., Canada, V2N 4Z9

**Phone No:** (250) 960-6061      **E-mail:** [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)

**Supervisor's Name:** Cindy Hardy, Ph.D., R.Psych

**Title of project:** An Investigation into the Needs of Parents with Fetal Alcohol Spectrum Disorder (FASD)

**Type of project:** Thesis

Date:

Dear Service Providers,

Thank you for indicating your interest in participating in this study. You are being asked to participate in study that investigates the needs of parents affected with FASD. If you agree to take part in the study you will be asked to participate in a series of focus group discussions that will be audiotape recorded. Groups will vary from 4 to 5 persons and the topics being discussed will relate to issues of common concern to parents with FASD with regards to their needs. You will receive a copy of the questions to be discussed a week prior to the scheduled date of the focus group.

#### ***What is the purpose of this study?***

The purpose of this study is to determine, from the perspective of service providers, parents with FASD, as well as their advocates, what kinds of needs parents with FASD have.

#### ***Who is being asked to take part and what they will do?***

Parents with FASD, advocates and service providers will be asked to give their opinions about what the needs of parents with FASD are. Parents and advocates will take part in individual interviews lasting about an hour each, while service providers will take part in focus group interviews lasting about two hours.

#### ***When and where will the study take place?***

The focus group will be held at a time and place convenient for all the participants between fall 2004 and winter 2005.

#### ***Explanation of Procedures:***

If you agree to participate in the study, the following will occur:

- First, you will be asked to complete a questionnaire individually, which will be used to collect demographic information such as your occupation and work experience.
- Second, you will be asked to participate in a focus group discussion of issues faced by parents with FASD
- The discussion will be audio-taped recorded.

The total time for your participation will be approximately 1 to 2 hours. Once the data from the first focus group session are collected and analyzed you will be invited to participate in a follow-up session which will be used to present a summary of the findings to you and you will be asked to confirm or provide further details. That session will be approximately one hour long. Altogether, the study will take two hours group discussion plus one hours follow-up session for a total of four hours.

***What are the risks and/or discomfort of the study?***

There are no known risks or discomforts associated with this research

***What are the benefits of this study?***

You may find the experience and environment of sharing of information about your experiences of working with a parent with FASD to be very useful. In terms of benefits to society as a whole, we hope to be able to learn about the needs of parents with FASD. The information you provide us will help us better understand the needs of parents with FASD. It will also allow us to make recommendations about how to meet the support and service needs of parents affected with FASD.

***Can I withdraw from the study at anytime?***

The decision whether to be in this study is entirely up to you. If you agree to participate, your participation is voluntary and you have the right to change your mind and withdraw from the study at anytime. You do not have to give any reason for refusing to participate or for withdrawing.

***Is the study confidential?***

All information collected will be kept **strictly confidential**. All personal references and identifying information will be eliminated when the recordings are transcribed, and you will be identified by numerical code only, thereby assuring ensuring confidentiality regarding your responses. All data will be kept on a secure computer and access to the document will be secure by use of specific passwords known only to the research team. The complete focus group schedules, field notes, transcripts and the audiotapes will be stored in a secure, locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. When we are done with the study we will write a report about what we found out. We will not use your name in the report No information will be released or printed that will disclose your identity. One year after completion of the research, all written and recorded material will be destroyed.

Before the focus group sessions begins, all participants will be reminded that the information shared during the session is confidential, and is not to be repeated to those outside of the group. However, there is a limit to the researcher's ability to ensure confidentiality for information shared during these sessions.

***Opportunity to ask questions:***

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. Or you may call the researcher at 960-6061.

***Rights and complaints:***

If you have any complaints about your participation, or would like more information about the study, you may direct any complaints about this study to the Vice President Research at UNBC; phone 250-960-5820. Thanks for your interest in this project. Please keep this letter for your records.

Sincerely,

.....  
Velma Abraham

**Department of *Psychology***  
**University of Northern British Columbia (UNBC)**  
**VOLUNTEERS NEEDED FOR**  
**RESEARCH IN Fetal Alcohol Spectrum Disorder (FASD)**  
**SERVICE PROVIDERS**

We are looking for caseworkers to take part in a study investigating the needs of  
 parents who have FASD

As a participant in this study, you would be asked to:

- *take part in focus group discussions, which will require you to discuss questions and provide your opinion about what the needs of parents with FASD are.*

Your participation would involve 2 sessions,  
 each of which is approximately 1- 2 hours.

For more information about this study, or to volunteer for this study,  
 please contact: Velma Abraham at 960-6061

*Department of Psychology*  
 at

Email: [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)

**This study has been reviewed by, and received ethics clearance  
 through, the Office of Research Ethics, UNBC**

<b>CASEWORKERS VOLUNTEERS</b>	<b>CASEWORKERS VOLUNTEERS</b>	<b>CASEWORKERS VOLUNTEERS</b>	<b>CASEWORKERS VOLUNTEERS</b>	<b>CASEWORKERS VOLUNTEERS</b>	<b>CASEWORKERS VOLUNTEERS</b>
<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>

## APPENDIX E

### Service Providers' Consent Form



### Informed consent form for Focus Group

I understand I am being asked to participate in two focus group discussions that will last approximately one to two hours each and that the discussion will be recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that during focus group sessions, all participants will be reminded that the information shared during the session is confidential, and is not to be repeated to those outside of the group. However, there is a limit to the researcher's ability to ensure confidentiality for information shared during these sessions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you understand that you are free to participate or withdraw from the study at anytime	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that all information collected will be kept in a secure computer which will be password protected. The complete interview schedules, transcripts, audio-tapes and other research data will be stored in a secured locked cabinet in a locked researched laboratory controlled by Dr. Cindy Hardy. One year after completion of the research, all written and recorded material will be destroyed.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that all notes and transcripts will not have my names or any other identifying information on them and no information will be released or printed that would disclose any personal identity.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I am aware that all information collected will be used only by the research team and that no other person will have access to them.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Any risks or benefits that might arise out of my participation have also been explained to me to my satisfaction.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Any questions I have asked about the study have been answered to my satisfaction. I will receive a signed copy of this consent form.	<input type="checkbox"/> Yes	<input type="checkbox"/> No

### Declaration of Consent

This study was explained to me by: \_\_\_\_\_  
*Print Name*

I agree to take part in this study:

\_\_\_\_\_  
*Signature of Research Participant* Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Research Participant*

\_\_\_\_\_  
*Signature of Witness* Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Witness*

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
*Signature of Investigator* Date: \_\_\_\_\_

## APPENDIX F

### Debriefing Summary Form

## Focus Group Debrief summary Form

Your Name \_\_\_\_\_

Your Role \_\_\_\_ Note taker \_\_\_\_ Moderator

Date of focus group \_\_\_\_\_

Time focus group began \_\_\_\_\_

Time focus group ended \_\_\_\_\_

Location of focus group \_\_\_\_\_

Number of focus group participants \_\_\_\_\_

Name of organization from which participants are drawn \_\_\_\_\_

1. What were the main issues or themes that struck you during this focus group?
2. What new questions emerged for you as a result of this focus group?
3. Anything else that struck you as salient, interesting, illuminating, curious or important during this focus group?

4. What new or remaining concerns, inconsistencies, or challenges emerged during this focus group?
5. How would you describe the general atmosphere of the focus group?
6. Did participants seem engaged?
7. Overall, how would you describe the group dynamics? For example, were there individuals dominating the group? Did all participants contribute at some level?
8. What else is important to capture about this focus group?

## APPENDIX G

### Parents' Information Letter and Poster

## **Study Information Letter – for Interview with Parents**

### **Psychology Program**

**Researcher's Name:** Velma Abraham

**Address:** 3333 University Way, Prince George, B.C., Canada, V2N 4Z9

**Phone No:** (250) 960-6061      **E-mail:** [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)

**Supervisor's Name:** Cindy Hardy, Ph.D., R.Psych

**Title of project:** An Investigation into the Needs of Parents with Fetal Alcohol Spectrum Disorder (FASD)

**Type of project:** Thesis

Date:

Dear Parents,

Thank you for indicating your interest in participating in this study. You are being asked to take part in a research study because we are trying to learn more about the needs of parents with FASD. If you agree to take part in the study, the study interview will be audio-taped recorded and you will be required to take part in two interviews, for approximately one hour each.

#### ***What is the purpose of this study?***

The purpose of the study is to investigate the needs of parents with FASD.

#### ***Who is being asked to take part and what they will do?***

Parents with FASD, advocates and service providers (e.g. case workers) will be asked to give their opinions about what the needs of parents with FASD are. You and your advocate will take part in individual interviews lasting about an hour each ( 1 hour for parents and 1 hour for advocates), while case workers will take part in focus group interviews lasting about two hours.

#### ***When and where will the study take place?***

You will be interviewed at a time and place (e.g. your home, or Northern Health Society) of convenience between fall 2004 and winter 2005.

#### ***Explanation of Procedures:***

If you agree to participate in the study, the following will occur:

- First, you will be asked some general questions such as how many children you have, and how old they are.
- Second, you will be asked some more in specific questions with regards to your experiences, and challenges with parenting.
- You will be audio-taped recorded during the interview

This interview will take approximately one hour. Altogether, the study will take one 60 minutes (1 hour) interview plus one 60 minutes (1 hour) follow-up interview for a total of two hours.

***Is the study confidential?***

All information collected will be kept **strictly confidential**. Each participant will be identified by number code to ensure privacy and the names of persons identified in interviews will be removed when the recordings are transcribed. All data will be kept on a secure computer and access to the document will be secure by use of specific passwords known only to the research team. The complete interview schedules, field notes, transcripts and the audiotapes will be stored in a secure, locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. When we are done with the study we will write a report about what we found out. We will not use your name in the report. No information will be released or printed that will disclose your identity. One year after completion of the research, all written and recorded material will be destroyed.

***What are the risks and/or discomfort of the study?***

The risks to you are minimal, though you may encounter certain questions that may probe sensitive areas about your experiences and challenges with parenting. You are not required to answer any questions that you do not wish to. It is unlikely that you will reveal any information that indicate child abuse or neglect (e.g. excessively harsh physical punishment, leaving child alone for hours without supervision or meals). However, I must inform you that if you do I am obliged by law to make a report to child protection authorities.

***What are the benefits of this study?***

The study may benefit you by allowing you to share your opinion about your needs. Your opinion, as well as that of others will be use to develop recommendations regarding appropriate support and services to meet the needs of parents with FASD

***Can I withdraw from the study at anytime?***

If you don't want to be in this study, you don't have to be. Being in the study is entirely up to you. If you agree to participate, your participation is voluntary; no one will be upset if you don't want to participate or even if you change your mind later and want to stop. You do not have to give any reason for refusing to participate or for withdrawing. Your participation or non-participation will not affect access to the services you receive at Project Parent north or Northern Family Health society.

***Opportunity to ask questions:***

You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me at **960-6061**.

***Rights and complaints:***

If you have any complaints about your participation, or would like more information about the study, you may direct any complaints about this study to the Vice President Research at UNBC; phone 250-960-5820. Thanks for your interest in this project. Please keep this letter for your records.

Sincerely,

Velma Abraham



## **Department of *Psychology***

**University of Northern British Columbia (UNBC)**

### **VOLUNTEERS NEEDED FOR RESEARCH IN Fetal Alcohol Spectrum Disorder (FASD)**

We are looking for parents with FASD and their advocates to take part in a study  
investigating the needs of parents who have FASD

As a participant in this study, you would be asked to:

- *Take part in interview that requires you to answer questions about your experiences and needs as a parents with FASD.*

Your participation would involve 2 sessions,  
each of which is approximately 1 hour.

For more information about this study, or to volunteer for this study,  
please contact: Velma Abraham at 960-6061

*Department of Psychology*

at

3333 University Way, Prince George, B.C., Canada, V2N 4Z9

Email: [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)

**This study has been reviewed by, and received ethics clearance  
through, the Office of Research Ethics, UNBC**

<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>	<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>	<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>	<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>	<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>	<b>PARENTS &amp; ADVOCATES VOLUNTEERS</b>
<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>	<b>960-6061</b>

## APPENDIX H

### Parents' Consent Form

### Informed Consent form for Interview with Parents

I understand that I am being asked to participate in a research study design to investigate the needs of parents with FASD.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I will complete two interviews of approximately one hour each and that I will be recorded during the interview.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have been informed that I do not have to answer any questions I don't want to, and at anytime I may stop the interview if I want to without any consequences.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I am aware that the audio-tapes and transcripts will be used only by the research team and that no other person will have access to them	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that the notes and transcripts will not have my names or any other identifying information on them. I understand that all information will be kept in a secure computer which will be password protected. The complete interview schedules, transcripts, audio-tapes and other research data will be stored in a secured locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. One year after completion of the research, all written and recorded material will be destroyed.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have been assured that no information will be released or printed that would disclose any personal identity.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Any questions I have asked about the study have been answered to my satisfaction	<input type="checkbox"/> Yes	<input type="checkbox"/> No
The risks and benefits that might arise out of my participation have also been explained to me to my satisfaction.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I will be given a copy of this signed consent form to keep.	<input type="checkbox"/> Yes	<input type="checkbox"/> No

### Declaration of Consent

This study was explained to me by: \_\_\_\_\_  
*Print Name*

I agree to take part in this study:

\_\_\_\_\_  
*Signature of Research Participant* Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Research Participant*

\_\_\_\_\_  
*Signature of Witness* Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Witness*

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
*Signature of Investigator* Date: \_\_\_\_\_

## APPENDIX I

### Advocates' Information Letter

## Study Information Letter – for Interview with Advocates

### **Psychology Program**

**Researcher's Name:** Velma Abraham

**Address:** 3333 University Way, Prince George, B.C., Canada, V2N 4Z9

**Phone No:** (250) 960-6061      **E-mail:** [abrahamv@unbc.ca](mailto:abrahamv@unbc.ca)

**Supervisor's Name:** Cindy Hardy, Ph.D., R.Psych

**Title of project:** An Investigation into the Needs of Parents with Fetal Alcohol Spectrum Disorder (FASD)

**Type of project:** Thesis

**Date:**

Dear Advocates,

Thank you for indicating your interest in participating in this study. You are being asked to participate in study that investigates the needs of parents affected with FASD that will be audiotape recorded.

#### ***What is the purpose of this study?***

The purpose of this study is to investigate the needs of parents with FASD.

#### ***Who is being asked to take part and what they will do?***

Parents with FASD, advocates and service providers (e.g. case workers) will be asked to give their opinions about what the needs of parents with FASD are. You and your advocate will take part in individual interviews lasting about an hour each ( 1 hour for parents and 1 hour for advocates), while case workers will take part in focus group interviews lasting about two hours.

#### ***When and where will the study take place?***

You will be interviewed at a time and in a place (e.g. your home, or Northern family Health Society) of convenience to you between fall 2004 and winter 2005.

#### ***Explanation of Procedures:***

If you agree to participate in this study the following will occur:

- First, you will be asked some general questions such as what is your relationship to the parent.
- Second, you will be asked some more in depth questions with regards to your experiences, and challenges when assisting \_\_\_\_ with parenting.
- You will be audio-taped recorded during the interview

This interview will take approximately one hour. Altogether, the study will take one 60 minutes (1 hour) interview plus one 60 minutes (1 hour) follow-up interview for a total of two hours.

***Is the study confidential?***

All information collected will be kept **strictly confidential**. Each participant will be identified by number code to ensure privacy and the names of persons identified in interviews will be removed when the recordings are transcribed. All data will be kept on a secure computer and access to the document will be secure by use of specific passwords known only to the research team. The complete interview schedules, field notes, transcripts and the audiotapes will be stored in a secure, locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. When we are done with the study we will write a report about what we found out. We will not use your name in the report. No information will be released or printed that will disclose your identity. One year after completion of the research, all written and recorded material will be destroyed.

***What are the risks and/or discomfort of the study?***

The risk to you are minimal, though you may encounter certain questions that may probe sensitive areas about your experiences and challenges with regard to assisting \_\_\_\_ in his/her role as a parent. You are not required to answer any questions that you do not wish to. It is unlikely that you will reveal any information that indicate child abuse or neglect (e.g. excessively harsh physical punishment, leaving child alone for hours without supervision or meals). However, I must inform you that if you do I am obliged by law to make a report to child protection authorities.

***What are the benefits of this study?***

The present study will provide you the opportunity to share your perceptions and concerns about the needs of parents with FASD. The information you provide us will help us better understand the needs of parents with FASD, it will also allow us to make recommendations about how to meet the support and service needs of parents affected with FASD. In terms of benefits to society as a whole, we hope to be able to learn about the needs of parents with FASD, so as to provide better support and service to meet their needs.

***Can I withdraw from the study at anytime?***

If you don't want to be in this study, you don't have to be. Being in the study is entirely up to you. If you agree to participate, your participation is voluntary; no one will be upset if you don't want to participate or even if you change your mind later and want to stop. You do not have to give any reason for refusing to participate or for withdrawing. Your participation or non-participation will not affect access to the services \_\_\_\_ receives at Northern Family Health society.

***Opportunity to ask questions:***

You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me at **960-6061**.

***Rights and complaints:***

If you have any complaints about your participation, or would like more information about the study, you may direct any complaints about this study to the Vice President Research at UNBC; phone 250-960-5820. Thanks for your interest in this project. Please keep this letter for your records.

Sincerely,

Velma Abraham

## APPENDIX J

### Advocates' Consent Form



### Informed Consent form for Interview with Advocate

I understand I am being asked to participate in two audio-taped interviews that will last around one hour each	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have been informed that I do not have to answer any questions I don't want to, and at anytime I may stop the interview if I want to	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I am aware that the audio-tapes and transcripts will be used only by the research team and that no other person will have access to them	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that the audiotapes and notes will not have my names or any other identifying information on them, and that all data will be kept in a secure computer which will be password protected. The complete interview schedules, transcripts, audio-tapes and other research data will be stored in a secured locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. One year after completion of the research, all written and recorded material will be destroyed.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have been assured that no information will be released or printed that would disclose any personal identity.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Any questions I have asked about the study have been answered to my satisfaction.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Any risks or benefits that might arise out of my participation have also been explained to me to my satisfaction.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I am aware that my decision to participate or not will not affect the services or support that <b>(Parent Name)</b> is receiving from Northern Health Society.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you understand that you are free to participate or withdraw from the study at anytime?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

### Declaration of Consent

This study was explained to me by: \_\_\_\_\_  
*Print Name*

I agree to take part in this study:

\_\_\_\_\_  
*Signature of Research Participant*

Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Research Participant*

\_\_\_\_\_  
*Signature of Witness*

Date: \_\_\_\_\_

\_\_\_\_\_  
*Printed Name of Witness*

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
*Signature of Investigator*

Date: \_\_\_\_\_