Searching for, Finding, and Experiencing Friendship:
A Qualitative Study of Friendship Experiences of Seven Young Adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects

by

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We accept this thesis as conforming
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Abstract

This qualitative study into the experiences of friendship of five young adults with fetal alcohol syndrome (FAS) and two young adults with fetal alcohol effects (FAE) helps us understand people with FAS or FAE, from their own voices, experiences and perspectives.

With some recent exceptions, much of the literature on FAS and FAE can be characterized as pathology oriented, that is, focusing on the deficits and inabilities of people with limited consideration of their perspectives or experiences. A great deal of attention has been given to socialising and behaviour problems of FAS and FAE in human services research, practice, and policy literature. However, people with FAS or FAE have had few opportunities to enter into these discussions. In addition, the experiences of people with FAS or FAE are lacking in our knowledge of friendship.

Utilising qualitative secondary analysis of interview data, experiences of friendship of seven young adults with FAS or FAE are examined. Specifically, through listening to the participants this study examines:

- their experiences of searching for, finding, and having friendships,
- the meanings friendships have for them, and
- their views of friendship experiences as they face the challenges of FAS or FAE.

The individual stories of participants' experiences of friendship are presented in their own words. The complexities of their collective friendship experiences are interwoven in a narrative analysis. Key aspects of participants' friendship experiences include: being different and being not different; school, not a good place for me; ruptured relationships, loss of birth mother and then losing count; longing and searching for friendships; finding, making friendships; company; shared qualities/experiences; links to meeting others; acceptance and unconditionality; confidante and confidentiality; reciprocal help and support; going through it together; and we work best together.

Key words: experience of friendship; Fetal Alcohol Syndrome (FAS); Fetal Alcohol Effects (FAE); narrative analysis; qualitative secondary analysis.

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Acknowledgements

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Foreword

Study I

In 1995, as a project of the Child, Family and Community Research Program, University of Victoria, I, with Deborah Rutman, undertook the qualitative study, *Young Adults with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE): Experiences, Needs and Support Strategies* (Copeland & Rutman, 1996), here forward referred to as Study I. The objectives of Study I were to explore and describe themes and critical issues of the experiences of young adults with FAS or FAE and their families. Our focus pertained to achievements, challenges (difficulties that are inherent in FAS or FAE), barriers (difficulties imposed by others), specific support needs and strategies, and recommendations for human services providers. Key findings related to learning, transitions to independent living, pregnancy and parenting as a young adult with FAS or FAE, and interactions with human services.

Study I used a qualitative research design. Employing purposive sampling techniques, I interviewed seven young adults (6 females and one male; age ranged 16 to 20 years; 5 diagnosed with FAS and 2 with FAE), eight parents (seven adoptive and one birth) of young adults and seven human service professionals. Two of the young adults whom I interviewed were sisters (birth); I also interviewed their adoptive mother. I interviewed two other mother/daughter sets: one young adult woman and her birth mother and another young adult woman and her adoptive mother. (The mother/daughter participants were interviewed individually, not jointly). All participants lived in the Southern Vancouver Island area. In acknowledgement of the value and effort of participation, we paid participants, other than human services professionals, for their participation.

Study I and its data collection were approved by the University of Victoria's Office of Research Administration Human Subjects Research Review (see Appendix B). I explained the consent form (see Appendix A) to each participant and began the interview after they gave their consent.

My interviews of the participants were informal conversational interviews that lasted from 1 to 5 hours and took place in their homes or in a location of their choice. Two young adult women, who were friends, were interviewed together by their choice.

Two of the parents of young adults were interviewed together by their choice. Prior to my interviews with the young adults in particular, I discussed with them what would make them comfortable, including having a family member home, interviewing together, privacy, and taking a brief break part way through the interview. My interviews with the young adults were informal and conversational and mainly focused on what they felt was important to tell me about themselves and their experiences. For example, I asked them "what is important to you that I know about you" and "what was being in school like for you?" On some occasions, I revised my question or response to the young adult to include a specific example to clarify what I meant.

In the development phase of the study, I drafted a topic area guide for the interviews. I provided this draft interview guide to young adult and parent advisory members for feedback. I used their feedback to revise the guide prior to interviews. Although the interviews were flexible and followed what the participant felt was important to tell me, I referred to the interview guide to aid our focus and provide for some commonalities in the data. Topics in the guide included:

- background, key experiences, and current situation of the person with FAS or FAE regarding her or his living situations, peer, friends and family relationships, schooling, employment and financial support

- diagnostic issues of FAS or FAE and participants' experiences of the assessment and diagnostic process

- key experiences, challenges, and successes regarding informal and formal supports and support strategies

- long term support issues with respect to transitions from adolescence to adulthood and pregnancies and parenting

- relations with human services, perceived knowledge and educational needs, and key messages

- recommendations for improving formal and informal support systems and support strategies

If the participant chose not to have their interview audio-recorded, I took handwritten notes. Participants read and verified these handwritten notes at the end of the interview. Of the seven young adult interviews, four were audio recorded and three (including the pair) were recorded by handwritten notes. Of the eight parents of young adults interviews, seven were audio-recorded and one was recorded by handwritten notes. All seven interviews with human service professionals were audio-recorded. All but one of the tapes and notes were transcribed in their entirety. I offered their individual interview transcript to each participant for review and most reviewed and verified their transcript.

The data resulting from these interviews are written transcripts with information-rich descriptions of participants' experiences and perspectives. The interviews were informally guided conversations that were responsive to what the participant felt was important to say. Participants had differing expressive styles, i.e., some were very talkative and some were less so. Thus, there are some variations in the length, detail and topics areas within the transcript data. The young adult transcripts vary in length from 20 to 35 pages; those of the parents vary from 20 to 60 pages; and those of the human service professionals vary from 10 to 30 pages.

These transcripts provided rich qualitative data and were analysed to explore and describe key themes and critical issues. Major findings of Study I include, contrary to previous literature on FAS, the young adult participants were quite reflective about themselves, their relationships with others, and how having FAS or FAE does and does not impact their lives. We heard from them that having FAS or FAE feels like living with a continuous experience of contradiction: running up against barriers, feeling both 80 years and 2 years of age at the same time, FAS being part but not all of self, and wanting the same as others but thinking and doing differently. Parent participants (mothers) spoke of the intensity and extended duration of the work required in parenting a person with FAS or FAE. Human services professionals advocated for greater understanding of FAS and FAE, not only by themselves and their colleagues, but by those who plan and manage policy and service delivery.

All participants spoke of the importance of respect, dignity and honouring the young person's need for independence. Despite the significant, inherent challenges of FAS and FAE, they believed that people with FAS or FAE were capable of being productive citizens. Participants explained that this positive outcome required being treated with patience and understanding, and provided with sufficient supports to help them in decision making and practical living skills. These supports must extend beyond the age of majority to provide development "catch-up time" through their 20s. Key supports noted by participants included community, peer and family advocates who could also promote self-advocacy, peer supports, and supportive/supervised living centres, with live-in resource people to assist residents with FAS or FAE in "staying on track" in their work, financial and personal affairs.

Although there were seven young adult participants, there are six interview transcripts. One transcript includes both of the two young women who were interviewed together, and their interview dialogue was interactive. Transcripts of each of the seven young adult participants' interviews provide information-rich descriptions of participants' experiences and reflections. All transcripts include detailed descriptions, thoughts, feelings, experiences, and stories of each of the topic areas of the interview guide described above and of key experiences that stood out for them from their early years to the time of the interview. All young adult transcripts provide detailed descriptions of participants' thoughts, feelings, and reflections of their experience of themselves and various aspects of their lives. They all include detailed descriptions, thoughts, feelings, experiences and stories, both positive and negative, about their relationships with others such as family, friends, peers, teachers, health and human service professionals, and others in their life. All transcripts provide examples of interactions and conversations participants had with others, as well as what certain relationships meant to them and how they made sense of their interactions and relationships. Importantly, all transcripts provide detailed description about participants' experiences and reflections about friendship, including longing for, searching for, finding and having friends. Most provide intimate details of their relationship experiences, and what their thoughts and feelings were about them, including those who spoke about their pregnancy and parenting experiences. The two young adults who chose to be interviewed together were close friends for over five years, and their transcripts include detailed and comprehensive descriptions about their relationship with each other.

The qualitative data collected for this study is voluminous and rich; we were able to only utilise some of what participants told us about their experiences for Study I. I was intrigued by what the young adult participants so strongly and passionately told me about - their experiences of longing for and having friendship. My interest led to pursuing a further examination into their friendship experiences. The following is a qualitative study of the experiences of friendship of five young adults with FAS and two young adults with FAE utilising qualitative secondary analysis of data collected for the Study I.

CHAPTER ONE: INTRODUCTION

"Dear World: We have Fetal Alcohol Syndrome" (Nancy, in FAS/E Support Network of BC, 1997b, p. 1)

We are only beginning to listen to people, such as Nancy, who have fetal alcohol syndrome (FAS)[1] or fetal alcohol effects (FAE), a multi-faceted and lifelong disability resulting from exposure to alcohol as a fetus. Moreover, we are only beginning to understand this disability and those who live with it, beyond a medical and pathology oriented perspective (Kleinfeld, Morse, & Wescott, 2000; McIntyre-Palmer, 1994; Streissguth & Kanter, 1997). With a few recent exceptions, the research literature and our health and human services policies and practices are concerned about the deficits and inabilities of people with FAS or FAE, with very limited consideration of their perspectives or experiences. The language that we use in our research, policy, practice and public discussions about FAS or FAE repeatedly include descriptors such as "tragic" or "tragedy" and "damaged" (for example, BC Children's Commission, 2001; Dorris, 1989; Health and Welfare Canada, 1992; Health Canada, 2000; Jones & Smith, 1973b). Huber (1998), in her discourse analysis of Canadian print media's portrayal of FAS, found that people with FAS are constructed to be tragically damaged victims or victimizers.

This pathology oriented portrait of people with FAS or FAE has been constructed, with a few recent exceptions, without the participation of the very people who know the experience, people with FAS or FAE. The portrait lacks knowledge of their experiences, who they are, what their lives are like, what having FAS or FAE is like for them, and what kinds of support are helpful for them to lead a fulfilling life. Through understanding their words and experiences, more dimension and definition can be added.

I have known many people who have FAS or FAE through my professional roles as a child and family counsellor, child and youth advocate, community consultant and my

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[1] For readability, the abbreviations FAS and FAE are utilised in this paper. However, I do so with concerns about the use of these terms to label people as nothing more than their disability. I believe that people must be understood holistically, and as unique individuals.

work as a researcher in Study I, *Young Adults with Fetal Alcohol Syndrome or Effects: Experiences, Needs and Support Strategies* (Copeland & Rutman, 1996). All of these roles challenged me to ask, listen and understand what living was like for people with FAS or FAE. I realized that I had much to learn from people who lived first hand with what I was attempting to understand. I believe that my learning from people with FAS or FAE must influence my professional and personal actions.

The seven young adults in Study I (Copeland & Rutman, 1996) shared with me their experiences, thoughts and feelings about living their lives: their struggles, achievements, losses, tenacity and their dreams and goals for themselves. I was impressed by the depth of their reflections of themselves, their experiences, their lives and relationships. Their presence so strongly contrasted with the portrait I had seen in the research, practice and policy literatures. What continues to intrigue me are these young peoples' stories and experiences of searching for, finding and having friendships. My impression is that their friendship stories are often hidden by other events such as stealing, lying, or getting pregnant. These events garner much attention from researchers and practitioners when discussing the behavioural consequences or medical deficits of FAS or FAE. Illuminating their friendship experiences provides an understanding of young people with FAS or FAE beyond medical and pathology oriented perspectives. Such insights from these young people can, I believe, inform us about their experiences and about how to better understand, learn from and support those who have FAS or FAE.

Statement of the Problem

"There are two things that I want you to know: Do not call me a victim and do not tell me what I can not do. Help me find a way to do it" (17 year old young woman with FAS, in Lutke, 1997, p. 188).

There is a growing call from people with disabilities that it is essential to seek and heed the voices of people with disabilities in order to understand their experiences and to join with them in developing and implementing supportive human services (Coalition of Provincial Organisations of the Handicapped, 1992; Doe, 1996; Roeher Institute, 1995; Shaw, 1994). Rioux and Bach (1994), in their critique, call for new paradigms in disability research. They characterize traditional research as focused on objectively identifying "deficits" that can be "rehabilitated", with the resulting construction of the person with the disability as "the problem" and expert intervention as "the solution". This focus can be characterized as pathology oriented, that is, focusing on the deficits and inabilities of people, with limited consideration of their perspectives or experiences.

Likewise, with some recent exceptions, much of the research, health and human services policy and practice regarding people with FAS or FAE excludes their perspectives and life experiences, and is primarily pathology oriented. We focus on diagnosing permanent and irreversible biological and medical deficits and managing behavioural problems of children with FAS or FAE (Kleinfeld, Morse, & Wescott, 2000; Kleinfeld & Wescott, 1993; McIntyre-Palmer, 1994; Morse, 2000). Numerous studies of the last two decades report on the physiological and neurological indicators and deficits of FAS and FAE and the difficulties with, and disorders in, informational processing, memory, speech, language, behaviours, emotional and impulse control, and decision making and judgement (for example, Aase, 1994; Abel, 1984; Astley & Clarren, 1997; Barth, Freundlich, & Brodzinsky, 2000; Malbin, 1990; McCreight, 1991; Stratton, Howe & Battaglia, 1996b; Streissguth, Aase, Clarren, Randels, LaDue, & Smith, 1991; Streissguth & Kanter, 1997). Some researchers and practitioners discuss superficial verbal abilities (i.e., ability to appropriately use words in conversations without understanding their meaning) and deficits in cognitive functioning of people with FAS or FAE as reasons for relationship and socialising problems (LaDue & Dunne, 1997; Malbin, 1990).

Until recently, little attention has been paid to young and older adults with FAS or FAE in the literature (Rutman, Wheway, & La Berge, 2000). This is perhaps because FAS was medically identified only a few decades ago by clinical research on a small group of young children (Jones & Smith, 1973b), as well as the maternal and prenatal information required for the medical diagnosis of FAS (Streissguth, 1991; Streissguth & Kanter, 1997). Moreover, most researchers have paid little attention to the achievements and perspectives of people with FAS or FAE, possibly due to the clinical setting of the majority of the investigations (Kleinfeld, Morse, & Wescott, 2000; Kleinfeld & Wescott, 1993; McIntyre-Palmer, 1994). With some recent exceptions, there are few opportunities provided for people with FAS or FAE to enter into research, policy and practice discussions about FAS or FAE (FAS/E Support Network of BC, 1997b; Kleinfeld et al., 2000).

The resulting portrait of those with FAS or FAE shown to the general public and human services providers and policy makers is that of "boys who get locked up" (sent to jail due to criminal activity for which medical clinicians report the youth don't have the capacity to understand consequences) or "girls who get knocked up" (pregnant and believed by professionals to be without capacity to be a safe and nurturing parent) (Loock, 1990). Some very recent literature has emerged with a "purpose… to undermine this accepted but destructive myth" (Kleinfeld, 2000, p. 4). Kleinfeld (2000) states that,

> "the image of young people with FAS burned into people's mind is the picture of a young man looking through prison bars… We are writing this book because we want people to realize that the possibilities for young people with FAS/E go far beyond the young man in prison" (pp. 4-5).

Kleinfeld et al.'s (2000) recent book provides stories about the achievements of adolescents and adults with FAS or FAE and their families. They discuss what is success for adolescents and adults with FAS, practical strategies for successful education, living and overcoming difficulties, and what families need from the community. Stories from young people with FAS or FAE, their families and supports are offered from their "wisdom of practice". They provide important information and perspectives to consider and contrast with the more pathology oriented clinical research findings. Similarly, Rutman et al.'s (2000) action research project, *Adults Living with FAS/E* offers insights from people with FAS or FAE and their support people, and provides examples of "support strategies and relationships that people with FAS/E have found to be effective in resolving problems-in-living" (p. 1). These recent innovative projects with specific aims to include the perspectives, experiences and knowledge of people with FAS or FAE in our knowledge base are encouraging. Additional efforts must be made to both continue this inclusion of people with FAS or FAE and to more extensively impact the broader research, policy, practice, public viewpoints and actions.

We have much more to learn about the experiences of people with FAS or FAE, from their own voices. We must seek, listen and attempt to understand what people with FAS or FAE want to tell us. We must build knowledge not only about people with FAS or FAE but *for* people with FAS or FAE. Some of the very recent literature (for example, Kleinfeld et al., 2000; Raymond & Belanger, 2000; Rutman et al., 2000) have broadened both our research inquiries, to include an examination of the importance of social support networks for people with FAS or FAE, and our research informants, to include people with FAS or FAE and their support people. Social support networks can both relate to and differ from experiences of friendship (Willmott, 1987). We are only beginning to explore and understand people with FAS or FAE 's experiences of friendship. In tandem, missing in our discussion and understanding of friendship are the experiences of people with FAS or FAE. This study aims to listen and take seriously the voices of seven young adults with FAS or FAE by exploring what they told us about their experiences and meaning(s) of friendship in their lives.

Significance

"You are not alone. Many People have FAS/E" (Tanya, in FAS/E Support Network of BC, 1997b, p. iii)

FAS and FAE are named as the leading causes of developmental disabilities (Abel & Sokol, 1987; Clarren & Smith, 1978; Health Canada, 2001; Morse, 2000; Streissguth et al., 1997). Concurrently, there is much discussion among researchers and human services professionals regarding the difficulties and factors involved in determining the incidence rates of FAS and FAE. Loock (1990) states that the incidence of FAS and FAE recorded on the BC Health Surveillance Registry is lower than the actual incidence due to Registry's voluntary reporting system, a lack of knowledge among health professionals and insufficient personal health history taking on maternal alcohol use. Winquist (1995) reports that epidemiologists (see Coles, 1993; Coles & Platzman, 1993; 1994; Quinby & Graham, 1993) estimate that one to three children in every 1000 in industrialised countries will be born with FAS, and that the rate is several times higher for children born with FAE. Health Canada (1996) states that these rates may be conservative, "given how difficult it is to establish the frequency of a birth defect that (1) is hard to identify at birth; (2) may be confused with other health problems, and; (3) must be diagnosed by physical examination and consideration of a person's medical history, rather than a laboratory test" (p. 1).

Studies show variation across sub-population groups with incidence rates as much as 100 times the general estimates (Winquist, 1995). British Columbia's incident rates are among the highest, with widely varying estimates, ranging from 5 to 200 per 1000 children (Health Canada, 2001; Raymond & Belanger, 2000; Robinson, Conry & Conry, 1987). Health Canada (2001) reports that at least one child is born with FAS each day in Canada. British Columbia's Children's Commission (2001) states that about 140 children are born with FAS each year, and "many more" are born with partial FAS (FAE). There are growing numbers of individuals in North America diagnosed with FAS or FAE, and/or self-identifying as having FAS or FAE (Beyond Consulting, 1997; Morse, 2000; Streissguth et al., 1997).

Tanya's (FAS/E Support Network of BC, 1997) message that "many people have FAS/E" (p. iii) could also apply to young people in the care of government authorities, such as the province of British Columbia's child protection authority, Ministry for Children and Families (MCF). According to A-M Huber, Research Officer, Data Analysis Branch, MCF, (personal communication, July 24, 2000, SWISMIS extract June 30, 2000), of the total 9, 873 children in care of MCF on June 30, 2000, 583, or 5.9%, had a 'YES' notation on their case file in the FAS category (of the 583, 340 were males), 911, or 9.2%. had a 'YES' notation on their case file in the FAE category and 194, or 2%, had a 'YES' notation on their case file in both, FAS AND FAE categories (may indicate uncertainty of which diagnosis). Although there is some ambiguity in these numbers, as they are based on case workers' data entry, this data does indicate that the numbers of children in care with FAS or FAE are higher than national population estimates. In addition, Fast, Conry, and Loock's (1999) study found that over 23% of youth at British Columbia's Youth Forensic Psychiatric Services were diagnosed with FAS or FAE, demonstrating that youth with FAS or FAE are also over-represented in our youth justice systems. FAS and FAE are significant issues confronting those in government care and custody and those authorities.

Much of the research, practice and policy discussion regarding FAS and FAE focus on prevention (Health and Welfare, 1992; Health Canada, 1996; Offord & Craig, 1994; Schorling, 1993). Until very recently, FAS and FAE were consistently described as "100% preventable" (Fetal Alcohol and Drug Unit, University of Washington, 1996; Health and Welfare Canada, 1992; Loock, 1990; Society of Special Needs Adoptive Parents & Ministry for Children and Families, 1999). This sentiment is pervasive in policy documents such as Canada's House of Commons Committee on Health and Welfare's (1992) report, *Foetal Alcohol Syndrome, A Preventable Tragedy* as well as Health and Welfare Canada's (1992) response to the committee's report. Health and Welfare Canada's (1992) response states that "FAE/S are among the few adverse outcomes/disabilities which are potentially completely preventable at society's current level of scientific knowledge" (p. 5). A common public perception regarding people who have FAS or FAE is that they are tragically damaged, and that this damage could have been prevented if only we had intervened and utilized our scientific knowledge; hence the "preventable tragedy" phrase in report titles. The prevention focus has often prevented us from attending to the lives and experiences of people with FAS or FAE. Rather than seeing people with FAS or FAE as people who have something to say and contribute to our society, we have seen them as something that should not have happened.

Some recent policy discussion has included considerations beyond prevention of FAS and FAE, such as Canadian Centre on Substance Abuse National Working Group on Policy (1996). This Canadian policy discussion document puts forward several policy recommendations regarding FAS including: employing a holistic view of FAS, resources for care providers, training for professional expertise and research to find the most effective professional treatment. The Federal Government of Canada took up some of these recommendations in 1999 by establishing the Fetal Alcohol Syndrome/Fetal Alcohol Effects Initiative. This initiative, administered through Health Canada, has been allocated $11 million over three years to enhance FAS/FAE activities related to: public awareness and education, training and capacity development, early identification and diagnosis, coordination, surveillance, and a strategic project fund to assist national FAS/FAE projects to enhance existing and new FAS/FAE activities (Health Canada, 2001). Over one million dollars have been awarded from this fund to the four year project, *FAS/E: A Manual for Community Caring*. This project is undertaken by the FAS/E Support Network of British Columbia, in collaboration with Health Canada, Population Health, First Nations and Inuit Health Branch, and the National Crime Prevention Centre (FAS/E Support Network of BC, 2001). This project is currently developing a training manual with, "up to date, consistent information on FAS/E to all those in the field" (FAS/E Support Network of BC, 2001). In addition, this project will also produce thirty trainers to help other communities disseminate and implement the manual's information and strategies.

The FAS/E Support Network of BC has been an important force in bringing forward the experiences and perspectives of parents/caregivers of people with FAS or FAE, and more recently, of people with FAS or FAE, in community conferences and some human services policy/practice discussions (for example, BC Children's Commission, 2001). People with FAS or FAE are involved in the FAS/E Support Network of BC's

(2001) training manual project, along with other "professional stakeholders". I am interested in how collaborative initiatives such as this one will balance the various perspectives of the stakeholders, given the continued and pervasive influence of the foundational research, policy and practice knowledge that has a more pathology orientation about FAS or FAE. Doe (1996) and Campbell, Copeland, and Tate (1998) report on the inherent difficulties within collaboration among people with disabilities and other "professional stakeholders". These authors found that even with positive intent of inclusive participation, without a strenuous, continuous attention to taken for granted power, experience and access differences, the perspectives of people with disabilities can easily be subsumed by the professional considerations and interests. Although Doe (1996) and Campbell, Copeland and Tate (1998) caution about understanding and addressing differences and inequities within collaboration among people with disabilities and professional stakeholders, they also report that such collaborations are useful and achievable since each group has essential and complementary knowledge and expertise.

Without significant inclusion of people with FAS and FAE and their perspectives, the actions conducted and knowledge obtained from the various policy, practice and research recommendations and initiatives would continue what Rioux and Bach (1994) advocate we end: the person with FAS or FAE objectified as "the problem" and the professionals' interventions seen as "the solution". This fission of problems and solutions within the literature is perhaps most prevalent regarding the social, or perhaps viewed as the anti-social, lives of people with FAS or FAE. A great deal of clinical attention is given to the "socialising problems" of FAS/FAE (LaDue & Dunne, 1997; Malbin, 1991; Streissguth, 1997). Some very recent literature specifically aims at refuting some of the problem oriented descriptions of people with FAS or FAE. Kleinfeld (2000) concludes that the young people's stories of living with FAS or FAE related in their collaborative book, "give the lie to the perverse and wrong-headedness stereotype that people with FAS/E lack conscience and empathy for others. Helping others is important to many and is an important source of their sense of self-worth" (p. 333).

Without listening to, and understanding, the everyday experiences of people with FAS or FAE we have an incomplete, if not inaccurate, understanding of FAS and FAE. We must continue this recent, although somewhat limited, effort to hear and understand what it is like to have and live with this disability, and its impact on relationships with self and others. There are gaps in the literature regarding social, relationship and friendship experiences of people with FAS or FAE. Missing from our knowledge, and from framing our knowledge, are these experiences from the perspectives of people with FAS or FAE.

Values and Beliefs

The following are my own values and beliefs related to this inquiry. I hope that by clearly stating what these are, the reader will understand my perspective.

- Alcohol use is an interwoven part of our social fabric and is collectively viewed with both celebratory and destructive designs.
- Alcohol addiction is complex.
- We must understand a person's life from their own perspective in order to understand their use of alcohol.
- Alcohol is a teratogenic drug which can adversely affect fetal development at any stage of pregnancy and can adversely affect infant development through breast feeding.
- We do not know how much alcohol is required to adversely affect a fetus; less than what is commonly regarded as heavy drinking can affect a fetus.
- A man's alcohol drinking may adversely affect his sperm which may have adverse effects on fetal (and child) development.
- A pregnant woman and her fetus are interconnected.
- Blaming and/or criminalising pregnant women for drinking will not prevent FAS.
- Creating and maintaining a caring and equitable society that supports women 's abilities to care for themselves and their fetuses is the best way to have healthy babies.
- The mother, father, family, and community all share responsibility for providing a healthy and caring environment for the fetus and when it is born, the young person.
- When a child is born they have rights to protection, provision, non-discrimination and participation, as stipulated in the United Nations Convention on the Rights of the Child.
- People who have FAS or FAE can have life-long challenges due to their disability and they are also capable of life achievements and social contributions. They are individual persons, as unique as others.

- People who have FAS or FAE are capable of self reflection, can seek and find meaning from their experiences, and can have inter-personal relationships.
- Friendship is a voluntary human experience and is not a rehabilitative or socialisation technique.
- Friendships are as diverse and unique as people are.
- Friendships, just as humans, have the potential to develop and change throughout the life course.
- People with disabilities are as valuable for friendship as people without disabilities.
- Friendship can not be programmed to occur; friendship can be supported by others but the relationship is best defined by the friends.
- A person's friendship experience is best understood from their own voice and perspective.
- The voices and experiences of people with disabilities, including FAS and FAE, have been excluded from the authoritative research and practices and are essential to produce knowledge that is useful to people with disabilities.
- Ultimately research is not value-free; all researchers and inquiries are influenced by certain beliefs and values about what is to be studied, how to study it, and its relations to other things. Making these beliefs and values explicit, however, provides important information about the inquiry and its findings.

Purpose and Objectives of the Study

The purpose of this study is to present and analyse experiences of friendship of seven young adults with FAS or FAE. Specifically through listening to the participants, I will explore:

- their experiences of searching for, finding, and having friendships
- the meanings friendships have for them, and
- their views of friendship experiences as they face the challenges of FAS or FAE.

Research Question

The research questions that guide this study are the following:

- What are the friendship experiences of seven young adults with fetal alcohol syndrome or fetal alcohol effects?
- What are the meanings of these friendship experiences for these young people?

CHAPTER TWO: LITERATURE REVIEW

A literature review enables the researcher to provide a picture of "what is known about a particular situation and the knowledge gaps that exist in the situation" (Berns & Grove, 1987, p. 152). Thus, this literature review provides a picture of our knowledge about experiences of friendship of young people with FAS or FAE, as well as how the picture is made and what is missing.

Conceptual Framework

This study focuses on examining the experiences of friendship of seven young adults with FAS or FAE. The conceptual framework of this study includes both the construction of knowledge about FAS or FAE and about the experience of friendship. Concepts that are explored in the literature review relate to both FAS and FAE as well as friendship. Key concepts include the pathology oriented construction of FAS and FAE; the voices and experiences of people with FAS or FAE; friendships of young people with FAS or FAE; defining friendship; influence of human development theory on understanding friendship; friendships of people with disabilities; and experiences and meanings of friendship.

The following provides a review and critique of literature relevant to this inquiry. This review is divided into two parts. Part One: FAS and FAE, explores the construction of knowledge about FAS and FAE. This includes examining: the pathology oriented construction of FAS and FAE; the voices and experiences of people with FAS or FAE; and friendships of young people with FAS or FAE. Part Two: Friendship, explores the construction of knowledge about the experience of friendship. This includes examining: defining friendship; the influence of human development theory on understanding friendship; friendships of people with disabilities; and experiences and meanings of friendships of people with disabilities.

Part One: FAS and FAE

The Pathology Oriented Construction of FAS and FAE

As I argue in the problem statement of this thesis, much of our knowledge about FAS or FAE is pathology oriented, that is, focusing on the deficits and inabilities of people, with limited consideration of their perspectives or experiences. The following outlines key events within the literature and key aspects of this pathology oriented understanding of FAS and FAE.

Researchers who have examined the effects of alcohol exposure in utero from an historical perspective (Graham-Clay, 1983; Jones & Smith, 1973; Rosett et al, 1978; Streissguth et al., 1980) cite references dating back to Biblical times and Greek mythology that warn of harmful effects of alcohol on the human fetus. Streissguth et al. (1980) also refer to medical reports in England during the 1800's that documented the high correlation between alcohol consumption and perinatal mortality, as well as reports that children born to alcoholic mothers were sometimes weak and had physical defects. In more recent times, French scientists (Lemoine, Harrouseay & Borteyru, 1968) reported on the similarities in facial characteristics, growth deficiencies, and psychomotor disturbances of 100 children they studied whose mothers were identified as alcoholics. Fetal Alcohol Syndrome was named as a birth defect by American researchers Jones and Smith (1973a) in their "landmark" study of eight unrelated children born to mothers with alcoholism, ranging in age from 11 weeks to four years, with a similar pattern of physical malformations, growth deficiencies, and central nervous dysfunctions.

Within a few years after Jones and Smith's (1973a, 1973b) studies, Chernoff (1977) and Randall (1977) published experimental studies of laboratory animals that found that alcohol is teratogenic, i.e., produces or tends to produce malformations in a fetus from prenatal exposure. Jones and Smith's (1973a, 1973b) studies brought international attention to FAS. These landmark studies were followed by other clinical researchers (for example, Clarren & Smith, 1978; Hanson, Streissguth, & Smith, 1978) reporting that prenatal alcohol exposure produces a whole spectrum of effects, rather than always the complete set of criteria (growth deficiency, facial anomalies, central nervous dysfunction, in a child who was known to have been exposed to alcohol in utero) initially established by Jones and Smith (1973a, 1973b).

There was, and continues to be, great debate about how people who have been prenatally exposed to alcohol should be diagnosed and what they should be labelled. Clarren and Smith (1978) suggest that variability and anomalies of the outcomes of prenatal exposure to alcohol could be due to variable levels of exposure at variable gestational timings, offset by the genetic makeup of the individual fetus. Abel (1995a;

1995b) reports that factors of the mother's life and biological environment, such as low socioeconomic status, cultural and ethnic patterns, use of tobacco and other drugs, malnutrition, environmental pollutants, and stress, can have variable effects on the outcome of prenatal exposure to alcohol.

Children who had some but not all the characteristics of FAS are referred to by researchers as having FAE (Hanson, Streissguth, & Smith, 1978), or Possible Fetal Alcohol Effects (PFAE) (Clarren & Smith, 1978), Alcohol Related Birth defects (ARBD) (Streissguth et al., 1991), or Alcohol Related Neurodevelopmental Disorder (ARND) (Stratton, Howe, & Battaglia, 1996). Researchers recognize that FAS was the most clearly definable, but not necessarily more prevalent than FAE (Morse, 2000; Streissguth et al., 1991). However, there is disagreement about whether only FAS is a medical diagnosis and FAE is simply "a descriptive term to describe observed effects that could have been caused by prenatal alcohol exposure" (Streissguth, 1994, p. 50). Leading researchers are calling for the terminology to be reconsidered (Aase, Jones & Clarren, 1995; Stratton, Howe and Battaglia, 1996b). These events and expert-driven clinical discourse in the research arena have significant influence on how people who have been prenatally exposed to alcohol and experience disabilities are perceived, labelled and treated by health and human services providers.

Estimating the numbers of people with FAS or otherwise affected by prenatal exposure to alcohol has been, and is, the subject of much debate and discussion (Fast et al., 1999; Morse, 2000; Winquist, 1995). Utilising their initial criteria for diagnosing FAS and data from the US National Perinatal Collaborative Project, Jones and Smith (1974) estimated that between 10 and 40 percent of children of heavily drinking women could be "diagnosable FAS cases" (p. 1076). Winquist (1995) reports that epidemiologists estimate that one to three children in every 1000 in industrialised countries will be born with FAS, and that the rate is several times higher for children born with FAE. British Columbia has widely varying estimates, ranging from 5 to 200 per 1000 children (Health Canada, 2001; Raymond & Belanger, 2000; Robinson, Conry, & Conry, 1987). However, May (1992) calls into question the high attention given to Aboriginal people in FAS research. May (1992) contends that myths about the "drunken Indian stereotype" (p. 1186) and the easy access to aboriginal people as research subjects on some reservations may obscure the prevalence of FAS and FAE in the overall population. Morse (2000) states that diagnosticians are reporting "over-diagnosis" (p. 311) of FAS, and that researchers are now reporting that developmental problems of aboriginal people in Canada and the United States are often assumed to be alcohol related, sometimes without diagnostic evidence.

Clarren and Smith (1978) describe FAS as the "most frequent known teratogenic cause of mental deficiency in the western world" (p. 1063). Abel and Sokol (1987) report that FAS is the leading known cause of mental "retardation" or developmental disabilities in the Western world. Health Canada (2001) and the BC Children's Commission (2001) identify FAS as "the leading known cause of intellectual disability in children" (p. 6). These global statements make FAS an issue of great interest to those involved with developmental disabilities research, policy and practice. There are numerous studies describing the negative correlation of severity of maternal alcoholism to IQ measures and correlation to physiological and neurological indicators and deficits associated with FAS and FAE, such as disorders in: informational processing, memory, speech, language, behaviours, emotional and impulse control, and decision making and judgement (for example, Aase, 1994; Abel, 1984; Astley & Clarren, 1997; Barth, Freundlich, & Brodzinsky, 2000; Malbin, 1990; McCreight, 1991; Stratton, Howe & Battaglia, 1996b; Streissguth, Aase, Clarren, Randels, LaDue, & Smith, 1991; Streissguth & Kanter, 1997).

Although the United States has been a primary contributor to FAS literature, some clinical studies on children suspected of having FAS have also been conducted in countries outside of North America. For example, Aronson's (1997) retrospective study of Swedish children with identified physiological and psychological difficulties, Germany's studies on the psychopathology of FAS (Majeski, 1993; Sphor, Willms, & Steinhausen, 1993), and Frances's Lemoine and Lemoine's (1992) follow up on the subjects of their original (1968) study, are similar to their North American counterparts in their focus on deficits and pathology of FAS. FAS has international attention from researchers, however their focus has not been broadened much beyond a clinical pathology oriented approach. In addition, most have not considered issues of FAS beyond childhood and adolescence, as noted by some studies regarding adults with FAS or FAE, including LaDue, Streissguth, & Randels (1992); Rutman et al. (2000); Streissguth (1994); Streissguth, Barr, Kogan and Bookstein (1997) and Streissguth et al. (1991).

Streissguth et al. (1991) took up their own call for studies on adults, examining FAS in 61 adolescents and adults ranging in age from 12-40 years. They report that, "the natural history of FAS can now be traced into adulthood" (Ibid, p. 1965). Their study examines physical characteristics of FAS, reporting that the facial characteristics associated with FAS were not as distinct in these older subjects. They also report indicators of pathology on the intellectual, academic and adaptive functioning of these adolescents and adults. The researchers look to neurological and cognitive deficits to explain their findings, asserting that, "the severity of their arithmetic disability, often masked by superficial verbal skills, appeared to be central to their difficulty with independent living, poor judgement, and generally dysfunctional lives" (Ibid, p. 1966). In addition to deeming the subjects' verbal skills as superficial, they also conclude that, "conduct problems such as lying and defiance, also characterized a number of these patients" (Ibid, p. 1966). The study differentiates the "severe behavior problems" and "maladaptive behaviours" observed in the subjects with FAS from other "persons who are retarded", reporting incidence as twice as high as in people with Down's Syndrome (Ibid, p. 1966). This study "traced into adulthood" a characterization of people with FAS as dysfunctional, both cognitively and socially. This study's quantitative methodology employed diagnostic examinations, including intellectual and academic examinations, physical measurements, medical record review and an interview with "the primary caretaker for social-behavioral information", including an adaptive behaviour scale. There was no reported inquiry into the experiences of the study's participants with FAS from their own perspective, which would have required qualitative interviews with participants. Thus, these findings provide no insight into their world, no information from their experience to understand and interpret behaviours of people with FAS.

In addition, Streissguth et al. (1997) extended their exploration into the "continuing adverse effects of prenatal alcohol exposure" with a study that, "aims to build a prevention information base fundamental to the amelioration of secondary disabilities in patients with FAS and FAE" (p. 27). These researchers define primary disabilities as "functional deficits that reflect the CNS [central nervous system] dysfunctions inherent in the FAS or FAE diagnosis" and secondary disabilities are defined as "those that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions" (p. 27). The results of their study indicate that people with FAS or FAE have a number of "secondary disabilities", described as mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behaviour, alcohol/drug problems, dependent living and problems with employment. Streissguth et al.'s (1997) methods of data collection (structured life history review by telephone interview with caretakers/professionals, rather than the people with FAS or FAE) and descriptive statistical analysis did not include the voices, perspectives and experiences of people with FAS or FAE.

Streissguth et al. (1997) are among the first researchers to regard difficulties of people with FAS or FAE beyond the physical body and consider their home and community environments. Streissguth et al.'s (1997) study also reports on "what helped to protect a person from such negative outcomes" (Morse, 2000, p. 317). These protective factors include: living in a stable home for most of one's life (eg., not multiple foster home placements), early childhood diagnosis (especially FAS rather than FAE, since FAS is more recognized and seen as eligible for support services), and difficulties are identified and appropriate developmentally disabled support services are provided. Streissguth et al.'s (1997) study appears to be regarded as a key current source of research knowledge about adolescents and adults with FAS or FAE as it is the most recent reference in works (such as Barth et al., 2000; Fast et al., 1999; Kleinfeld et al., 2000) and in discussions of current knowledge of FAS and FAE.

This literature review concerning the pathology oriented understanding of FAS and FAE can not exclude *The Broken Cord* - the highly influential popular book by Michael Dorris (1989). Perhaps even more influential to the public's understanding of FAS than the above mentioned research studies, *The Broken Cord* has been made into a TV movie, translated into a variety of languages and shown internationally. Dorris' (1989) story speaks emotionally from his own perspective and experience about his adopted son, Adam, who was eventually diagnosed with FAS. Dorris and his son, who are both now deceased, were from aboriginal heritage. A hopeless picture of those with FAS or FAE is provided by Dorris with passages such as:

> My son will forever travel through a moonless night with only the roar of wind for company... Don't ask him to swoon at sunrises or marvel at the filter of light through leaves. He's never had time for such things, and he does not believe in them. He may pass by them close enough to touch on either side, but his hands are stretched forward, grasping for balance, instead of pleasure. He doesn't wonder where he came from, where he's going. He doesn't ask who he is or why. ...my son, conceived and grown in an ethanol bath, lives each day in the act of drowning. For him there is no shore (p. 264).

Dorris' (1989) emotional memoir is both acknowledged as passionately shining a bright light on families facing great difficulties as well as, in recent years, respectfully criticized as overly pessimistic about those with FAS (Kleinfeld et al., 2000; Kleinfeld & Wescott, 1993; McIntyre-Palmer, 1994). Dorris' (1989) popular story, coupled with clinical research describing the pathology oriented aspects of FAS and FAE has influenced us all – including researchers, human services policy makers and practitioners and the general public. This results in some people constructed to be "FAS/E kids" who are tragically damaged, retarded, incapable of self reflection, unlikely to finish school, become employed or live independently, destined to become involved in criminal, negative and "anti-social" behaviours and to have "dysfunctional lives". This pathology oriented legacy has been a powerful one to counteract; Kleinfeld et al. (2000) provide a compilation of successes of people with FAS or FAE in order to show that, "the possibilities go far beyond the most famous FAS poster child of all, Michael Dorris' son, Abel, dead at age 23" (p. 5).

Voices and Experiences of People with FAS and FAE

Much of our knowledge about people with FAS or FAE is, with some recent exceptions, without the participation of people with FAS or FAE. The following outlines key events within the literature and key aspects of the voices and experiences of people with FAS or FAE.

People with FAS or FAE have not been viewed as credible informants or participants in research. Researchers have viewed them to have "superficial verbal abilities... that mask their cognitive difficulties" (LaDue & Dunne, 1997, p. 147). In other words, a common perception about people with FAS or FAE that has arisen from the literature is that what they say about their lives and experiences may not be the way it "really is". Some literature, such as LaDue and Dunne's (1997) report on legal issues and FAS, purports cautions and strategies to use when questioning people with FAS or FAE to assess for competency. The emphasis here is in establishing fact from fiction of events, rather than attempting to understand their experience or perspective. Unfortunately, these discussions further compound negative perceptions of the credibility of people with FAS or FAE and further push their voices and perspectives out of the dialogue about FAS or FAE. It is useful to acknowledge that this exclusion of groups of people, who are viewed by some as lacking capability to be credible research informants, is not unique to people with FAS or FAE. For example, other researchers interested in older persons or younger children have also faced similar challenges and have adapted the research environment and inquiry approach to match the particular communication needs and style of their participants.

The experiences and knowledge of people with FAS or FAE are, with some exceptions discussed below, not included within much of the literature. Similarly, with a few exceptions such as Dorris' (1989) book discussed above, until recently little attention was paid by researchers to the work and knowledge of parents, teachers, practitioners, and others who support young people with FAS or FAE. Dorris' (1989) experiential book does need to be acknowledged as an important story about the traumas he experienced and what he saw his son experience. With his passionate words he reached many who had never heard of FAS (Streissguth et al., 1997). However, there are other stories to be told of people with FAS or FAE and their families. A significant departure in the discourse on FAS occurred with the publication of the book, *Fantastic Antone Succeeds!* (Kleinfeld & Wescott, 1993). This compilation of optimistic stories and practical strategies for FAS or FAE worked out by parents, teachers, practitioners and young people with FAS or FAE utilises their "wisdom of practice... the lessons and inventions of experience" (Ibid: p.14). Successes, accomplishments and personal depth are highlighted in these stories, showing that, "the reality of FAS is far more hopeful and far more complex" (Ibid: p. 16). Kleinfeld and Wescott's (1993) book has become a catalyst for parents, practitioners and young people to come together in forums, conferences organised by dedicated parent support groups and to share their experiences, questions and information about living with FAS (for example, the FAS/E Support Network of BC).

The publication of the sequel, *Fantastic Antone Grows up* (Kleinfeld, Morse & Wescott, 2000), was eagerly anticipated by those who are interested in similar discussions regarding adults with FAS or FAE. Kleinfeld et al.'s (2000) recent book provides stories about the achievements of adolescents and adults with FAS or FAE and their families, discussing what is success for adolescents and adults with FAS, practical strategies for successful education, living and overcoming difficulties, and what families need from the community. Successes include overcoming shyness, playing a musical instrument, earning a college degree, learning basic sign language to help a deaf/autistic friend, public speaking about living with FAS, maintaining a job, paying living expenses bills, living in own apartment, living in supportive group home, marrying and being a parent. Kleinfeld et al. (2000) also provide stories of how various supports and structured environments worked for some young people in achieving independent living. Also, for those who were not able or interested in independent living, they identified the need for support homes for adults with FAS or FAE near their family. Various effective practical strategies are described in different families' stories, highlighting those that came from the young people themselves. For example, one young woman put her principle of "if you'll lose it – wear it" into practice by designing fanny packs and jewelry to hold her everyday possessions, while another young woman brought her running gear with her to a family wedding so she could run off her over-excitement. Kleinfeld (2000) concludes that "effective parents prepare young people for adulthood by encouraging them to take control of their own problems" (p. 335). Many parents, professionals and young people emphasize the need for the people with FAS or FAE to have self advocacy skills (Kleinfeld, 2000). Morse (2000) has a message to people with FAS or FAE: "If the opportunity presents itself, participate in research. People with FAS or FAE who are willing to tell researchers about their lives can contribute greatly to understanding and treating this disorder" (p. 321).

Morse's (2000) message to people with FAS or FAE to speak about their lives has a broad relevance. Sometimes we take for granted that we understand another's experience, especially if we have a personal relationship with that person. Jan Lutke, a parent of several young people with FAS or FAE, is one of those who have dedicated themselves to FAS/FAE support networks. However, Jan Lutke (1997) acknowledges that she had to learn more about listening to and understanding the voices and perspectives of young people with FAS. Lutke (1997) explains how she underwent a paradigm shift that moved her from "doing to" to "doing with" people with FAS. She describes her dialogue with her daughter, who said that having FAS was "like spider web walking" (p. 187). Jan tells us that she reflected back to her daughter what she thought this metaphor meant, but her daughter "carefully explained that [Jan] had misunderstood her" (p. 188). Jan explains that she realized that she must understand her daughter's experience from her daughter's point of view. Another of Jan Lutke's daughters with FAS provides an important message about listening to people with FAS in her rebuttal to a Federal Government Minister's comments at a conference about "the victims" of prenatal alcohol exposure. The young woman asserts: "There are two things that I want you to know: Do not call me a victim and do not tell me what I can not do. Help me find a way to do it" (Lutke, 1997, p. 188).

The sharing and insights gained by people with FAS and FAE, family members, and practitioners through conferences, support networks and internet websites/email discussion groups have nurtured some recent projects that offer the voices and experiences of young people with FAS about living with FAS. Parents and young people of the FAS/E Support Network of BC worked together to produce two booklets for young people that begin to make visible and audible some voices of the life experiences of young people with FAS or FAE. One booklet, *My Name is Amanda and I have FAE* (FAS/E Support Network of BC, 1997a) tells the story of a brother and sister with FAS or FAE and is "intended to provide basic information and encourage discussion" (p. 1). Another booklet, *Dear World We have Fetal Alcohol Syndrome: Experiences of Young Adults*, (FAS/E Support Network of BC, 1997b) provides basic information about FAS/E and its impact on physical health, mental health, education, employment, and "family, friends and fun", as well as profiles the words and "voice of experience" of a group of young people with FAS/E from British Columbia, Alberta, Yukon, and Washington state.

Some of these resources profiling the knowledge and perspectives of young people with FAS or FAE and their families have been utilised by recent human service support guides. Lasser (1999) provides a comprehensive set of information and practical teaching strategies related to FAS and FAE. In addition, Lasser identifies students with FAS or FAE's low self esteem as contributing to poor peer relations and strategies to enhance self esteem. Quotes from students with FAS or FAE and their parents are presented from sources, including, Copeland & Rutman, 1996; Dorris, 1989; FAS/E Support Network of BC, 1997b; Kleinfeld et al., 1993; and Malbin, 1993.

Parents and young people of the FAS/E Support Network of BC continue to work together, along with other community members and researchers. A recent example of this collaboration is Rutman et al.'s (2000) action research project, *Adults Living with FAS/E.* The FAS/E Support Network of BC partnered with the University of Victoria to "identify the independent living and support needs of adults with… FAS/E… and to examine and document the support strategies and relationships that people with FAS/E have found to be effective in resolving problems-in-living"(Rutman et al., 2000, p. 1). The project involved several regions of British Columbia, for both its research and action components. The researchers conducted open ended interviews with 32 adults with FAS or FAE and 35 "support people", such as partners, parents and caregivers. An "Action Planning Round Table" was held for project participants and others to review preliminary findings from their research interviews and to achieve other action goals, including facilitating relationships among people with FAS or FAE, their supports and human service professionals and developing community action plans arising from the project findings.

Rutman et al.'s (2000) project concluded that they were able to "emphasize people's strengths and capacities, while at the same time not shying away from challenges and concerns" (p. 12). A comprehensive range of issues in relation to FAS or FAE are explored, including education, employment, independent living, justice, mental health and parenting. In addition, they report on "an important finding of our project: the value of a person's knowing that s/he is affected by fetal alcohol, and its impact on mental health, community participation, and involvement in FAS prevention activities" (p. 7). Participants report that knowing that they have FAS or FAE, and understanding this disability, positively impacted their understanding of themselves and relationships with others. Approaches and/or action plans for supportive people, programs and services are identified with a community-based focus. Supportive networks for people with FAS or FAE, including peer support groups, mentors, coaches, counsellors, and cooperative or supervised housing are prominent in Rutman et al.'s (2000) findings and recommendations.

Friendships of Young People with FAS or FAE

With some very recent exceptions, knowledge and discussion about friendships of people with FAS or FAE are lacking in the literature found for this study. The following outlines key events noted within the literature regarding young people with FAS or FAE's friendships.

The social lives of people with FAS or FAE are often framed within a "socialising problems" discussion of the deficits of FAS and FAE in the literature (LaDue & Dunne, 1997; McCreight, 1991; Streissguth, 1997). LaDue and Dunne (1997) state that, "[P]eople with FAS/FAE also tend to have a high need for interaction but lack the social or cognitive skills that... [may result in] difficulty distinguishing between strangers and friends." (p. 146). Although such discussion may raise important issues regarding the lives of people with FAS or FAE, such conclusions are not informed by actual experiences and perspectives of people with FAS or FAE. This work lacks inquiry into or testimony from people with FAS or FAE about their behaviours or socialising experiences.

In contrast, experiences and perspectives of some young people with FAS about friendship are briefly introduced in the booklet, *Dear World We have Fetal Alcohol Syndrome: Experiences of Young Adults* (FAS/E Support Network of BC, 1997b). This booklet begins with:

> Dear World:
> I would like you to know that it isn't easy having FAS. ...It's hard to make friends. I'm very shy and quiet. The friends I do have are very special to me. FAS isn't what I wanted but I got it and I have to live with it. ... Later, Nancy (p. 1).

Nancy refers to her experiences of making and having friends as special and hard, as do some of other young people in this booklet. They report that "making friends is usually easy for us, but keeping them is hard" (p. 16). They express that they may "want friends so badly that we try too hard" (p. 16). Their experience of what some clinical research literature has deemed as "behaviour disordered" or "anti-social" shows a different perspective on their behaviours and relationship challenges. For example, they explain:

> Sometimes we have fights with our friends because we borrow things and forget to give them back. They call it stealing. When we realize our friends are mad at us, we're afraid we'll lose our friendship so we lie and say we don't have it (p. 16).

From the above, we are offered insights into these young people and their experiences and perspectives on misunderstood behaviours and motivations to maintain friendships. These young people who participated in this booklet recognize a difference between how they see their behaviour and how others see it.

In addition, we begin to learn about some of their experiences of friendship and the significant support role friendship plays in their lives. Candice (FAS/E Support Network of BC, 1997b) shares some of her thoughts about herself and her friendships:

> My friends know that I depend on them for their advice and decisions in a crisis I go through. When I am lonely or sad, I will call them up.

> They also know what and how FAS has affected me. If I go away, they make sure I take my medicine, because they know it helps me (p. 15).

Similarly, Lutke (2000) speaks about how she saw her daughter Karen's friendship with Kelly, a neighbourhood girl, continue and develop over the years and the positive, caring nature of Kelly's regard for Karen:

> Over the years, Karen maintained a close friendship at home and in school with a neighbourhood girl, Kelly, who accepted her as she was. By the time they attended junior high school, their friendship was solid even though Kelly pulled ahead of Karen socially and academically. All through high school, Kelly was there for Karen, explaining to, advocating for, supporting and protecting her. Most important, Kelly truly liked Karen. She saw her spirit, her joy of living, her compassion for others, her innocence not as qualities to be exploited but as traits to be protected and admired (p. 23).

These sources and references to friendships of people with FAS or FAE are very brief, and give only a beginning insight into their experiences. Friendship experiences have yet to be extensively explored, shared or included in what we know about FAS and FAE.

Summary

The FAS and FAE literature shows the extensive investment in determining the pathology of FAS and FAE, from the perspective of clinical experts, in our efforts to prevent FAS and FAE, or 'diagnose and treat' people with FAS or FAE. In addition to the primary disabilities of FAS and FAE, the literature conveys that there are secondary disabilities, demonstrated by mental health problems, disrupted school experiences, and trouble with the law, that arise out of inadequate or inappropriate support to people with FAS and FAE and their families. With some recent exceptions, people with FAS or FAE have not been viewed as credible informants or participants for research. This pathology orientation has been recently challenged and supplemented by literature and projects that have more inclusively brought together people with FAS or FAE, their families, service providers, researchers and others. These more inclusive works aimed to document and learn from the achievements, successes, challenges and practical living strategies that have arisen from people's experiences. Valuable knowledge is gained by shifting from an approach of "doing to" to "doing with" people with FAS or FAE and their supports. Various practical strategies that their experiences have proven to be effective now inform some of our knowledge and actions in building supportive networks for people with FAS or FAE and their families.

The social lives of people with FAS or FAE are often viewed within a "socialising problems" discussion of the deficits of FAS and FAE in the literature. Recently, we are beginning to hear from some people with FAS or FAE about some of their experiences of friendship and the importance of friendship in their lives. We also gain insights into these young people, their experiences and perspectives on misunderstood behaviours and motivations to maintain friendships. We learn that they recognize a difference between how they see their behaviour and how others see it. These inquiries into friendships of people with FAS or FAE are brief, and give only a beginning insight into their experiences. Friendship experiences need to be more extensively explored, shared and included in what we know about FAS and FAE.

The recent events and works that include the voices, experiences and perspectives of people with FAS or FAE are an encouraging step forward in developing a more inclusive source of knowledge about people with FAS and FAE. Furthermore, experiences of people with FAS or FAE are lacking in what we know about friendship, as Part Two of the literature review demonstrates.

Part Two: Friendship

Defining Friendship

This study involves understanding friendship experiences. A common starting place within friendship literature is asking what is friendship? The following outlines key aspects of defining friendship.

Richardson and Ritchie (1989) declare that "the concept of friendship is a complex one." (p.1). Hutchison (1990) argues that the term friendship is hard to define because everyone is supposed to know what it means. Donelson and Gullahorn (1971) compare friendship to jazz: "if you need a definition for it, you'll never understand it" (p. 37). Often, the conclusion is that friendship is at the core of being human. Uditsky (1993) offers that, "there is no question that friendship is integral to the human spirit and condition. It is part of what defines us as humans; it is part of what is necessary to the expression of humanness" (p. 85). Hutchison (1990) defines friendship in its loosest sense, as "an affectionate bond between two people" (p. 37). A key feature of Krappman's (1996) multilingual philological exploration of the word 'friend' is the voluntariness of friendship relations embedded within the word. This highlights the significance of individual choice inherent in the meaning of friendship.

Some literature attempts to put definitive boundaries on what is and is not friendship. Willmott (1987), in his exploration of the characteristics of friendship networks and social support, differentiates relatives, neighbours and friends, but states that there is no agreement on the meaning of friendship. Willmott acknowledges that his examination of research participants' social connections was dependent on people's own interpretations, and that 'friend' had many meanings, "so not all relationships with friends are the same kind of thing" (p. 81).

Some literature is more definitive about friendship. Bukowski, Newcomb and Hartup (1996) identify the key defining features of friendship as:

> (a) reciprocities, that is, mutual regard, behavioural mutualities and equivalencies in the 'benefits' that derive from the social exchanges occurring between individuals; (b) liking... the desire to spend time with one another in greater proportion to time spent with others; (c) affection and having fun (p. 3).

Ayres, Copani, Davis, Ironside, and Slavin (1992) include in their friendship criteria physical proximity, similarity or complementarity, and self-disclosure. Berndt (1982) identifies self disclosure as a sign of intimacy, distinguishing adolescent from childhood friendships.

From these sources, we understand that friendship is at the core of being human, and some view friendship as difficult to define due to its individuality. Friendship can be defined by specific features or conditions of friendship that include aspects of mutual experience.

Influence of Human Development Theory on Understanding Friendship

Friendship literature is heavily influenced by human development theory; the following outlines key aspects of the influence of human development theory on understanding friendship.

Friendship developmental literature usually focuses on a particular stage of human development such as childhood (Aboud & Mendelson 1996; Asher & Gottman, 1981; Bigelow, 1977; Bukowski et al. 1996; Howes, 1996; Youniss & Volpe 1978) adolescence (Azmitia, Kamprath, & Linnet, 1998; Burhmester, 1996; Laursen, 1996), parenthood (Doyle, & Markiewicz, 1996) and older age (Mathews, 1986). Stages and needs of human development are utilised to frame why and how friendship is important to the human experience (Hartup & Stevens, 1997; Sullivan, 1953) and portray how "friendship exerts a positive force on development" (Bukowski, Newcomb, & Hartup, 1996, p. 10). There is extensive developmental literature documenting the role of interpersonal relationships in supporting self esteem, learning and social competence (Asher & Gottman, 1981; Bryant, 1985; Bukowski et al., 1996; Damon, 1984; Tharpe & Gallimore, 1989; Urberg, Degirmencioglu, Tolson, & Halliday-Scher, 1995).

Most of this developmental literature focuses on children's relations and friendships. Piaget's (1932) and Sullivan's (1953) conceptual work has been assigned pioneer and seminal status within children's friendship literature (Furman & Bierman, 1984; Laursen, 1996; Youniss & Volpe, 1978). Both Piaget (1932) and Sullivan (1953) assert that a relation is an interactive process that forms the analytic unit for social science inquiry. Both their works argue that, "different types of interpersonal relations which children experience and know, serve distinct developmental functions" (Youniss & Volpe, 1978, p. 6). This proposition provides a framework that identifies the developmental nature of children's friendships as hierarchical, one phase providing the groundwork for the next phase of growth. (Bigelow, 1977; Furman & Bierman, 1984; Youniss & Volpe, 1978).

The often cited study of Bigelow and La Gaipa (1975) follows the above premise in their exploration of children's expectations of their friends. They collected from almost 500 children from grades one through eight, written responses comparing and contrasting expectations of their friends and of their acquaintances. Bigelow and La Gaipa found that older children expect more loyalty, intimacy, acceptance and genuineness from their friends and younger children expect more play and sharing from their friends. Across all age groups, children expect reciprocal liking, sharing and ego reinforcement from their friends. Bigelow (1977) applied a statistical cluster analysis to the above data and found that certain dimensions of friendship emerge together at certain ages. As children age and develop, their expectations of friends hold a broader range of characteristics.

Moreover, Youniss and Volpe's (1978) series of studies on over 100 children, aged six through fourteen are based on the relational premise established by Piaget and Sullivan, and are intended to add descriptive data to substantiate the pioneers' work. Youniss and Volpe found that children, in addition to regarding friends as peers, regard friends as those who share ideas, feelings and interests. These researchers report that children recognize that people in a relationship are individuals with sometimes similar and sometimes different personalities. Children between ages six to seven in their study identified and understood the specific rules of interacting with friends that were grounded in equality and reciprocity, and put the rules into action when playing and sharing. Children between ages nine and ten integrated the rules into a relational concept based upon principles of equality and reciprocity. Children between ages twelve to thirteen, related similar understanding, and provided further articulation of the equality and reciprocity principles through the development of their personal experience and reflection. Youniss and Volpe concluded that, "children's understanding develops from systems of interactive rules to procedures and eventually into systems of relations" (p. 21). Similarly, Furman and Bierman (1984) utilised a story-recognition task and written questionnaire with children in second, forth and sixth grades, and conclude that as children age, their expectations and understandings of friendships are built on systematically, in congruence with their developmental advancement.

Developmentalists have devoted much attention to the developmental significance of friendship, or the role of friendship in developmental outcomes. Newcomb and Bagwell (1996) contrast two points of view regarding friendship, friendship as a developmental necessity and friendship as a developmental advantage. Newcomb and Bagwell point to philosophical and literary works to illuminate the distinctions in these two viewpoints: Erasmus characterizes the necessity of friendship as "the most desirable of things; more necessary than either air fire and water" (p. 290), and C.S. Lewis describes the advantage of friendship with, "friendship is unnecessary like philosophy, like art… It has no survival value; rather it is one of those things that give value to survival" (p. 291).

Sullivan's (1953) interpersonal theory of development is from a necessity view. He asserts that friendships emerge in the preadolescent stage when the developmental need for acceptance, met by general peer group interactions, shifts to the developmental need for interpersonal intimacy, met by individual friendship. Sullivan asserts that certain social skills and competencies are acquired through collaborative interactions and relationships with friends. These relations are driven by a concern for one another, which derives personal satisfaction. Sullivan suggests that without mutual and collaborative friendship experiences, one does not have opportunities to gain a range of competent social behaviours. Sullivan also points to the therapeutic value of the affective, cognitive and social aspects of friendship relations. He states that friendship relations provide a context for improving aspects of development that have been previously compromised or absent in earlier childhood. However, he claims that a child's developmental success is constrained, if without the experience of a collaborative friendship relation in early adolescence.

Alternatively, those who hold the developmental advantage viewpoint assert that the collaborative relationship between friends may be advantageous but not essential for a healthy developmental outcome. Smollar and Youniss (1982) suggest that friendship provides a context to develop cooperation, mutual respect, and interpersonal sensitivity that can then be applied to other social relationships. However, Hartup and Sancilio (1986) assert that friendship is not the only context or relation to develop and refine these social behaviours. As such, friendship provides only a developmental advantage that facilitates acquiring these social competencies.

In further contrast, a few developmentalists, such as Berndt (1992), raise questions about the assumptions of positive outcomes of friendship popular within their theoretical community. Berndt provokes us to consider the developmental hindrances or negative features of friendship. Berndt (1992) explores negative features of children's friendships, such as poor quality relations and unresolved conflict, which correlated with low self esteem and lower peer group involvement. He also points to friends as important socialising agents, and explores the influence of friends in promoting antisocial behaviour, i.e., "peer pressure", or pushing a young person toward a maladaptive developmental pathway by promoting "deviance".

Most of the developmental theory and research on friendship have focussed on children's friendships, rather than adolescents' or young adults'. Most extensive studies of friendship extend only though middle childhood (Furman, 1993; Laursen 1996). Laursen (1996) identifies that there is "a dearth of theory concerning adolescent close peer relationships" (p. 186). Furman (1993) characterizes the typical "practice" in research on adolescent friendships as referencing the "seminal" works of Sullivan (1953) or Youniss (1980) and then proceeding with the empirical study. Laursen (1996) asserts that with this theoretical neglect, the adolescent friendship literature is not integrated and is difficult to relate thematically.

Exposure of these deficits to adolescent literature is interesting, given the well acknowledged developmental position that close relationships with peers play an increasingly important role in socialization across adolescence and young adulthood. Adolescents shift from parents to peers as a primary source of companionship and intimacy, where parents and peers are complementary rather than competitive influences (Furman & Buhrmester, 1992). Laursen (1996) points out the dynamic nature of friendships, given that relationships grow and change over time, and so do the individuals in that relation. Thus, we must examine friendships over the span of development of both the individuals and of their relationship, beyond middle childhood.

Laursen (1996) applies Kelley's (1983) work in social relational exchange theory of interpersonal relationships, in his elaboration of a theoretical model of adolescent close peer relationships. This exchange theory purports that interdependent relationships develop as interpersonal interactions remain mutually rewarding and each person increasingly depends upon each other for rewards. The thoughts, behaviours and emotions of those in interdependent relationships are causally interconnected (Kelley, 1983).

Laursen (1996) examines the literature to integrate themes of interdependence in adolescent and young adult friendships. For example, the following two studies are consistent with Kelley's (1983) conceptualization of interdependence. Savin-Williams and Berndt (1990) concludes that intimacy and loyalty are primary characteristics that distinguish adolescent friendships from other relations. Intimacy involves an openness that reveals thoughts and feelings; loyalty involves interpersonal commitment to share attitudes, values and activities. Similarly, Hartup (1993) identifies three attributes of adolescent friendships: reciprocity, involving expectations of intimacy as well as common interests and activities; commitment involving loyalty and trust; and equality, involving shared power.

Within adolescent friendship research, attention has been given to both same-sex friends and opposite-sex friends, including romantic partners. Sharabany, Gershoni and Hofman's (1981) study compares and contrasts reports from adolescents, aged eleven through nineteen, regarding intimacy with both same-sex friends and opposite-sex friends. These researchers utilise a composite rating of dimensions such as sensitivity, trust, and exclusivity. Intimacy remains consistent across all age groups for same sex friends and increases greatly with age for opposite-sex friends. For the study's young people in the oldest age range, intimacy ratings are the same for both same-sex friends and opposite-sex friends. Similarly, Furman and Buhrmester's (1985) study with the same age group utilising the Network of Relationships Inventory scale found that adolescent friendships and romantic relationships share many similar characteristics: intimacy, companionship and commitment. These also reflect a inter-dependent relation as described above.

The extensive child development literature on friendship has been most influential to our understanding of the developmental nature and imperative of friendship. It is of interest to note that Meyer, Park, Grenot-Scheyer, Schwartz, and Harry (1998b) found the child development literature to be restrictive, usually only involving caucasian children and limited data such as surveys, interviews or analogue experiments carried out in hypothetical contexts of scripted peer interactions. The developmental literature regarding child and adolescent friendships found for this study did not specifically identify any young people with disabilities as research subjects. However, many developmental, psychological, and sociological reasons are cited for supporting friendships of young people with and without disabilities. For example, Asher and Gottman (1981) argue that friendships promote social development, and a variety of communicative, cognitive and social-emotional skills. This developmental and rehabilitative role of friendship will be further examined in the following discussion regarding literature on friendships of people with disabilities.

Friendships of People with Disabilities

This study involves friendships of people with disabilities; the following outlines key events and aspects of the literature on friendships of people with disabilities.

In the last few decades, most people with disabilities have moved from institutional living into group or individual arrangements called community living. Historical segregation of people with disabilities meant that their opportunities for close relationships were largely limited to family members and other individuals with disabilities. The inclusion movement has sought to remove this constraint. This recent societal phenomenon sparked interest in relations of people with disabilities. Richardson and Ritchie (1989) note that there has been recent growth of interest in the "broad subject of friendship" (p. 11) in relation to those they describe as "people with learning difficulties" (p. 11). Baxter (1997) echoes that, "the issue of friendship, at one time largely overlooked, has been recently acknowledged as an essential component in promoting quality of life for individuals with a developmental disability" (p. 112). Baxter (1997) states that friendship allows us to satisfy primary needs such as acceptance, appreciation and respect, and asserts that these needs are no different for people with developmental disabilities.

Much of the literature regarding friendships of people with disabilities includes an underlying assumption that people with disabilities have some kind of deficit in development that friendships can ameliorate in some way (Daniel, 1987; Perske, 1988; Richardson & Ritchie, 1989). Grenot-Scheyer, Staub, Peck, and Schartz (1998) report that "friendships may form a network of relationships that will allow children with significant disabilities to grow up, go to school, and live, work, and recreate within communities of their choice" (p. 149). Richardson and Ritchie (1989) suggest that the three distinct functions of friendship for people with disabilities, in order of importance, are intimacy, company and practical help. Hutchison (1990) suggests that people with disabilities need friendship for intimacy and affection, feeling valued, breaking away from formal services, support and advocacy, a greater chance of a normal life and teaching acceptance. Although friendship may ameliorate difficulties for all of us, friendship is described more like a therapeutic intervention for people with disabilities, rather than friendship with a reciprocal (Bukowski et al., 1996) and a voluntary (Krappman, 1996) nature.

Many studies focus on barriers to social relationships for people with disabilities, the most common being limited opportunity (Grenot-Scheyer, Coots, & Falvey, 1989). This includes limitations to access, sense of belonging, and continuity (Kishi & Meyer, 1994; Schnorr, 1990). Richardson and Ritchie (1989) found that the circumstances of people with learning difficulties may be different from others, such as practical obstacles such as transport and money. Hurley-Geffner (1995) also identifies limitations in therapeutic supports such as interventions focussing on discrete social skills, many of which have been shown to increase social interactions but contribute little to the development of friendships. Hurley-Geffner also cites as barriers negative professional attitudes, such as beliefs that the child with the disability must be changed to seem more appealing and that such a child is incapable of sustaining social relationships. Hutchison (1990) proclaims that despite the accepted importance of friendship, the vast majority of people do not consider friendship with people who have a disability a priority or even a possibility.

Some literature compares and contrasts friendships between two people with disabilities and two people without disabilities, utilising scales and measurements derived from normative development theory. Zetlin and Murtaugh (1988) state that there has been little research on friendship patterns of "mildly handicapped adolescents (i.e., mildly mentally retarded and learning disabled)" (p. 447) and their social adjustment. Zetlin and Murtaugh (1988) conducted a study utilising participant observation to document friendship patterns of mildly learning disabled youth, and to contrast the characteristics of intimacy, empathy and stability over time to those of non disabled youth. Youth with disabilities were found to have fewer and less stable friendships than did their nondisabled counterparts. Zetlin and Murtaugh found less evidence of intimacy and empathy between pairs of disabled peers. They characterize many of the relations between disabled peers as superficial or quasi-intimate and found that there were distortions and falsehoods in their personal disclosures such as,

> boasting falsely about boys/girls who were interested in them, feats that they had accomplished, possessions they had acquired... Such claims attracted attention and elicited favourable comments, but they presented confused and distorted impressions of the teller's lives, making it difficult for their friends to know them accurately. The fabrications seemed to be designed to make the teller appear normal (pp. 450-451).

Zetlin and Murtaugh conclude that their subjects' fabrications were not indicative of pathology, but of low self esteem. Zetlin and Murtaugh point to restrictions imposed by limited and separated learning and recreational environments of the youth with disabilities that accounted for the lack of opportunities for experience of social relations and friendship development. Referring to Tesch's (1983) argument that friendship behavior changes with experience, Zetlin and Murtaugh recommend the social opportunities of young people with disabilities be broadened. However, the study did not include interviews with young people to gain insight from their perspectives and experiences.

Grenot-Scheyer, Staub, Peck, and Schartz (1998) did include some perspectives of young people with disabilities. These researchers point out that the complexity and severity of conditions that characterize young people with severe disabilities, such as autism, make them particularly vulnerable to experiencing poor social relations with peers. These complexities are illustrated in this young person's reflections:

> This has been an extremely trying time for me as I have had to fight my autism and many times it overcomes me... I am fortunate to be alive at a time when facilitation [a communication technique] was discovered and I was opened up as a person who can demonstrate unusual behaviours and intelligence too.... I am a lot busier than I would have been but I am also happier. I am still trying to make friends. This is not easy because my behaviours sometimes scare people (p. 150).

Difficulties such as those experienced and shared by this young person with autism have continued to motivate researchers' and practitioners' efforts to identify the friendship problems of people with disabilities and then strategies for others to facilitate friendships for people with disabilities (Richardson & Ritchie, 1989; Hutchison, 1990).

Richardson and Ritchie (1989) focus on how to create conditions within which people with learning difficulties can make and maintain friends. They argue that there are certain conditions necessary for the development of intimate friendships: opportunities to meet people who may be compatible, ability to develop and sustain relationships, expectations of continuity of contact, and reciprocity or mutual recognition of relationship. They cite Landesman-Dwyer and Berkson (nd) who conclude that, "we know of no principles about social behaviour that appear unique to retarded individuals, nor are there any theoretical reasons that affiliative patterns should be guided by different factors in this population" (p. 149). Richardson and Ritchie (1989) had discussions with 60 people with learning difficulties regarding the nature of their friendships, how these developed and needs for greater social contact and support. They point to a problem concerning the often implicit assumption that the most desirable social contact is integrated. Social, intimate in particular, relationships for people with learning difficulties seem to be more highly valued when they are with non disabled people. They assert that people with learning difficulties want to and do achieve close friendships with one another.

However, much of the recent literature focusses on fostering relations between people with disabilities and other (non disabled) members of the community (Gold, 1988; Hutchison, 1990; Lutfiyya, 1988; Perske, 1988). Perske (1988) describes friendships of people with disabilities as helping them move beyond human service goals and families. He paid tribute to uplifting stories of young people with disabilities and their non disabled friends. This work does not, however, move beyond the human services strategy of facilitating a circle of friendly helpers around a person with disabilities. The perspectives of the people with disabilities are not included in this discussion; we do not know how the young people with disabilities regarded these relationships.

Bogdan and Taylor (1987) define friendships between disabled and non-disabled people as, "one between a person with a deviant attribute and another person, which is of long duration and characterized by closeness and affection, and in which the deviant attribute does not have a stigmatizing or morally discrediting character" (p. 35). The use of deviancy as a descriptor and definer of a person with a disability is reminiscent of the pathology oriented research on FAS.

Within recent years, some researchers and practitioners have been attempting to create opportunities for young people with disabilities to develop meaningful friendships with peers without disabilities. The motivation for this effort came from findings that simply putting children together was not enough to ensure positive interaction, let alone the development of friendship (Hurley-Geffner, 1995). The inclusion movement provoked an explicit effort to identify those settings, situations and supports that would facilitate meaningful relationships and positive attachments between young people with disabilities and those without disabilities (Ayres, Copani, Davis, Ironside, & Salvin, 1992, Hurley-Geffner, 1995). Nevertheless, Day and Harry (1997) and Park (1997) question the powerful bias in favour of relationships with peers without disabilities. Spindler and Spindler (1990) also raise the issue that North American society's commonly held value of equity in relationships tends to promote a preference for peer relationships because of the fear of an imbalance of power or lack of reciprocity between nonpeers.

Meyer, Minondo, Fisher, Larson, Dunmore, Black, and D'Aquanni's (1998a) participatory inquiry regarding social relationships among adolescents with diverse abilities (with and without significant disabilities) raises questions about social interactions among young people and how they enter into friendships. The study utilises interviews and observations of interpersonal relations of classmates in an integrated high school, conducted and interpreted by different constituent groups such as young people with and without disabilities, parents, educators and researchers, which also included cultural and social diversity. Meyer et al.'s (1998a) findings are organized into six "frames of friendships" that seemed, from the interpretations of the different constituent groups, to characterize the social relationship of students with severe disabilities and without disabilities. They found that some young people with significant disabilities can and do have best friends as well as helpers, but also some relations that are assumed to be friendships seem instead to be facades where interactions stop at hallway greetings.

There is a growing critique of friendship literature, in particular those that relate to friendships of people with disabilities. Hurley-Geffner (1995) concludes that studies have focussed on social interactions rather than friendship and recommends that future studies should make friendship "the variable of study" (p. 122). Meyer et al. (1998a) report that much of the literature on students with severe disabilities uses a 'black and white' framing of a friend vs. helper or rejection vs. best friend. They posed questions to look at friendship differently. Most typical answers to why a peer without disabilities was named as a best friend were because he or she can share secrets and enjoys similar activities and interests. When asked this same question about why a student with severe disabilities was named as a best friend or a regular friend, the reasons given most often focussed on helping or thinking that the student was "fun" or "nice to me". This would appear to be qualitatively different, and such differences have led to concerns that friendships between young people with and without disabilities might lack essential components of reciprocity for long-term friendship. But Meyer et al. ask how do we know? They wonder if the feelings and self-esteem that arise from helping someone else entail as much personal reinforcement for a child as the feelings that arise from sharing secrets or playing the same games together. They challenge the assumption that one "type" of friendship has more or less value than another, regardless of the levels of reciprocity.

Meyer, Park, Grenot-Scheyer, Schwartz, and Harry (1998b) advocate for changes to the conceptualization and conduct of friendship research. Meyer, et al. (1998b) provide an innovative collection of US research and literature regarding the influences of culture and development on young people's social relationships. This collection critiques traditional research on friendships, converging on the need for a "far more integrative relationship among research, practice and constituent beliefs and values" (p. 2). This collection presents a variety of participatory and collaborative research studies regarding friendships among young people. Participant groups of these studies are described as having diversity with respect to culture, social and disability.

In keeping with Krappman's (1996) philological finding of voluntary choice inherent in the word friendship, Harry, Park, and Day (1998) discuss "friendships of many kinds" and advocate for valuing the choices of young people with disabilities. Harry et al. (1998) struggled with the assumption that helping has to be reciprocal to be an acceptable feature of friendship. An emphasis on equity and reciprocity is in response to the frequent finding of excessive helping interactions by the individual without disabilities in these relationships (Meyer & Putnam, 1988). Although Harry, Park and Day (1998) believe that there are reciprocal benefits for both friends, they struggle to identify and define the meaning of reciprocity in the context of relationships where one has more abilities than the other. They question if we have implicitly devalued relationships and friendships that differ from the peers without disabilities model. There is little evidence of interest in how friendships between individuals with disabilities develop and whether they resemble what is known about friendships of typically developing children and youth.

Similarly, upon reflection of their study, Richardson and Ritchie (1989) argue that, "a real concern with friendships should focus on what people get from their relationships - not the origin of a relationship nor the individual characteristics of those involved" (p. 10). I interpret this as a recommendation to seek to understand a person's experience of friendship.

Experiences and Meanings of Friendships of People with Disabilities

This study focuses on the experiences and meanings of friendship of people with FAS or FAE. Although I did not find reference to people with FAS or FAE in the friendship literature, a pivotal aspect of this study's analysis concerns this disability in relation to friendship. Thus, the following section of the review selects and discusses key aspects of literature experiences and meanings of friendships of people with disabilities.

I found limited references to experiences and meanings of friendships of people with disabilities. As the above discussion argues, we are only beginning to conceptualise and understand friendships of people with disabilities, particularly from a position of their perspective and experience. This may require us to look at friendship differently, and question our taken for granted assumptions and values about what is friendship. If we apply Krappman's (1996) voluntary nature of friendship, then we must take a look at the choices of people with disabilities and understand "friendships of many kinds" (Harry et al., 1998).

Harry, Park and Day (1998) offer emerging data on friendships between youth with disabilities from their recent studies which employ participant observation and in depth interviews. These studies are producing unsolicited, unexpected data on spontaneously occurring friendships between youth with disabilities. Park (1997) reports that in her study (in progress) of social relationships at the worksites of eight young people with disabilities, "spontaneous and consistent friendships emerged as a key aspect of the data" (p. 396).

Day and Harry (1997) attempted to assist a pair of high school friends in pursuing school social activities together. The young women shared with the researchers some barriers to the friends' after-school activities, such as logistical issues and cultural and familial concerns. Interviews with both young women and participant observation of their joint social activities further their understanding of the nature and importance of friendship. Day and Harry categorise it as a typical friendship, as indicated by strong evidence of the three features reported by Bukowski et al. (1996): reciprocity (helping each other), mutual liking (describing each other as wonderful, understanding), and affection/fun (giggling, looking at boys) as well as Berndt's (1992) feature of intimacy ("can talk about everything").

In Day and Harry's discussion of the commonalities between the two women, they state that it is not unusual to expect shared experience and group membership to be one source of mutual attraction. Romer, Faus, Fredericks, Reiman, Neal, and White (1998) report that people who are deaf-blind have emphasized the importance of relationships with others with the same disability because of a shared understanding of their life experience. A similar stance by the deaf community and people with physical disabilities (with sporting activities as community-builders) is popularly known (Detweiler, 1987). Shared membership in any group, whether by ethnicity, nationality or language tends to be correlated with choice of friends (Bukowski et al., 1996). Harry, Park and Day (1998) acknowledge that some advocates for inclusion may find their discussion disturbing because of fear that it may promote a return to the stance of expecting people with disabilities to be "better off with their own kind", as many people were advised before inclusion. They state this was not their intention and agreed that continued efforts in research and practice are needed to support and understand positive relationships and friendships between people, both with and without disabilities. They, however, would like to see the field explicitly endorse its support for and interest in "friendships of many kinds" for people with disabilities, especially when they are freely chosen. Harry, Park and Day (1998) assert that attempts to assist in enriching the social lives of young people with disabilities should provide them with diverse social opportunities while offering support for the relationships that they initiate and to which they are attracted. Social inclusion, they purport, should mean respecting and supporting a wide range of individual choices and values.

Netherlands researcher Mulderij (1996; 1997) provides unique insights into experiences of friendship of children with physical disabilities from her 5 year study involving open interviews and participant observations of 65 children in the diverse settings of their 'life world'. Case studies are utilised to illuminate the children's life world including perception of one's body, experiences of friendship and the role of helpers. She found that children with invisible or inconspicuous disabilities have more difficulties than those with visible disabilities in having peers understand their differing participation in activities, and can be more easily rejected. She describes various strategies such as creativity and compensation that the young people used to deal with peer exclusion. What sets this study apart from others is that Mulderij (1997) reveals to us the perspectives of some of her participants on friendship. For example, the significance of helpfulness is shown in a conversation between two boys with disabilities:

> I think myself that friendship with disabled children that it's .. even better than friendship between able-bodied children. That's because, for example, if I bump into something and my hand gets bent back double or my head falls down, Rico is there, then Rico puts my head back right ... If then for example, two regular children are walking in the street and one of them trips over.. he's just got to stand up all by himself (p. 384).

Rico continues their point:

> Yes he just gets up again without the other having to help him, get it? So he hasn't got anything really to thank the friend for. No he can do it himself, so just let him take care of things himself then (p. 384).

Mulderij (1997) concludes that empathy, consideration, flexibility and helpfulness are necessary for friendship with a child with a disability, and that the child with disabilities values this reciprocity. Rico and his friend's discussion embodies this valuing of interdependence of friends. Mulderij also presents aspects of friendship that were important to her participants, such as sticking up for your friend when, for example, others tease them about their disability. She acknowledges this happens in other friendships but points out that it happens sooner and more often for her participants with disabilities.

Summary

Friendship literature, heavily influenced by normative human development theory, focuses on younger children's relations and friendships. This literature is guided by a framework that identifies the hierarchical developmental nature of children's friendships, one phase providing the groundwork for the next phase of growth. With attention to the developmental significance of children's friendship, or the role of friendship in developmental outcome, methodologies have primarily used standardized tests or rating scales. Given the focus on children, some assert that there has been a theoretical and empirical neglect of adolescent friendships. Within the adolescent and young adult friendships literature, there is an emerging theme of interdependence, involving intimacy, companionship, loyalty, reciprocity, commitment and equality.

The developmental literature regarding child and adolescent friendships that I found and reviewed for this study did not identify young people with disabilities. However, many developmental, psychological, and sociological reasons are cited for supporting friendships of young people with and without disabilities. Some view friendship as a necessity for development, others view friendship as advantageous. Given that I share the common belief that friendship is at the core being human, I agree that friendship is integral to our development. Perhaps because I also value the individuality and voluntary nature of friendship, I believe that we must consider that the impact of friendship on one's development also relates to the individuality of one's experience of friendship.

This developmental literature has included an underlying assumption that people with disabilities have some kind of deficit in development that friendships can ameliorate in some way. After people with disabilities moved out of institutions, and concerns of community integration and inclusion emerged, barriers to friendship for people with disabilities were identified with an aim to support friendships between non disabled and disabled people. Some approaches to supporting friendships of people with disabilities appeared to be more of therapeutic intervention, rather than supporting reciprocal or voluntary friendships. Although I do not agree with this approach, I do not know whether or not these relationships were positive or beneficial for people with disabilities, as their perspectives were not thoroughly examined. We must explore and better understand the experiences and perspectives of people with disabilities regarding their interactions, relationships and friendships.

Many researchers and practitioners have continued to operate with their adult, non-disabled perspectives and values. These values appear to favour certain kinds of relations over others, rather than exploring the choices and experiences of friendships of people with disabilities. Despite such gaps in the literature, there is a new call for understanding "friendships of many kinds" and emerging work attempting to understand a person's experiences of friendship from within the context of her or his 'life world'.

Conclusion

I conclude that an examination of experiences and meanings of friendships of young adults with FAS or FAE will provide useful contributions to our knowledge about FAS and FAE and our knowledge about friendship. In both literature sets, there are emerging works that show that we are beginning to recognize the value of listening to and understanding the perspectives of those who know through their own experience. I am particularly intrigued by stories where there are differences between how someone views their own experience and behaviours and how others see them, for example, Nancy's (FAS/E Support Network of BC, 1997b) explanation of her behaviours and motivations to maintain friendships and Rico's (Mulderij, 1997) value of interdependence over autonomy in his friendships. I am also interested in stories where there may appear to be contradictions in what a person describes about their experience, for example, the young people with FAS or FAE's comment, "making friends is usually easy for us but keeping them is hard"(FAS/E Support Network of BC, 1997b, p. 16). I believe that these differences and apparent contradictions provide valuable entry points into exploring the complexities of the experiences and issues.

With the above literature review, I attempt to establish a context for my exploration of seven young adults with FAS or FAE's experiences and meanings of friendships. My literature review explored the construction of knowledge about FAS and FAE, including the pathology oriented construction of FAS and FAE; the voices and experiences of people with FAS or FAE; and friendships of young people with FAS or FAE. I also reviewed the construction of knowledge about the experience of friendship, including defining friendship; the influence of human development theory on understanding friendship; friendships of people with disabilities; and experiences and meanings of friendships of people with disabilities. Reviewing and attempting to synthesize the literature related to FAS and FAE and friendship aids me in understanding the complexities of the concepts, knowledge, issues and experiences related to friendship experiences of people with FAS or FAE. These complexities contribute to, and are further examined, in my data analysis.

CHAPTER THREE: METHODOLOGY

This qualitative study aims to address some of the gaps in the literature regarding FAS and FAE and experiences of friendship. By exploring, presenting and analysing what participants with FAS or FAE voice about their experiences, including their experiences of searching for, finding, having and experiencing friendships, the meanings friendships have for them, and their views of friendship experiences as they face the challenges of FAS or FAE, this study aims to help us better understand, learn from and support those who have FAS or FAE.

The research questions that guide this study are: What are the friendship experiences of seven young adults with fetal alcohol syndrome or fetal alcohol effects?; and What are the meanings of these friendship experiences for these young people?

Given that friendship is a personal experience involving personal reflections and interpretation, I decided that a qualitative research approach was best suited to developing an understanding of such experience. The following outlines the methodological considerations of this study.

Philosophical Approach

I am influenced by both feminist and ecological theories. Feminist theory assumes that there is an uneven power distribution in society and that making these inequities visible is crucial to understand the everyday living experiences of those who are oppressed (Kazan, 1994). Moreover, the voices, experiences and perspectives of those who are oppressed have been made invisible and must be heard and understood in order to change social power (Rose & Innes, 1992). Power, feminists argue, is not simply one aspect of a society but is the basis for society and therefore shapes all aspects of one's life (Briskin, 1990). Feminist theorists assume that knowledge and what is believed to be true and right is socially constructed, and is used to create and maintain power inequities within both societal and personal relations (Kincheloe & Maclaren, 1994). These assertions are consistent with Rioux and Bach's (1994) critique of traditional research regarding people with disabilities (and its use by policy makers and practitioners) that results in the problem constructed to be people with disabilities and the solution to be expert intervention to rehabilitate their deficits.

Ecological theory describes and explains the processes, patterns and interrelationships between entities such as people, feelings, interactions, experiences and environments (Berns, 1989). Ecological theorists explain the interactions and interrelationships amongst different levels of systems. These levels range from the microsystem, the individual person or entity and its immediate environments, the mesosystem, relationships among the immediate environments, the exosystem, the specific social structures that impinge on these environments, and the macrosystem, overarching societal, ideological and cultural institutions and values (Garbarino, 1985). Reinharz (1992), a feminist researcher, reflecting upon Collard's (1989) description of ecology (eco=house; logos=word/thought/speech) as woman-based, explains how she came to see feminist research as an ecological system of the "housed contexts" of people, institutions and ideas, connected to each other in complex ways. For example, Reinharz (1992) explained, feminist researchers are housed in the contexts of academic institutions and particular academic disciplines and theories, as well as the contexts of the women's movement and their own personal lives and relationships.

Reinharz's (1992) reflections upon the connections between feminism and ecology resonated with my own beliefs and experiences. From the etymology, I have regarded ecology as the language of house(s), houses meaning living beings, people, places, ideas, and things. I see research as a process of visiting these houses. Perhaps by inquiring, the houses are opened, providing a viewpoint that I didn't have before. And perhaps, by revisiting the houses and seeing and experiencing relations amongst them - a community is formed, with different interacting houses of beings, ideas, languages, voices and experiences. However, given my feminist beliefs about power and privilege inequities, I also see how there can be a lack of connection between some of these houses for reasons of viewpoint and power. I believe that some, such as the "subjects" of research, have been portrayed as standing still within their house while others with more advantages, such as researchers, have had the power and abilities to move among the houses and communicate what is learned from the research. I believe that the voices and experiences of those who have been "subjects" must be sought, heard, and made central to understanding the "community" and its relations.

While feminist theory explains to me the necessity to raise the profile and participation of certain perspectives and experiences, such as those who have FAS or FAE, ecological theory guides me to specifically examine the social aspects and multiple contexts of those voices and experiences. The four system levels of ecological theory provides a specific framework to consider both interpersonal and social aspects of the contexts of their experiences.

Feminist and ecological theory guides and supports my philosophical approach to this study. I attempt to bring forward the voices, perspectives and experiences related to friendship of the five young adults with FAS and the two young adults with FAE. From my literature review and my professional experiences, it appears to me that the voices, perspectives and experiences of those with this disability have not had the power or the privilege to be adequately included within our discussion and knowledge about FAS or FAE, nor about the experience of friendship. In addition, with what I learned from conducting the data analysis, I decided that in order to understand what these young people were sharing about their friendship experiences, we need to see the inter-connections among their life and friendship experiences.

Research Design

Denzin and Lincoln (1994) state that a research design, "describes a flexible set of guidelines that connects theoretical paradigms to strategies of inquiry and methods for collecting empirical material" (p. 14). Guba and Lincoln (1989) state that a paradigm represents a patterned set of assumptions concerning ontology (what is the nature of reality?), epistemology (what is the relationship of the knower to the known/knowable?), and methodology (how do we know or gain knowledge?). Ely, Vinz, Downing, and Anzul (1997) speak of paradigms as overarching philosophical systems with particular ways of being, ways of knowing and ways of doing. Thus, an inquirer's paradigm situates her place of world view, provides ways of making sense of that world view and of constructing knowledge of the inquiry.

Denzin and Lincoln (1994) explain that qualitative researchers underscore the value-laden nature of inquiry. Qualitative researchers highlight socially constructed reality, the intimate relationship between researcher and what is studied, and what shapes the inquiry. They question how social experience is created and given meaning, and seek to show these processes. Patton (1987) states that qualitative methods allow us to study selected situations or issues with rich and detailed information through direct quotation of what participants say about their experiences and views about what is being studied as well as careful descriptions of what the researcher observes. Qualitative methods provide open ended narratives of people's experiences and observed events.

A qualitative research design provided the framework with which I could undertake this study, aimed at understanding what participants with FAS or FAE voice about their experiences. My focus includes their experiences of searching for, finding, having and experiencing friendships, and what their friendship experiences mean to them. This study aims to help us better understand, learn from and support those who have FAS or FAE. All of these aims are consistent with the above descriptions of qualitative research design. Specifically, this study employs the qualitative research method of narrative analysis.

Narrative Analysis

Qualitative research has underscored the importance of narratives in our lives and the usefulness of narrative as a research method. Riessman (2000) relates her early experiences of interviewing participants who, rather than concise answers to her "seemingly straightforward" questions, would provide long stories about their experiences. Feminists and others transformed our thinking about participants' stories from being digressions to being a reflection of the life world of naturally occurring conversation (Mishler, 1991) and of how we organize and express meaning in our lives (DeVault, 1999). Story telling is "a primary act of the mind... that plays a major role in our sleeping and waking lives... In order to really live, we make up stories about ourselves and others, about the personal as well as the social past and future" (Hardy, 1978, p. 12).

Although inter-related, I am drawing a distinction between the terms story and narrative. In this study, stories refer to experiences and events that are lived and told by participants. Stories become narratives after they are re-constructed and written from the analysis process (Carr, Taylor & Ricouer, 1990). This is "the reasonably well-established device of calling the phenomenon story and the inquiry narrative"

(Clandinin & Connelly, 1994, p. 416). Thus, "people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect stories of them, and write narratives of experience" (Ibid, 1994, p. 416). Narrative analysis takes as its object of investigation the story itself and allows for systematic study of personal experiences and meaning (Riessman, 1993). Given my research questions involve examining participants' experiences and meanings of friendships, I decided that narrative analysis is an appropriate method for this study.

Narratives are personal, relational and social. Schultz (1997) posits that "no story can be told in its entirety, a text always leaves gaps in the telling of the story which readers must fill, and which individual readers fill in different ways" (p. 133). Each of us, given our individuality of beliefs and experience, will gain different learning and insights from both participants' stories and from the research narrative. Moreover, narratives offer both personal experiences and their social contexts. Personal experience is located in particular historical and societal contexts (Mills, 1959). Narratives can illuminate "individual and collective action and meanings, as well as the social processes by which social life and human relationships are made and changed" (Laslett, 1999, p. 392).

The narrative approach "does not assume objectivity but, instead, privileges positionality and subjectivity"(Riessman, 2000, p. 2). The narrative serves as both the process and outcome of analysis, given that "how we arrange and rearrange text in light of our discoveries is a process of testing, clarify and deepening our understanding of what is happening in the discourse (Mishler, 1991, p. 277). Narratives are constructed from our understandings which involve "the rearrangement of events – that is the compressing, emphasizing, ignoring, and sequencing of stories" (Ely et al, 1997, p. 64). Narrators create order from disordered stories of experience to allow themselves and others to make meaning of what was researched (Shultz, 1997).

Narratives are interpretive; decisions regarding the inclusion/exclusion of content and its presentation are shaped by the researcher's theoretical interests and research questions (Riessman, 1993). Some researchers provide detailed transcripts of participants' speech so that readers can see the stories apart from the narrative analysis (Ely et al, 1997; Riessman, 2000). In this study, I present each participants' stories of friendship in a chapter preceding my narrative analysis chapter. I do acknowledge that the very acts of my collecting, recording and presenting participants' speech and stories influence these accounts of their experiences. Thus the written stories differ from their actual experiences and from their own story-telling. I include both participants' friendship stories, composed from direct quote excerpts of their interview transcript and remaining in first person voice, and then my own narrative analysis, where my analysis is in first person voice and each participant is referred to by name. By doing so, I attempt to offer the reader both the participants' own voices and stories as well as my own interwoven narrative analysis. I hope that both participants' stories and my narrative analysis are meaningful for the reader. In addition, I aim to make as visible as possible my analytic interpretations.

This analytic visibility relates to evaluative criteria regarding narrative research. Although there are no established criteria for the "trustworthiness" and value of narratives (Connelly & Clandinin, 1990; Riessman, 2000), I am following Ely et al's (1997) suggestions to use established criteria for qualitative data analysis, including auditability (Sandelowski, 1986). I discuss this study's consideration of qualitative data analysis evaluative criteria in the Analysis section of this thesis. Since this study also employs secondary analysis, I now turn to further theoretical discussion.

Secondary Analysis in Qualitative Research

There has been a growing discussion of the benefits and challenges of secondary analysis in qualitative research (Lobo, 1986; Thorne, 1994; Woods, 1988). Thorne (1994) identifies several opportunities of research involving qualitative secondary analysis. These opportunities include analytic expansion in which the researcher makes further use of her own original database to answer questions at the next level of analysis or to ask new questions as the available theory base expands, and retrospective interpretation, in which the database is used to consider new questions that arose, but were not thoroughly examined, in the original study.

Thorne (1994) points out that where the secondary analyst was involved in primary data construction, the researcher's relationship to the data will be inherently different from that of the researcher looking at the data for the first time. Researcher(s) of the original study can be a valuable informant source for the secondary analyst (Brody, 1992). A key issue in deciding whether secondary analysis is appropriate for an inquiry is the degree to which the secondary research question fits the available data. One element of fit involves whether the question posed in the secondary analysis is adequately close to the topic of the original inquiry (Thorne, 1994). Another element of fit involves consideration of the influence of the methods used to produce the original data set. The research processes and orientation of the original study will shape the nature of the data. In addition, qualitative data construction is interactive, so the nature of the data changes as the research progresses (Scheff, 1986). For example, data about a theme that arises spontaneously in the early phases of the inquiry may be different than data triggered by increasingly focussed probes during the final phases of the research (Thorne, 1994). Finally, these issues of uniformity have a heightened relevance if the secondary analysis involves comparison of several distinct data sets (Thorne, 1994; Miller & Crabtree, 1992).

Secondary analysis in qualitative research has value in opportunity and important considerations in its design and implementation. The above issues underline the importance of all qualitative research to make the processes of research and inductive analysis explicit and to leave an auditable decision trail (Catanzaro, 1988). The secondary analyst also should account for limitations that could impose on secondary interpretations. With thoughtful attention to such rigour and auditability, Thorne (1994) asserts that, "secondary analysis offers great promise for another layer of meaning to the work in which we are engaged" (p. 276).

This study's secondary analysis considerations are discussed after the following sampling discussion.

Sampling and Data Collection

Issues of sampling in qualitative research differ from those of quantitative research (Morse, 1991; 1994; Sandelowski, 1986). Morse (1994) states that the selection of participants and the "situation of the sample is determined according to the needs of the study and not according to external criteria, such as the random selection" (p. 229). The needs of this study include "information-rich" descriptions of experiences, and participants need to be selected so that they can illuminate this experience. Morse (1991) describes a 'good' informant as someone who is knowledgeable about the experience, can speak about and reflect upon her or his lived experience, and is willing to share these life experiences and reflections with the researcher.

Purposeful sampling also involves informational adequacy, gathering data until reaching the point of saturation, when one no longer hears "anything new" and there are no thin areas in the data (Morse, 1991). One would ask if the data collected is relevant, complete and rich in description. Practically, one must balance sampling that results in in-depth information with a variety of experiences and contexts, yet in a volume that is manageable to analyse. Having some variability within the sample allows examining both common themes that cut across variations of context as well as unique experiences or circumstances (Morse, 1994; Patton, 1980).

Sample and Sampling

Participants

The seven young adult participants had similarities and differences that provide a variety of experiences and contexts. Six are women; I only successfully recruited one young male participant. The young man was 16 years of age, has FAS, was living in foster care and was in high school. The two young women who are (birth) sisters were both aged 19, have FAE, are of aboriginal heritage, were living with non aboriginal adoptive parents, had graduated high school and were beginning post secondary education. The two young women who were interviewed together were 20 years of age, have FAS, had lived in group and foster homes, had graduated high school and were currently living on the street together. One of the pair had a one year old child, whom she had cared for in his first year, but at the time of data collection was in the care of his paternal grandmother. One of the pair was of aboriginal heritage. Another young woman was aged 20 years, has FAS, had lived in adoptive, group, and foster homes as well as the street, and was currently living on her own. She had left school at grade 9, and had a two year old child, who she had cared for, but was then in the care of the child's father. Another young woman was aged 18 years, has FAS, had lived in foster and group homes and was currently living with her (birth) mother. She had dropped out of school but was going into an alternative high school program. All young adult participants but one were diagnosed with FAS or FAE at the same children's health care institution. All were currently living in the South Vancouver Island area but four had lived on the lower mainland of British Columbia at different times in their lives as well.

Data Description

Although there were seven young adult participants, there were six interview transcripts as a sample for data analysis. One transcript included both the two young women whom I interviewed together, and their interview dialogue was interactive. Transcripts of each of the seven young adult participants interviews vary in length from 20 to 35 pages and provide information-rich descriptions of participants' experiences and reflections. All transcripts include detailed descriptions, thoughts, feelings, experiences, and stories of each of the topic areas of the interview guide, described in the Foreword of this thesis, and key experiences that stood out for them from their early years to the time of the interview. All young adult transcripts provide detailed descriptions of participants' thoughts, feelings, and reflections of their experience of themselves and various aspects of their lives. They all include detailed descriptions, thoughts, feelings, experiences, and stories, both positive and negative, about their relationships with others such as family, friends, peers, teachers, health and human service professionals, and others in their life. All transcripts provide examples of interactions and conversations participants had with others, as well as what certain relationships meant to them and how they made sense of their interactions and relationships. Importantly, all transcripts provide detailed description about participants' experiences and reflections about friendship, including longing for, searching for, finding and having friends. Most provide intimate details of their relationship experiences, and what their thoughts and feelings were about them, including those who spoke about their pregnancy and parenting experiences. Two young adults chose to be interviewed together; they had been close friends for over five years. Their interview transcript includes detailed and comprehensive descriptions about their relationship with each other.

As the above descriptions of the data and of the young adult participants indicate, the requirements of informational adequacy (Morse, 1991) were met. The data sample is relevant, complete and rich in information related to friendship. The data includes descriptions of experiences, stories, thoughts, feelings, and reflections, with a variety of life experiences and contexts for an examination of the common themes and unique experiences and meanings of friendship for some young adults with FAS or FAE. I kept in mind that there are practical limitations in volume so that the data is manageable to analyse. I decided that the data sample of the seven young adults was saturated, given there are patterns of common themes related to friendship experiences across participants' data and some unique experiences as well. It provided sufficient, in-depth, complete and substantial information to analyse and yield understanding. I was seeing similar friendship-related experiences, stories and connections to life experiences, such as multiple relationship losses, over and over again, and I was also seeing some individual experiences and information that could be informative.

In addition, the data sample demonstrates that the young adults with FAS or FAE participants, having been purposely selected, are good informants (Morse, 1991). They are knowledgeable about their experiences of friendship, and chose to speak about and reflect upon those experiences during their interviews. I believe from my own experience that young people with FAS or FAE can be good informants and are capable of speaking reflectively about their life and experiences. Furthermore, the interview data transcripts of the seven young adults are evidence to support my belief and claim to their capacities. These transcripts provide detailed and complete information about participants' descriptions and reflections about their experiences. Moreover, one of the primary motivations for my decision to have friendship experiences as the topic of this study came from hearing what these young adults had so strongly, passionately and specifically told me about - their experiences and reflections of longing for, searching for and having friendships. I saw this as further evidence of their knowledge, willingness and capacity to provide data for analysis, making them good informants.

Secondary Analysis Considerations

As a researcher in the initial study (Copeland & Rutman, 1996), I considered how the issues, processes, and orientation of the initial study influenced the production of the data set in order to determine the appropriateness of its use for the secondary research question (Brody, 1992; Catanzaro, 1988; Thorne, 1994).

One key influence on the initial study was our belief in the capacity of people with FAS or FAE. Contrary to the available literature, we wanted to explore and present not only the challenges and barriers that people with FAS or FAE dealt with, but also their achievements and their successful strategies for learning and everyday living. This view of people with FAS or FAE as capable in their lives is consistent with the secondary study. I regard them as knowledgeable about their experience, and believe they can speak about, reflect upon and share their experiences of friendship.

Furthermore, the evidence to support my belief and claim to their capacities is contained within the interview data transcripts of the seven young adults, which provide detailed and complete information from their descriptions and reflections about their experiences.

Another key influence on the initial study involved a preliminary objective to examine the parenting experiences and challenges of people with FAS or FAE. This objective had originated from the interest of the (then) Ministry of Social Services which funded the project. Before data collection began, however, we consulted with members of the project's advisory group (including people with FAS and their families) about the project's objectives. Advisory members spoke about the scarcity of knowledge and literature about age of majority transitions and emphasized the importance of the contexts surrounding pregnancy and parenting as a young adult with FAS and FAE. So this issue became framed within the broader contexts of the transition processes of young adulthood for people with FAS or FAE. This approach broadened our participant recruitment to include young adults in their teens and twenties who have FAS or FAE, and who may or may not have had children. The project information that I shared while recruiting participants included as one of its aims to explore transitions in young adulthood and parenting experiences. This would have influenced what participants understood I was interested in hearing about their experiences, thus influencing the nature of the data. It may be possible that this interest influenced how some participants spoke about some of their friendship experiences, possibly emphasizing some of their experiences in the context of pregnancy and parenting. This influence, although not contrary to the secondary question, will be accounted for as a possible limitation on secondary interpretations. On the other hand, the initial study seeking information from participants about their pregnancy and parenting experiences, provided valuable information, experiences and reflections related to participants' friendship experiences and illuminated the depth of their longings for friendship.

As a researcher and interviewer, in the contexts of the initial project objectives regarding learning and living with FAS or FAE, I was interested in hearing from the young adult participants what their experiences were like for them, what was important to them and what stood out for them as they reflected upon their early years to the time of the interview. Many participants approached the interview by telling me their life story. The informally guided approach to the interviews and the variations in personalities of participants resulted in some variations in length, detail, and content of the data. As discussed in the Data Description section of this thesis, all young adult participants shared experiences about their relationships with friends and family. Indeed, all spoke very passionately about certain relationship experiences and what these meant to them, friendships in particular. Although not entirely uniform, this data fits well with the secondary research question. It must be acknowledged as well that Study I, and I as an interviewer, was focused on hearing from these young people because they have FAS or FAE. This interest in FAS and FAE may have influenced how the participants spoke about their experience, possibly emphasizing FAS or FAE more than they normally would have when they discussed their friendship experiences.

The two young adults who chose to be interviewed together were close friends for a number of years and thus, spoke in detail about their relationship with each other. The two sisters knew that the other was interviewed and referred to their relationship with each other. These factors may also have shaped these four data transcripts, influencing the emphasis regarding their relationships with the other. These two pairs, the two friends and the two sisters, also provide valuable and informative information about their experiences of their relationship with other; interestingly both pairs described their relationship in both familial and friendship terms. The interactive dialogue between the two young women was rich with information, thoughts, feelings and reflections and provides in-depth insight into the very subject of this study.

In consideration of the above discussion regarding the issues, processes, orientation and methodology of the initial study that may have influenced the production of the data, I decided that the data appears to be appropriate for the secondary research question, with acknowledgement of the above limitations on secondary interpretations.

Ethical Considerations

The original study (Copeland & Rutman, 1996) received ethical approval from the University of Victoria Committee on Research and Other Activities Involving Human Subjects. (See Appendix B)

I sent a request to the Associate Vice President Research, Research Administration, University of Victoria, that my proposed thesis study be considered an extension of the original study and therefore that the Ethical Approval/Consent process used in the original study be considered sufficient. I was granted this request and provided with a *Notice of Waiver of Ethical Review.* (See Appendix C)

The focus and intent of my thesis study is absolutely consistent with the purpose of the original study. Therefore, it is also in keeping with the description of the study provided to the participants in the consent process. Any analysis conducted in my thesis study would abide to the terms of the original consent (e.g., use of pseudonyms, confidentiality of data, etc.). (See Appendix A)

Analysis

Qualitative analysis entails exploring open ended stories of people's experiences, examining both common themes that cut across variations of context as well as unique experiences or circumstances (Morse, 1994; Patton, 1980; 1987). Ely et al. (1997) described the qualitative data analysis process as systematic, reflective, comprehensive, but not rigid. Taylor (1984) asserted that, "you must... look for themes by examining your data in as many ways as possible" (p. 130).

For the purposes of auditability (Sandelowski, 1986), and for the evolving processes of analysis, I made notes of my thoughts, feelings, hunches, ideas, interpretations and decisions throughout the analysis process. I also kept and compiled in order of progression, printed copy and/or computer file of each step of my evolving analysis. These compilations documented my progression and were also a resource to which I could refer back if I needed to bring forward some information to explain/fill out my later discoveries.

Initially, I read and re-read the entire transcripts of all seven young adults several times. I got a sense of each of them, individually and as a whole, and got to know them "inside-out". I recalled meeting and interviewing each of these young people, their faces, expressions, and the interest and openness with which I was received by them. I recalled the seriousness that they approached their interview with me and the messages that they most wanted to convey through their interview. Their messages emphasized what we need to understand about them, how best to support them, and that they wanted to help others as well. I recalled my own experience of interviewing and being impacted by the profoundness of their lives, of their struggles, achievements, losses, tenacity and their dreams and goals for themselves. I recalled being impressed by the depth of their reflections of themselves, their lives and relationships. Vividly, I saw that their presence and words provided a stark contrast to the literature on FAS in which I had immersed myself. Once again, as I reviewed the transcripts, I felt the passion with which I heard them express about friendship, including for most, longings for, meeting, and being with their friends. I began to have a sense of each participant, seeing their individuality in their expressions, personalities, and stories as well as a sense of their commonalities, that provided a 'wholeness' to the set of transcripts.

Then I read all the whole transcripts again, looking for, noting and recording emerging themes (patterns of commonalities and inconsistencies). My aim was to explore, describe and understand participants' experiences of searching for, finding, having and experiencing friendships; what their friendship experiences mean to them; and how they view friendship experiences as they face the challenges of FAS or FAE. It was apparent to me that my decisions about the purpose, objectives and research question of this study had arisen out of what had stood out for me when I had interviewed them and conducted the initial study. This included that not only were their experiences of friendship highly important to them, but that these experiences involved an extensive journey. Within each transcript, using colour codes, I noted and highlighted the emerging themes in relation to friendship, for each individual and where there were shared patterns. I noticed that my notes on the sides of the transcripts and the passages I highlighted also included their life experiences, such as their FAS or FAE, family relationships, school, and homes. These experiences connected to what they expressed about friendship. I decided that it was important to include these in the blocks of "friendship data" I was selecting.

I continually assessed for whether the data was sufficient to answer the proposed research questions. In my judgement, it consistently met the criteria for secondary analysis. I was seeing similar friendship-related experiences, stories and connections to life experiences, such as multiple relationship losses, over and over again, and I was also seeing some individual experiences and information that could be informative. Over and over again, I reviewed, noted and highlighted the transcripts until I became comfortable with my selections from each of the transcripts of both their friendships experiences and the life experiences and reflections that I saw connected to these. Then, for each transcript, I copied these excerpts into separate new computer files entitled "friendship data excerpts" and included my notes in comment columns. Since the dialogue, experiences and stories of the two young women who were interviewed together were interconnected, and each further informed my understanding of the other, I decided to not separate their data and stories from each other. I kept both of their friendship-related excerpts together in their computer data file, (therefore making six computer data files in total).

Most of the participants had picked their own pseudonym, and names for others they spoke of, at the time of their interview. These pseudonyms then had been used when transcribing the interviews. For those data files that still had actual names, I changed the names contained within the excerpts to ensure confidentiality and to help me think of each participant, and the people in their lives, with the names that I would use for my discussion and analysis. In my name selections, I attempted to still capture my sense of their personality, but still different enough for confidentiality.

I reviewed each of the individual data files, and continued to note and code themes. I noticed that each participant's data file told their story in relation to their friendship experiences. Within each separate file, I decided to organize participant's excerpts to tell their individual story of their friendships experiences, still including some of their life experiences that were embedded within and surrounded by friendship experiences. I kept the two young women's (Leslie and Erika) together, while still attempting to present both some of their individual story and their inter-connected stories. Upon review, I thought that all of these individual stories could provide a useful introduction of the participants and could form the preceding chapter to my data analysis discussion. Although at that point I was unsure if I would do this, as I wondered if this would be redundant to my data analysis discussion.

I then reviewed and made notes on these story data files, which still included my previous coding notes. In order to look at the data in many different ways, I asked myself different questions, including: What seems important to her about this? What is important to me? How does this experience connect to that situation or those other experiences?, What do these have in common? What is different? What are these contradictions about? What am I thinking? What am I feeling? I paid attention to not only the similarities but also the incongruencies within and across the data files. This allowed me to see the subtleties and richness of the data.

To prepare for coding and organizing the participants words together, but still taking care to keep their words separate and keeping track of which participant said what, I changed the computer text to different colours for each of the seven participants. I began to cut and paste together participants words and organize them thematically together, still retaining and refining my notes.

I further coded and categorized the data with these themes, taking care to make the analysis fit the data rather than vice versa. I reviewed the codes and excerpts and I asked myself if they were consistent. I also considered the connections, overlaps, and distinctions among the coding and organising categories. I then reviewed what data was included and what data was left out by this process. I paid attention to not only the coding themes but also the connections to the 'whole' of the data. Based upon my evolving understanding of the data, and the analysis, I refined and revised the coding, themes and organization of data. I found that the coloured computer text provided a useful portrait of the combination of participants' words, and a useful visual gauge of how I was attending to each participant's experiences.

As this analysis 'crystallized' and a synthesis of the themes emerge, I began developing a 'story-line', that still contained connections to participants' life experiences, to provide the analytical thread(s) to unite and integrate the major themes. I began to write up this story-line, further organizing the data into narratives of participants' words to illuminate the key essences of their experiences of friendships. Recognizing that this work was emerging as my data analysis chapter, I added my descriptions and narrative commentary. I brought together the words and reflections of these seven young adults, Erika, Jen, Justin, Leslie, Michelle, Sara and Tina, and wove them together with my narrative analysis. I intended to not obscure the individuality of each participant and their experience, but to show both their collective and unique voices of their experiences of friendships. Since their names were now specified in the commentary, I changed the computer text to be uniform in colour, which also reflected this stage of thematic integration.

It was useful to experience my struggles with my initial reluctance to cut down the participants' excerpt quotes, and to include substantial amounts of my thoughts, feelings and interpretations in my own narrative commentary. My struggles were not surprising to me. My initial commentary was mostly descriptive, and it was with no surprise that my supervisor's feedback was that, "we need to see more of you in here". I agreed with and understood this critique. I also understood my beliefs and values that underlied my reluctance. In my life and work, I know that I am not hesitant to critique, interpret and analyse what many, especially those whom I see as having power and privilege, have to say and do (hence my commitment to advocacy). However, I have struggled with how to balance expressing my points of view, interpretations and challenges regarding those whose voices I believe have been unheard and excluded from power and privilege, such as youth and people with disabilities, especially in relation to having control and agency over their lives. I was initially reluctant to take away the stories surrounding and connected to participants' words, and reluctant to highlight myself within the analysis. I knew and believed that the voices and perspectives of young people with FAS or FAE have rarely been sought, let alone heard and understood. However, I also know, through experiences with other projects, the usefulness and importance of sharing my knowledge, insights and perspectives with and about others, including youth and people with disabilities. Once I decided that the presentation of participant's individual stories that I had previously organised through excerpt quotes would be the preceding chapter to my data analysis discussion, I was then comfortable with further cutting and shaping participants' quotes about their friendship experiences with my own sense and understanding of what was important to say in my analysis.

I then synthesized together the summaries of each theme to bring some final conclusions and selected what I thought was important to discuss in relation to some key concepts of the literature, including the contrasts to the portrayal of young people in the FAS literature and also similarities to some of the friendship literature. I also brought forward the key messages and findings that I believed to be important and informative to human services practice, policy and research.

CHAPTER FOUR: PRESENTATION OF PARTICIPANTS' STORIES OF FRIENDSHIP

Introduction

The seven participants' individual stories of their friendship experiences are in their own words are the focus of this chapter. Chapter Five analyses the complexities of their collective friendship experiences, interwoven in a narrative.

The following introduces each of the seven participants through what they told me about who they were and their key friendship experiences. Each participant's story is composed from direct quote excerpts of their interview transcripts that related to friendship. Some of their related experiences that are embedded within and surrounded by their friendship experiences, such as their experiences of their disability, family relationships, school and home are included. These stories enable each participant to create a picture of their life, experiences and reflections, through their own voice.

It is important to note that the stories below are only excerpts of their interview, and therefore not the complete story they told of themselves. Some participant's stories are longer than others, reflecting some differences in the expressive style among the participants. The stories of two participants, Erika and Leslie, are told together as this reflects their joint interview and how they believed their story needed to be told and understood. In order to identify for the reader which quotes are Erika's and which are Leslie's, I have inserted their name in front of their quotes.

Erika's[2] and Leslie's Stories

> ERIKA: I'm Erika and, me and Leslie, we both have FAS, we're the same age, 20, and know what it's like for the other one. We've been together through a lot of stuff and a lot of places. No one else knows how I think but she does;

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[2] All names and identifying information of all research participants and others included in stories have been changed for confidentiality.

we finish our sentences for each other
LESLIE: all the time
ERIKA: like that!

LESLIE: Have you seen that movie, Thelma and Louise? We think that we're both of them - buds forever through anything.
ERIKA: Yeah we will always be here for each other. I think we are really sisters in the spirit and soul sense. She is my family, and my only family who really cares if I live or die, or if I'm happy or not. She is really my true sister, not like my adopted sister.

ERIKA: See I was adopted, I never have met my birth mother… I was adopted when I was really little - still a baby. But then when I got to be about 9 they turned me in. They gave up on me; they returned me for a refund like I was a pair of jeans. I didn't fit them anymore and wasn't their style. They're rich, living in North Van and didn't like me having so many problems at school. No matter how hard I tried - and I tried and I tried - they didn't love me. … I just couldn't be who they wanted me to be. And I went to so many schools cuz I was in so many foster homes.

ERIKA: Even at elementary school they write you off, as retarded, special needs, learning disabled… Except for my grade 2, when my favorite teacher, Mrs. Whitely, gave me a reward for working so hard - a diligence award. I kept it… I used to want to live with Mrs. Whitely, she seemed to really like me and believe that I could do the work. When I got my grade 12 grad I wanted to go back to that school, and to the principal, and say look I graduated no thanks to you. You never thought that I could do it, but I did.

LESLIE: I wasn't adopted like Erika but I've been in foster care all my childhood. I've never known my mom either. I don't know how many foster homes and group homes I've been in; I lost count. For a while every weekend I'd be at one home and then on the weekdays I'd be in another one. It was crazy. I didn't know the neighbourhoods; I'd get lost just trying to go for a walk to the store for smokes.

LESLIE: And the ...schools were so crazy with so much noise and people and I just couldn't sit in my desk and concentrate. For me, being in a classroom was like being at Playland park or what Disneyland must be like, too much to deal with, and too much to be able to focus.

LESLIE: We're called special needs and so everyone thinks that we're stupid and retarded.
ERIKA: Yeah, a lot were so disrespectful. I used to say I'm human, you don't have to treat me that way.

LESLIE: [Erika and I] met years ago in a group home for runaway retarded teens. Well that's what it felt like anyway.
ERIKA: When I was 15 and got pregnant [my foster home] didn't work out. So that's when I went to the group home and met Leslie who was also pregnant.
LESLIE: Yeah and we decided to get an abortion and we went through it together. I never would have made it without Erika.
ERIKA: Me neither. I didn't think it would be as hard as it was.

ERIKA: And then especially when I was 17 and got pregnant again, but then lost the baby. It hurt so much, and I really thought that it was my fault for what I did for the first one. I was in a foster home with a really religious woman who told me that it was God's way of punishing me for my sins. I didn't need that so I ran away to Leslie's foster home. And she hid me in her room for over 3 weeks before anyone found out. And it was only because I was so sick that I had a major fever and needed to go into the hospital that we told.

ERIKA: And things got better for a while, we both stayed at the same foster home and then we went to Glendale at the same time when we were doing those correspondence courses together and had a tutor from the school board to help us.
LESLIE: And it was the first time that I actually liked doing school. Being at home with Erika and the tutor was so much better.
ERIKA: Yeah... so we finished everything then except 2 courses which we finished this year and we both graduated this May.

LESLIE: But back then I met this guy, Steve, and then I got pregnant when I was 18 and I decided to keep the baby, which didn't go over well with anyone except Erika.

LESLIE: We wanted to just get our own place together and we'd take care of the baby together because it felt like both of ours. All the workers freaked at that thought and we just couldn't find anyone to help us do what we wanted. We tried to get income assistance cuz we were told by a worker before that we both would be able to get handicapped pension cuz we both have FAS and other learning problems that tons of doctors have said and written down. But…we also had probation officers too, so everybody thought we were bad.

LESLIE: We weren't really; we were with this group of kids who would do this team shoplifting thing at the malls. We were told what to take and if we didn't then we would have gotten beat up really bad; they were bigger than us.

LESLIE: So for a year we had to go to a PO office and we had different ones and our appointments were in different days, even though we asked for the same day and time so we could help each other remember. But everyone was always trying to break us up, saying that we spend too much time together. So we'd forget whose appointment was when and then we both got in trouble for breaching. And then we really got in trouble when we didn't appear in court for the breaches so then the probation would go on longer. Finally we had a system where we'd each bring in a calendar to the offices and write down the next appointment, and it would be in the same day and time for both of us and then that worked.

ERIKA: But when Leslie got pregnant I took off for a while cuz it was really hard for me remembering what happened to me before in my 2 pregnancies, and I think now I see how I was mad at Leslie in some ways.

LESLIE: And I moved in with Steve and his mom. And sometimes I'd even call her mom because I really needed her at that time. I needed a mom. And then I gave birth to Erik.

LESLIE: When I was breast feeding it was wonderful; I was the only one who could give that to him and I felt so loving and loved. Erik would look at me with his big eyes and I think that's when I would feel true love. True love, love that I've never had before. Nothing like how I feel about Steve. We stopped having sex after I found out I was pregnant. We're sort of like brother and sister now, and he's 24, so sort of a bigger brother not like a boyfriend.

LESLIE: Now Steve's mom takes care of Erik, my baby, and I'm not sure how it happened. I'm the one who gave birth to him; I want to be there for him, but I don't have money for diapers and everything. I sort of felt pushed out, like it was Erik that she wanted, not me. I still don't know how to figure this out. It hurts, but I don't know how to get my baby back.

LESLIE: So I'm trying now to find a way to get Erik back from Steve's mom. She's now saying that she has legal custody cuz I took off and left him with her. But I never said that I didn't want Erik. I just felt there was no longer a place for me there and I needed to get my act together to be able to get a place for me and Erik, and Erika will always be there too. Erika says I need a lawyer to help me and we're trying to find legal aid. Shauna is going to take me there this week. But I'm worried once people find out that I have FAS that they'll say I can't be a mom. I know I can be. I didn't drink or do drugs when I was pregnant. I ate all good things - lots of milk and yogurt and ice cream and Erik was big - he was 11 pounds at birth - as much as I weighed when I was 6 months old, says one of my workers. I might just need some support for a while and some money support, which I'm supposed to get anyway with having FAS.

LESLIE: But I don't always want free money. I want to be able to get a good job and I know that I need some school or training for that. But I'm good at a lot of things. I'm good with people I love talking with people. I want to work in tourism like be a tourist guide or agent.

ERIKA: Last week we took over for this girl at the concession stand who got the flu and it was great. We were selling big pretzels and fruit ice and stuff. It was great, and the girl said that she was going to ask her boss if he had anywhere else that we could do concession carts. That'd be perfect for this summer.

LESLIE: And then in September we'll look at what school we need to go to and to get Erik back. Shauna, that counsellor, says that with the papers showing that we have FAS we can get support for a training program.

ERIKA: We need someone who will give us information and show us how to get things like our doctors records, how to apply for training and how to get our handicapped pensions while we're in school. But we need someone who will support us in what we say we want, and not to laugh at us or ignore us or forget about us or to decide things without asking us, like all the social workers have done.

LESLIE: And we need this support person to really understand and support Erika's and my friendship. We know that we work best when we're together, and we need people to understand that and not jump to conclusions about us or not say that we shouldn't spend so much time together.

ERIKA: Like getting help for Leslie to have Erik, and getting help to care for Erik. I love Erik like any auntie does. I'm Auntie Erika.
LESLIE: I named him after her because she's my only true family and Erik needs to have true family.

LESLIE: Listen to us and what we say we need and want for our lives. Understand that we're not much different than you and that we want the things that everybody else wants out of life. And that we may just need to do things and think through things in just a different way than you, but believe us when we tell you that's the way we need to think about and learn it. Listen to us when we ask for support and know that it's not easy to ask for help. And that we deserve respect and don't deserve to be laughed at or to be treated like little kids.

ERIKA: And don't blame us, or feel sorry for us or be mad at us for having FAS. It's not our fault, it's no one's fault really and it's not the end of the world. Trust me, we will be ok. And with love and caring we will have a good life and we will give love and caring to others too.

LESLIE: Yes we will, like with Erik. Like trust and respect us enough to think that Erik will have a better life by knowing and loving me, his mother, and Erika, his auntie. Respect me for being a mother even though I might not be able to handle it on my own right now. And listen to me when I say I want support to get a job and to be able to support my son. See me as Leslie, not as an FAS kid. See me as a 20 year old adult who is a mother, who has a son named Erik, and who loves him very much. See me as someone that you'd like to get to know, to talk with, and maybe learn something from.

Jen's Story

I'm Jen and I'm 20. I'm taking my GED… because I only have grade 12 left. I just want that certificate that says I graduated. … all my friends have it. The only reason why I don't have it is because I got pregnant at 15, and I got pregnant at 17. I've got two kids so… my life was over by then; so I'm just going to start over again.

Growing up was hard. I used to get called names in school... They were so mean to me. I was called every name in the book: stupid, retard, everything. And it wasn't because I was a retard, it's cuz I was slower than they were. And they couldn't understand it, the teachers couldn't understand it. I mean they all thought they were smart and just cause I didn't know it, they all looked at me like, 'look at her, she can't do it, ha ha ha'. I would never do that to anybody. If I saw somebody who couldn't do it or was trying to… figure it out, I would always try to help them if I could, or get somebody to help them.

I had learning assistance, …but they didn't realize that I had a disability …. They all just thought, 'well Jen's not trying, she's just not trying at all'. It's nothing to do with me not trying … I couldn't do it. I can't do it and I kept on telling people that, but no one would listen. When you're younger, no one does listen.

When I went to Glendale for tests a couple of years ago, I wanted to be treated as an adult, or as a person. I wanted to hear what other people had to say about me, not behind my back. Cause it hurt too much as a kid.

I wish I'd had friends to support me. To help me out when I needed it. But I didn't have it.... I was sick with encephalitis when I was a kid. And I left school after having all these friends ... and getting to know them, and I had to leave, and I was really sick in the hospital, and then I'd come back to visit once and a while, but when I eventually came back, they just looked at me and said you are a completely different person. And I was really the same person, and I was really the same person, I wasn't any different than anybody else, I just hadn't been there.

And they had formed their own groups and... they stayed with the group, kind of thing. Then all of a sudden we went to high school and it was like they still had their same group, they were still hanging out with the same people, but I was excluded, and that's what hurt. And they were so mean to me. So I went to the point where I was trying to prove myself to these people. And sometimes it came to being really mean. Like I was harsh, insulting them back like they did it to me.

But then I got in with a crowd. They were older, the older group, ... I hung out with grade 12's when I was probably twelve... because I couldn't stand my group. Like I wasn't into listening to all the names that I got called. It really hurt. So I went to the older crowd... they were into having friends that were friends.... They had maturity... they were into having friends that were friends. They weren't into knowing what happened to you while you were a child, or into gossip sessions in the hallway, or calling people names or putting people down.... They were more into let's graduate, let's get out of here, let's have fun on the weekends, or go for coffee or something, or talking, so that's what I was into.

[But] it was so hard to have a real friend, you know, someone who sticks with you in the long haul. No matter how hard I tried, everything was just so hard, like school, and no one listened to me. I was all alone, really, other kids just seemed to have it easier - they could do everything, they had it together. So, I wanted to get pregnant. I felt to the point where I was so lonely, even though I had my mom and my dad and my little brother and his friends, I had no friends of my own.

I felt so lonely that I wanted someone else to love me back, like, so I just had, I don't know, I ended up getting pregnant, and I was happy from then on. Through the pregnancy anyway, then I did give her up for adoption… I think when you're young, you look at other people and you go, look at them, they're a family and they're happy and it doesn't look like they have too many problems.

And then I came back to [city] after giving birth and then my baby to adoption. I got in with the older crowd… And they were into partying and all that stuff and having fun, and so I basically started not listening to my parents anymore about their rules. I ran away from home a couple of times and then just decided that I didn't want to live with them anymore and went to the streets, and that was fun – not! I just look back at it now and I just go, "NO, why did I do that?"

Cuz I had friends… I stayed at [the] Youth Shelter… If you miss a curfew, you can't come back, so I think it helped when I had friends who were okay, we need to go back, it's 10:00… and just run down the street. So, I usually just hung out in the park across the street and just talked. Goofed around, so yeah, we just walked across the street and there we were.

And then I went into foster care. The support was good [from] the other kids. They are just there for being friends, you just go out for coffee if you want and blah, blah, blah, that kind of thing. A way to spend a couple of hours. And they live at your house so you are not going to get in trouble with them… You just stay out of trouble with them and go and get into trouble with your other friends. That's what I used to do… I tried to stay out of trouble, but . . . I don't know, it depends who you're hanging with and what they're doing. If they're doing something that looks interesting, then I'm gonna try it. But if it doesn't look interesting, then I don't know. I probably still would try it, but I don't know. Never went to jail though. I was one of the few … I know a lot of my friends were thrown in jail at 17 or 16. I didn't do too much though. I tried to stay out of trouble… and then I went back to the being on the street.

[Living on the street] was scary. But it's not, if you got friends, like I had friends on the street, and we call each other brothers and sisters… And if you stuck with them you were okay…. like as a female you wouldn't be by yourself… Weirdos are out to look for mostly females….Or they are going to be dragged into prostitution, or they're gonna be dragged into bad stuff. … Women, we always stuck together, the girls. And usually we had a guy with us too, so it was like 2 girls and 1 guy… just friends. And we would usually just like sleep just behind [the] Pool, at the heaters, cause they're warm.

I only worked [in the sex trade] one night, cause I was so scared. It was just so scary. … made me feel dirty… But when you've got a big huge, a big, huge guy standing in front of you going you have to do it, kind of thing, it's scary. I had friends, who knew this person, and they helped me get out... Like if you have friends that know the people down there, then you're all right. But if you don't, you're totally messed. That's it, you're gone.

And then I lived with Joe, and being pregnant the second time and had my second daughter Brittney. [Joe's] different. He's a lot older than I am. He's 37 … but he knows what he wants out of life and I don't. But at the same time, he was helpful, before I did something stupid, he could tell me what it was all about. But it was no real experience for me… It's kind of like living with another mom or a dad. I thought I had been looking for a real best friend to go through things together with and to have fun but I ended up with a mom or dad. But…he was always there when I needed him for Brittney or whatever.

I love [Brittney], but at the same time, I know I can be her mom part time, but I can't be her mom full time. Like it was to the point where I was, I felt like I was always at home by myself with just her, and I didn't know what to do. …, I watched other people have fun with my daughter instead of myself. Because I wanted my freedom back... I just wanted to go out and party and I wanted to go out and have friends.

I left Joe and I went into the transition house. They've helped a lot. They have groups there and we all eat together and we all introduce ourselves and by the end of the week you know everybody there and ... like having a great time. Like you're going out for walks with each other, and you make serious friends.

It felt so good to be at home. It's like I want to go home. I want to see my roommates. I want to see all the girls. I made lots of friends too. Especially Stacey - that's where I met Stacey. And we also met and became friends with Tami too. And she also knows Rob.

[Stacey and I] became good friends cuz we can get what the other has gone through. Like Stacey is going through the same, my girlfriend is going through the same thing I am. Like if we didn't have each other, we'd be so depressed, we'd be so bored, we wouldn't know what to do with ourselves, she'd be just working, and then she'd go home to bed, and she'd have no life. But now she said, she's met me, I've totally taken her out here and taken her out there, like I've introduced her to people that she needs to see and needs to know. You know what I mean? Like she needs, like you need to get new friends. It's almost like a new life.

Stacey, who's coming over later, she has the same thing - FAS... Her mom was an alcoholic. Her mom is a drug user too. So she's got the exactly the same thing. And we have the same, actually, it's kind of cool, we have the same, like she's smarter in certain ways than I am, but we can still see the same qualities in ourselves, you know what I mean? Like we can see learning being actually the same. Like she has problems listening to things. Like it goes in one ear and out the other, kind of thing. That's the exactly the same with me. And then, this is the way we are, we're just like, okay, 'do you do this and do you do that, and do you do this?' And 'yeah, I do'. And it's so neat cause we can totally understand like what we're talking about. Like she can say something to me and I'll go, 'isn't that,' and we just totally mak[e] comments back and forth about it, and we both agree. But, you know, she's learned how to deal with it a lot easier than I have. I don't think her mom was that harsh on her alcohol. And I think I have it worse than she did. But, I don't know. I would never know, until I asked my [birth] mom.

That's what I call [FAS], learning disabilities. No big deal, I can get over it. But you can't. It's still there. Like my ex, he still brings that up. Like it's the first thing he slams in my face is … having a mental capacity of an eight year old instead of a twenty year old. He still, to this day, uses it against me and makes me feel like, oh, gee, thanks, you have a lot of faith in me. Like thanks for giving me a try. And I don't want that.

That's why I think I'm happy now. Because I have good friends now. Like I have really good friends now. They're like Jen, you can do anything you could possibly want, and I know you could do that. Like Stacey. So, it's good to have friends like that.

And I have a new relationship with a guy, Rob. I can communicate with him. I can share whatever I want with him. He's not there to judge me, ... he's more there to support me. I mean I could cry on his shoulder and he just, he was more like a friend, it was more like a comforting friend. It wasn't like Jen, you're not allowed to cry, or it wasn't shrugging me off, or I don't want to listen to it, it's more like what's wrong, are you okay? Are you going to be okay? Talk to me. And that's what I needed. I needed a friend in case I needed a shoulder to just bawl my eyes out, I could and I felt comfortable with that, and that's good.

And [Rob] made me feel comfortable, say if we went out on the town, he'd introduce me to all his friends. He would never leave me out. He'd always introduce, this is my girlfriend, Jen, this is my girlfriend, Jen. And he would always make it known who I was, and he would treat me with respect. Like if he had a problem and I had a problem, this is like, and what's your problem today? You know, it's come to that point where I am slowly actually starting to realize that I can do that now. I never did it with Joe, I'm now doing it with other people.

This baby is [Rob's] and he's all excited to be a daddy, but I'm not excited to be a mom... My best friend, Stacey is gonna hold my hand all the way through it [having an abortion] because she's been through it before, when she was younger. But she's 23. I'm seeing all these different sides of it.. And you have to talk to someone who's done it.

Decision making is very hard for us [people with FAS] .... you need help to make decisions. You need someone to sit there and say, okay, well, this is the decision you have to make, ... how are you going to make it? ...But I can't make decisions if I'm forced into it. It has to be more like a friend, helping somebody out. It has to be really low key, it can't be like, this is what you have to do… I can't stand that when workers start doing that. ..then (I say) I don't have to do anything, and I don't do it usually, I just yell or whatever.

Kids with FAS need to have someone like a buddy, like a big sister, or big brother. Just someone to talk to, like say if you get really stressed out or low down, or something like that, you need somebody that you can call upon and say, I need help or something, you know. If you don't have that, you're gonna be totally lost. That's all I'm gonna say. You're gonna be lost. It really helps. I have buddies… Tami and Stacey. I think it's just knowing that I have someone out there. I think that just what it is. I think it's just cause I'm scared to be on my own.

Tina's Story

I'm Tina. It's weird but I'm 18 and in some ways I feel like 80 or something and in some ways I feel like I'm 2. Sometimes I just feel so tired of life and old, sometimes I feel like it's all exciting and sometimes I feel like I don't know anything about life and how to make it in this world. Sometimes I feel so lonely and sometimes I wish I could just be alone. I guess that's part of what my life has been like - full of opposites. Like no one believes that I'm really 18. I know I'm short and small I look like I could be in grade 7 and actually some grade 7's know more than I do! But also I have been through a lot in my life that no grade 7 could say they've been through all the hospitals, foster and group homes, all the different schools, lots of scary home and street stuff and also the good stuff.

I've always gotten a lot of attention about my looks. I know I have FAS. I know I have that same face as on those pamphlet and books. Or at least I had, my mom says I've grown out of that look now.

The teachers and others think that I'm native when they hear about my FAS. Some of the kids at the group home used to call me 'the little Indian'. I know my mom likes to be very private about her life and I do too because people will do and say things to you that are very mean and not respectful. If wouldn't mind if I were Native, but I'm not, and calling me a 'little Indian' was mean to me and to people who are Native.

School was all just too much for me. My head would feel like it was spinning and swimming. I used to get in trouble for being late for class. But I just went to the bathroom and waited till the rest of the people had gone to class and then I went to my next class cuz I would just go nuts in the hall ways in between classes when the hall ways would be jammed with people going to their lockers and moving to the next class. I tried to explain this to my teachers but they just said that I was smoking or talking in the washroom. I have never smoked in my life but they never believed me. I was seen as a bad kid by a lot of teachers.

I never have liked people touching me too much. It feels prickly sometimes and sometimes it even hurts for people to just tickle me. Kids were mean at school. They used to tickle me and tease me, and I'd be shouting and crying and saying that it hurts, and they would laugh and call me crybaby.

And the kids everywhere just thought I was stupid and weird. I tried to fit in, to make friends, but no one cared. It was just too much to deal with at school and all the kids had their own friends and fun after school; and I moved around a lot anyway. I just couldn't memorize things the way the others did. I tried to explain that to my teachers but they wouldn't listen. No one at school would listen to what I wanted to say. I felt so stupid and so bad at school.

I was so lonely and there was no one like me or that liked me. That's what I wanted so much for so long - to have friends or at least a special friend that I knew I could just be me and not have to try so hard and who really liked me and we could talk and do things together.

I also used to get into trouble a lot at school and at the foster and group home for stealing. I don't think I was really trying to be mean or dishonest or steal. I do know that I would want things that other people had or had made. But I remember just wanting to feel friends or close to them and having something of theirs - like stupid things like a letter they wrote or a picture of them or a picture they made - it made me feel like we were friends. I used to show my foster mom Mabel pictures that this girl Melanie had made at school and then I would tell Mabel that Melanie made the picture to give to me. When I was older the stuff I took was more valuable like little necklaces. I know it was wrong and I should never take anything that doesn't belong to me, but no one would ever understand that I wasn't trying to be mean or bad when I took things. I guess I was just trying to fill that hole in my heart any way I knew how.

I wish people had seen that about me and helped me see that then. I just didn't know what to do or say when I was caught. Then I would get into more trouble for lying about it or just being quiet.

I felt lonely and it was a way to try to fill the hole in my heart. I've always thought that I've had 2 holes in my heart, one that the doctors sewed up and one that has never been filled up, the hole in my feelings and I think in my spirit or soul. I used to think… that [my birth mom} didn't love me and that's why she drank… My hole in my heart was always about my mom and me. Even loving God and Christ has not filled my feelings hole. Having sex with Mike sure didn't and now after losing my baby I feel like it made my heart hole bigger. It's not like we were going out with each other or anything; we just knew each other for a while and we had sex 2 times.

Amy is a good find for a friend. I wish I met her before I met Mike. I went to this picnic with the church that's on my street and there was this game and you had to find the other person who had the other half of your joke. She came over to me and we were a match and we laughed about the joke and she was just so nice and friendly.

[Amy's] helped me feel more comfortable with kids and groups of people. And with myself. And she says that I have helped her too. She says she feels happier since we've been friends too. Amy has had hard stuff happen to her too - not FAS - but we talk about lots of stuff I wouldn't say to anyone else, like Mike and the baby and feeling so lonely and confused, and then we do something and laugh and cry.

Amy's nice and she invited me to things where I met other kids of the youth group, like Linda who I go swimming with. I feel like they like me for who I am. Lots don't know about my FAS and it doesn't matter. I'm just me to them.

I do want to be able to have a good life. I want all the things that my friends want, job, money, family. …I think I feel more able to tell people when it's not working for me rather than just disappearing like I did before. And I think I know how to make friends better than I did before. The kids at my youth group from church have been nice and I think I learned how to get to know people at church.

But sometimes I'd like to have a friend with FAS too. Because she would know exactly what it's like to have a body and brain like mine. It might be like we're sisters or something. Just someone who goes through the same thing as I do everyday and then we could talk about it and figure out how we can work through say our memory problems or problems with too much noise or people or activity. I'd like to have somewhere that sometimes I can talk with other girls with FAS because there are some things that are just different than what the girls from the youth group talk about.

My message to everyone is… Care about who we [people with FAS] are as people. Get to know who we are in our hearts... See who we are, who we want to be, and not the problems we have. Ask us what it's like for us, and what we need. Don't blame me or my mom for the FAS, it's not our fault - we didn't have the help we needed when we needed it… Believe that I can do what I want to do and support me and my mom [about] what I need to help me reach my dreams. Believe that I can help and teach [you] and other people. Be quieter and patient and listen to what I want to tell [you].

Justin's Story

I'm Justin. I'm sixteen and I just got out of Juvie. Well, I actually just got probation since my worker and foster mom said that they would watch out for me. Last year I took this car. Other kids said they'd done it and that they'd pay me 50 bucks if I took them to the beach in it. I don't know why I did it. I just wanted them off my back - they kept razzing me.

I was always really picked on. All through elementary school. I hated going outside at lunch cuz I knew that I would be beat up. People were so mean. I just wanted to be part of things, to be included in the soccer games. I used to try so hard to fit in and then I would get jumped by 2 or more guys. They would beat me up and then I would skip the rest of school.

I had no friends. Nobody asked me how I was doing and often the foster home people got mad and then I just ran from them too... I would be happy to change schools when I changed foster homes, but then it would be the same thing again. No one really cared at school; the teachers just thought I was stupid or wasn't trying or couldn't concentrate. It would have been nice to even just have someone to do stuff with to have fun with and school probably wouldn't have been so bad.

Before, I really had a hard time everywhere. At school, home. I never felt like I fit in or felt like I was liked by anyone. Just a problem. To everyone. Not a person. I had no one to tell me that I wasn't stupid. I had no real family or friends. I've never met my birth mom. I've wondered if I'd find out what really happened to me as a baby if I ever see my mother.

I used to wonder why things were so hard. It did really help to have that doctor say that I have FAS and that what is different about me wasn't my fault. I just wished I'd have know sooner cuz I really beat myself up too. Some subjects were really hard. Like I remember grade 8 math – there were these team games you did in math and so everybody knew who could do it and who couldn't. I couldn't do these problems and I wanted to give in to the ridiculing, leave and never come back. But I knew that I could learn it when I felt like I was in control, rather than the math controlling me. I didn't want them to be right - that no one with FAS can understand math.

FAS is part of me, like an extra arm or something. But it's not all of me. People need to know that.

High School has been better than elementary school. In high school it changed with the girls, though...Like I'm not alone anymore. I don't know what happened but, in grade 8 it started that all these girls would always call me, and it made me feel good, I guess. I had always been teased and beat-up all through elementary school and then all of a sudden at high school I had friends, even though they were girls. And then the guys would say, "You're doing it, eh?" So I just did it, like sex, whenever and wherever I could.

That was a bit crazy too, I've calmed down now, once I met one girl - Kyla. She is really nice... I met her when I was going to the beach one day last summer. She was just sitting by a tree by herself and she smiled and said hi. She works at the DQ and is my age. She has problems too. For the first time I felt understood and accepted for who I am. I didn't know that I would have friends, someone to just be with, like sit on the grass and just talk about whatever, until Kyla.

Kyla's important - she's what makes me think that I can have a good life even though I have FAS and it's hard to do a lot of things. Kyla thinks that I can finish school and get a good job and I believe that I can do it now too. It won't be easy and I will have to speak up for myself more but she makes it easier, knowing that she believes me. That I am hard working. It's not like fake like some people who are just saying that I'm smart to be nice but don't really believe it.

I like doing things for her too. Like cheering her up when she's down. I am good at telling her jokes to make her laugh and she likes my drawings I do, like comic book stories with her and me and her dog. I even did one for her mom about their cat chasing their big dog and she laughed - in a nice way - and put it on their fridge.

Sara's Story

I'm Sara; I'm 19, and Michelle is my twin sister. I came from a big family but we were all taken from the home. They separated us from my other sisters but Michelle and I got adopted by my mom and dad.

I have never met my biological mom. The thing is we're nineteen now and our records are open and so she could be trying to find us but she hasn't yet. But we're just gonna wait and see.

I have FAE, like a learning problem. It's always been a difficult thing for me cuz I failed grade 6. Mostly my difficulties has something to do with fetal alcohol because my mom - my biological mom. She had us… she was really depressed and she drank all time. She had a lot of problems. She was by herself and living in [city]. Most Indians - they usually stay with the Band but she was like all by herself. When we were in her stomach she only lived on bread and jam, and beer. … But we were born 1 month premature and that's what really saved us because we were saved from having any more stuff coming into us. That's what Dr. Shutt told us, so we're not as bad off because we were born premature. Me and Michelle.

I never told my teachers that I had a problem and… I was kind of left behind. Because I've never been one to go up and say I'm having problems, can you help me? I don't ask for help… I hate asking for help. … But after I found out that I had FAE, my mom told all my teachers. I was glad mom told them so they could help me, like my math teacher…he was helpful once he knew…

I never liked school. It wasn't a good place for me. I was so happy that I graduated and it was over. I disliked it very much.

Well, mostly the attitudes of the kids. It's a small town and the kids are really mean. I just don't like the kids, they're really mean, like name calling and snobbish with all their little groups and cliques and stuff. … They just totally snubbed you and they'd talk behind your back. You could tell.

I have a couple close friends and I hang out with them quite a bit; they accepted me right away. But most of the time I just hang out by myself.

Vanessa - she's my best friend. We've been friends since grade 6 . Vanessa came over and said hi and asked me if I wanted to play. Through everything we've been together - everything. She accepts me the way I am. We just hang out together and we tell each other things and talk about things that I wouldn't tell anyone else. Just telling her the things that go on in your life, things that I don't usually tell other people. We can talk about stuff and it's really good and I know that she won't tell anybody.

I don't see much of Vanessa now cuz she's got a boyfriend and she's pretty busy with her boyfriend and stuff and they're getting married in July.

I have another friend, Kim. She's in grade 12. And her friends, I hang out with them too - Lynn and Liz. We hang out together quite a bit.

What's it like to have a twin sister? It's fun. We're best friends. Some sisters don't get along, but me and [Michelle] get along. What do I like about her? Everything. She is the absolute opposite than I am. She's outgoing and she does sports. She helps me with problems that I'm going through. She's a really good support and she knows me so well - without having to explain.

I'm not as much as a busy person as Michelle, she constantly goes out. I like just staying at home some times and she's like 'I have to like go out, I have to go out'. So, I guess she's good for me cuz she gets me out doing stuff and meeting people.

The pool hall is where we play lots of pool with each other, and I'm pretty good at that. We're both getting pretty good at it and we go out to friend's houses and watch movies, and go to [city] and watch movies. Just normal stuff I guess.

I do babysitting and Search and Rescue. Some sports I like but I was never into them. I like outdoor stuff like hiking, camping and boating.

Michelle's Story

I'm Michelle, I'm 19, and I'm Sara's twin sister.

I'm always on the go. I'm on a volleyball team. I'm on a softball team. I play softball twice a week. I love pool. I play pool a lot. I like to bike, like trail riding. I bike ride with Sara and I exercise. I run and play racquetball and go swimming and stuff like that with my friends. I'm doing piano theory right now as well, so I can get my grade 8 certificate. I'm a lifeguard and I work life guarding in the summer. Sports and working with kids, so recreation is it. Those are my career goals. That's where I'm going.

I'm good at talking. Kids, working with kids. I'd say ... I work really well with kids. I'm good at relating to others. I can relate pretty well with others and put myself in their shoes and experience, or just to help or whatever. I find I can relate to a lot of people.

The fetal alcohol ... from our birth mom... is, like a few differences, but nothing you can't overcome. I don't think about it much, some things are hard to do, like concentrating is hard to do. I'm real hyper - I'm just totally hyper all the time. I get excited too much. I'm just who I am, and the less people know the better because I mean I don't act different, I don't look different. There's just a little difference. Like a little bit of a learning disability and stuff like that. A little bit of hyper activity, attention deficit, like just not concentrating and stuff like that.... Little - some times in Math - just not being able to grasp concepts. Once I get it, it's like easy. But just getting there is the hard part. And my memory ... everybody else remembers and I'm like nope, sorry I don't remember. It's really weird.

I did home school for a year a few years ago. I redid grade 9 at home through correspondence. Which was different cuz I lost contact with my friends and I was dying because I wasn't on any sports teams. Basketball, soccer, I couldn't do anything. And I didn't, because I was home I didn't. I could have gone to the school and done all those things, [I] could of been on the teams. I just didn't; I don't know why I didn't

But then I came back [to school] in grade 10 to whole different set of kids I did not even know, like just didn't know at all. I felt like I was coming into a new town. Like it was really weird. Like not that friends weren't there but they, you know, you're with the class you hang sort of thing. ... Cuz like, I'm mean you're a grade ahead of them and you don't associate with anyone below you.

But Sara knew all the kids cuz she was a year behind me and she caught up with me when I stayed back a year. So I was coming to all these new faces... And then all of a sudden you're there and you [say] hi and so you meet all these people. And people were asking like so where are you from, how long have you been in town and you're like 'I'm actually Sara's twin sister and I've lived here like 13 years now'. Cuz like I didn't go to school for a year. So I wasn't seen around school, but it was really weird.

But I got over that and we got new friends and stuff like that. Yeah, school was all right. School was all right because I had the outgoing - I was involved in everything you know.

There were times where like 'I don't want to be here' and 'some people are such idiots' and stuff like that... like there's different classes. There's the snobs or the cool people but I never really experienced that problem because... I had that link to everybody... I was involved with everybody. Because with sports teams - everybody was on the sport teams and like there's a whole range and so you got to know people that way. Like I had some friends and stuff so I could hang around.... Like it was all right.

Sara, of course... we support each other. Cuz I know Sara's a bit different from me, she's not as active as me and outgoing as me, so I support her by dragging her out and introducing her to everyone. She's like a friend I can talk to and stuff like that.

It was a bit different when [Sara and I] were in a different grade. But when we got into the same grade we got even closer, but we have our different friends and stuff. We still have our space and our different likes and stuff. Like she's not into sports and stuff like that. Like some her friends I wouldn't want to hang around with, but maybe some of my friends she wouldn't care to hang around with. So we still got our own identities but we're pretty close.

I think I failed English this semester cuz I just lost my motivation sort of thing.

College was a very negative thing for me. I just didn't find - it was exciting cuz it's my first college right but it sort of died out cuz there wasn't any friends… The age range in the classes were quite different. Maybe 3 people just graduated and the rest of them are all like have families, like mature students, like older students. And so you feel intimidated to approach them… cuz they're like so older.

I'm waiting to hear where I can go to [post-secondary] school. Well there is answers from one school because I have been accepted for sure into that program in [another province]. In some ways I wouldn't mind going there because it's different. It's far away. It's finding out about yourself by yourself, doing things on your own. But them I'd be leaving Sara behind. She doesn't want me to go too far.

CHAPTER FIVE: ANALYSIS OF PARTICIPANTS' EXPERIENCES OF FRIENDSHIP

Introduction

The previous chapter presented the seven participant's individual stories of their experiences of friendship, in their own words constructed from excerpts of their interview. This chapter collectively describes, synthesizes and analyses their stories and experiences of friendships. As I brought together the words and reflections of these seven young adults, Erika, Jen, Justin, Leslie, Michelle, Sara and Tina, and wove them together with my narrative analysis, I intended to not obscure the individuality of each participant and their experience but to show both their collective and unique voices of their experiences of friendships.

I once again considered the research questions that guide this study: What are the friendship experiences of seven young adults with fetal alcohol syndrome or fetal alcohol effects?; and What are the meanings of these friendship experiences for these young people?

In order to understand them, including their friendship experiences, each participant explained in their interview that we have to understand what their life had been like for them, which was summed up by Tina, then aged 18 years, with, "I've been through a lot in my life". When I was interviewing these young adults, and even more so when I was reviewing and analysing their words and life reflections, I appreciated the depth and complexities of their life experiences. These experiences provide explanations for the complexities of their sense of themselves and their experiences and relationships with others, including friendships. Therefore, my analysis not only includes participants' experiences of friendship, but also their long and winding road to friendship.

This chapter's analysis begins with their reflections and sense of themselves. This includes the complexities of themselves and their lives, such as being different and being not different. These complexities clashed with school, a key place young people have opportunities for friendship; however participants found that school was "not a good place for me". My narrative continues with their ruptured relationships, beginning with their loss of birth mother, and for most, becoming relationship loss as a way of life. My narrative then draws in their intertwined experiences and conclusions that people are mean, including being written off and being picked on, which left participants feeling profoundly alone, longing and searching for friendship.

My narrative then moves to the significant and long awaited event for participants, finding and making close friendship(s), where they make a good find for a [close] friend. My analysis then moves to their experiences of having and being in close friendships. This discussion examines key qualities of their close friendship experiences, including having: the company of friends; shared qualities/experiences; links to meeting other friends; acceptance and unconditionality; confidante and confidentiality; help and support, including being believed in and "then so did I"; reciprocity in helping; and going through it together. My narrative culminates with what I learned from Erika and Leslie's experience of their friendship as a co-worker partnership: "we work best… together". I learned that "working together" worked well for Leslie and Erika, and demonstrates the importance of understanding the perspectives of these young adults about their experiences, relationships, friendships, and how they want and need to live their lives.

The following draws an outline of the framework of my narrative. My analysis fills in the portrait of participants' collective and unique voices of their stories, experiences and meanings of friendships.

- Being Different and Being Not Different
- School - Not a Good Place for Me
- Ruptured Relationships – Loss of Birth-mother then losing count
- People Were Mean
- Longing and Searching for Friendships
- Finding and Making Friendships
- Participants' Experiences of Having and Being in Close Friendships
    - The Company of Friends
    - Shared Qualities/Experiences
    - Links To Meeting Others
    - Acceptance and Unconditionality
    - Confidante and Confidentiality
    - Help and Support
        - Helped Me, Believed in Me and Then So Did I
        - Reciprocity in Helping
        - Going Through It Together
        - Erika and Leslie's Co-Worker Partnership: "We Work Best… Together"

Being Different and Being Not Different

All seven participants reflected upon and explained their sense of themselves, the complexities of who they were and what their lives had been like, often explicitly referring to their FAS or FAE. All described the dualities and contradictions they experienced within themselves and how these influenced their relations with others. Both being different, and being not different, was integral to their experience of themselves. They expressed that they were both different, and not different, from everyone else. In addition, they explained that, at times, they were different than how they appeared to others, and sometimes not. Many further described their sense of contradictions within themselves, feeling one way and then the opposite. They also asserted that people needed to look beyond the surface assumptions they felt others often made about them, based upon how they may have appeared, or upon their disabilities, rather than their own individuality.

Most participants had direct messages they wanted to send to us through their interview. Their messages emphasized what we need to understand about them, often involving the complexities about themselves they experienced or what they felt others did not understand about them. Justin expressed that people needed to understand the duality of his FAS, being part but not all of who he was. He advised that, "People need to know that FAS is part of me, like an extra arm or something. But it's not all of me."

Leslie emphasized and wanted to send a message through her interview with me that we needed to, "Listen to… and believe… us [she and others with FAS] [but] what we say we need and want for our lives." Her message also conveyed the contradictory nature of her life and being different and not different, in that she wanted the same as the rest of us, but she must do and think differently. She directed us to, "Understand that we're not much different than you and that we want the things that everybody else wants out of life… We may just need to do things and think through things in just a different way than you."

Like Leslie, Tina also expressed that she wanted, "to be able to have a good life… [and] all the things my friends want - job, money, family". However, she also pointed to her differences from her friends when expressing her desire "to have a friend with FAS too, … because there are some things that are just different."

With regard to her FAE, Michelle, like other participants, had contradictory reflections about how she may have appeared to others, how she thought of herself and what she experienced. On one hand she described her differences as not significant, on the other hand she spoke of her experience of difference as being "really weird". She described herself as having, "just a few differences… I don't act different, I don't look different. Like a little bit of a learning disability… a little bit of hyperactivity, attention deficit, like just no concentrati[on]." At the same time, she identified some of her differences from others when explaining how her memory works, or doesn't work. She related, "my memory… everybody else remembers and I'm like, nope, sorry I don't remember. It's really weird." Adding to the complexities of, and contradictions within, her sense of herself, Michelle also identified herself as "real hyper", rather than just "a little bit", when further describing her experience of FAE. She explained, "Some things are hard to do, like concentrating is hard to do. I'm real hyper - I'm just totally hyper all the time. I get excited too much."

Michelle's stories and reflections about her friendship experiences had some similarities to the other participants, however she sometimes presented differing points of view, experiences and strategies for dealing with her disabilities, school and friendships. In some respects, Michelle provided some illuminating contrasts. Her stories showed the contradictory nature of her experience of her disabilities related to FAE, but with more of an emphasis on not having her differences explained to others. Rather than wanting to have her differences seen and understood, as advocated for by other participants, Michelle saw benefit in others not knowing about her differences, and in not seeing them as significant. She stated that, "the less people know the better." Michelle appeared to have a strategy to deal with being "real hyper", and to be "not much different". After listing the multitude of very active activities in which she was engaged, she explained, "I'm very much into sports and doing something. I'm always on the go."

Like Michelle, Tina described her experience of herself as "weird". However, Tina more directly expressed her awareness of the dualities and contradictions within herself and her experiences. Tina summed up her life as being "full of opposites", and described the contradictory ways she felt about herself. She expressed, "in some ways I feel like 80… and … 2. Sometimes I just feel so tired of life … and sometimes … it's all exciting." In addition, despite her extensive life experience, and "feeling so old", she also expressed that, "Sometimes I feel like I don't know anything about life and how to make it in this world." These self contradictions she experienced also concerned how she related to others. She expressed, "Sometimes I feel so lonely and sometimes I wish I could just be alone."

These contradictions, Tina continued, also related to others not believing who she was, or not seeing past the surface of how she may have appeared physically, or because of lacking some types of knowledge. She explained that although she looked young, "I know I'm short and small, I look like I could be in grade 7", she certainly had extensive life experience. She added, "but also I have been through a lot in my life that no grade 7 could say they've been through - all the hospitals, foster and group homes, different schools, lots of scary home and street stuff and also the good stuff." She laid another layer onto the complexities of herself, and of being different but not different from how she appeared, by also pointing out that she also lacked what some people may expect from her, gauging from her young appearance. She remarked, "actually some grade 7's know more than I do!"

Like most other participants, Tina stated that she wanted to be believed and understood about who she felt she really was and what she had experienced. She advocated that we, "care about who we [those with FAS] are as people. Ask us what it's like for us, get to know who we are in our hearts…, see who we are, who we want to be… and don't just go by the problems they see." Appearances of problems had significance for Tina, given her awareness of having, until recently, the facial characteristics associated with FAS. She stated. "I've always gotten a lot of attention about my looks. I know I have FAS… I know I have that same face as on those pamphlet and books. Or… I had, my mom says I've grown out of that look." In many ways, Tina saw that she was different than what she appeared to be and not different than what she appeared to be – a person with FAS. But she asked to be seen and understood as an individual, as who she was, from her own perspective and her own experience, rather than the FAS literature and stereotypes or by others' assumptions.

Erika also advocated that we look behind her surface appearance, to see her real feelings of hurt behind her anger. She spoke for people with FAS, based upon her own experience, asserting that, "we [those with FAS] need understanding… [you] need to remember to look behind our anger to see our tears. I always have tears close to my eyes and [you] need to see those even when I don't feel safe showing."

Jen wanted us to understand that she, like others with FAS, had difficulties with decision making. She noted, "decision making is very hard for us [people with FAS]". However she clarified that she must make her own decisions, stating, "But I can't make decisions if I'm forced into it... It can't be like, this is what you have to do." On one hand, she said, she needed help to make decisions, but on the other hand that help must be not be overly directive, but rather "more like a friend", calmly guiding her step by step through the process. She explained, "You need someone to sit there and say, okay, well, this is the decision you have to make, ... how are you going to make it. It has to be really low key." Her explanation of her process of decision-making provides another example of participants' messages about being different and not different than us, and/or in particular than young adults or people with disabilities. Jen recognized that she needed more help than others to make decisions, but she also shares commonalities with the rest of us, such as the desire to make her own decisions, to have agency over her own life and to be treated with respect.

The complexities and contradictions that participants described about themselves, of who they were, of both being different and not being different from everyone else, than how they appeared or how others assumed, and feeling one way and the contrary, as well as their assertions that their individuality needs to be recognized, forms an important frame for understanding their lives, experiences and their relationships with others, including friendships. These complexities and their significance will be further illuminated as their stories and experiences related to friendship are examined in this chapter.

School - Not a Good Place for Me

Much of all participants' messages and advisements about understanding who they were, their individuality, and their complexities and contradictions that came with their experiences about being different and not different, arose from their experiences of not being understood, being disrespected, and labelled as who and what they were not. Often these negative interactions took over their experience of school, typically a key place for young people to have opportunities for developing and experiencing friendships. Participants recounted the many changes of schools, teachers and classmates they underwent. Most participants also described school in general as "crazy" and "not a good place for them." In this regard, they referred to their experience of FAS or FAE and the lack of fit with the structure and expectations of school.

Leslie explained that the noise, activity and people in the classroom created a "crazy", overwhelming setting that made it impossible for her to cope, let alone learn. She related that, "For me, being in a classroom was like being at Playland park or what Disneyland must be like - too much to deal with or to be able to focus."

Tina detailed a similar experience of being overwhelmed by what others may regard and experience as just a normal part of a day at high school – being in the halls during change of classes. She explained that, "It was all just too much for me. My head … was spinning and swimming … I would just go nuts in the hall ways …jammed with people." Tina coped by finding a quiet refuge, the washroom, but then she would "get into trouble for being late for class." Tina then related that, despite her attempts at explaining her overwhelmed experience and what she did to cope with it, she was "never believed" and "seen as a bad kid" by her teachers.

Jen also described her experiences of not being believed and then blamed for her learning difficulties at school, which led her to conclude that "no one listens". She stated that although she sometimes was in a learning assistance program, "they didn't realize that I had a disability…. They all just thought, 'well Jen's not trying'." She asserted that although she did not have a diagnosis for her difficulties at that point, she did know that, "it's nothing to do with me not trying, … I couldn't do it. I can't do it." However, Jen's voice remained unheard, she recounted, "I kept on telling people that but no one would listen."

Justin recalled how the classroom team structure made his learning difficulties public, "everybody knew who could do [math] and who couldn't", and led to him experiencing more "ridiculing" from his peers. He expressed how on one hand he wanted to escape, "I wanted to give in to the ridiculing, leave and never come back", but on the other hand he was determined to reclaim control and appeared to feel a sense of responsibility to his own reputation and to that of people with FAS. He stated, "But I knew that I could learn it when I felt like I was in control, rather than the math controlling me. I didn't want them to be right - that no one with FAS can understand math." His strategy involved finding control, or a sense of self–power or agency, to increase his ability to master his challenges, both academically and socially.

Sara also spoke about her negative experience of school, expressing that, "I disliked [school] very much… I was so happy that I graduated and it was over." Sara's assessment of school as "not a good place for me", points to structural aspects of teaching and learning expectations that played out in the difficulties that all participants described. Their differences in need and experience were not acknowledged, respected or accommodated, giving rise to situations where participants had to focus on survival at school. They were not able to regard school as a place to meet and befriend peers, which they saw their classmates experiencing.

Throughout their stories, participants spoke of seeing their peers experience success in school and friendship and pass them by. Some, such as Jen, Tina, Justin, Leslie, and Erika, reached a point where they had little faith they would be listened to or understood if they asked for assistance, given their negative experiences. Sometimes participants lacked the skills, confidence, or inclination to advocate for themselves or seek assistance. Sara expressed that she was often "left behind" at school, given her difficulties and her reticence to ask for help. On one hand she characterized herself as, "never been one to go up and say 'I'm having problems, can you help me?'" She explained that, "I never told my teachers that I had a problem… I hate asking for help." But on the other hand she was glad when others knew her needs for help and when she received that help. Sara continued, "But after I found out that I had FAE, my mom told all my teachers. I was glad… so they could help me, like my math teacher…he was helpful once he knew".

For most participants, their overwhelming, negative and mis-fit experience of school, where their needs, perspective, individuality and complexities were not understood, interfered with their opportunities for developing and experiencing friendships for much of their childhood. In addition, during these years, participant's lives also were subsumed by a series of primary relationship losses.

Ruptured Relationships - Homes… Schools… I Lost Count

I was struck by the depth, frequency, and severity of relationship losses, especially losses of primary or familial relationships, that all participants had experienced in their lives. Their primary relationships were ruptured, severed and disrupted by a variety of events. There is an aspect of violence to my descriptors here. It reflects my impression of the violent nature of their experience of these relationship losses, and of the resulting pain they experienced. During their childhood, all seven participants experienced changes in with whom they lived and called their family or their community, be it through apprehension by, or relinquishment to, child protection authorities, adoption, adoption breakdown, and/or multiple foster placements. All participants except twin sisters Sara and Michelle, who had lived with their adoptive family since age 2, had lived in many (greater than 6) foster and group homes as well as different communities.

Loss of Birth Mother

For all participants, this rupturing of primary relationships began with their birth mother. At the time of each participant's interview with me, only Tina had a current relationship with her birth mother. Sara, Michelle, Leslie, Erika, Justin and Jen all reported, "I have never met my [birth] mom", as they had either been adopted or placed in foster care at a very young age. As participants reflected upon their experience of themselves as being different but not different from others, given their FAS or FAE and their primary relationship losses, all participants expressed a variety of, and sometimes conflicting, thoughts and feelings about their birth mother.

Many expressed that some of the explanations about the origin and nature of their FAS or FAE remained with their birth mother. Jen expressed that she, "would never know [the extent of alcohol that led to her FAS], until I asked my [birth] mom." Justin wondered if he would learn "what really happened to me as a baby" if he ever saw his birth mother. Sara identified her birth, or "biological" mother as the origin of her difficulties, explaining, "Mostly my difficulties has something to do with fetal alcohol because ... my biological mom... she drank all time. When we were in her stomach she only lived on bread, jam and beer." She concluded that she and her twin sister Michelle were saved by being born premature, severing that inter-connection with their mother. Sara reported, "But we were born 1 month premature and that's what really saved us because we were saved from having anymore stuff coming into us... so we're not as bad off."

Most also wondered what their birth mother's life was like when she was pregnant with them, and some expressed empathy and caring about her well-being. Despite seeing her birth mother as detrimental to her well-being at that time, Sara also expressed empathy, and perhaps concern, about her mother's life while pregnant with her and Michelle. Sara reflected, "She was really depressed… She had a lot of problems. Most Indians - they usually stay with the band, but she was like all by herself… and living in [a city]." Tina recalled that she "wanted Debbie [Tina's foster mother] to take care of my mom too", as she was concerned about her mother's well-being.

Some participants took care to not blame their birth mother for their difficulties or disabilities. Tina, who was reunited with her birth mom a few years prior, stipulated, "I don't blame my mom… she did the best she could." Erika, while asking us to not blame her for her FAS, added, "it's no one's fault, really." At the same time, Leslie, Jen, Tina and Erika stated that they would never drink, or did not drink when they were pregnant. Some participants spoke about how their pregnancies and/or giving birth to their own child(ren) brought additional feelings and thoughts about their own birth mother. Jen expressed, "With my girls, in some ways I understand what it was like for her, but in other ways I don't understand at all."

Most also wondered how their birth mom was doing currently, and whether she would make contact with them now that they were young adults. Sara wondered whether her birth mother thought about her and was waiting to see whether her mother will try and find her and Michelle. She expressed, "The thing is that we're nineteen now, and our records are open, and so she could be trying to find us. But she hasn't yet. But we're just gonna wait and see."

Sara's and other participants' reflections and expressions about their ruptured relationship with their birth mother hold many different and conflicting feelings and expectations of their past and future connections with her. In addition to the primacy that I believe one's birth mother holds for all people, whether one has "met her", or has an ongoing relationship with her, or not, these young adults also had the complexities of their birth mother's role in the origins of their FAS or FAE, and their birth mother's voluntary or non-voluntary role in the rupturing of her relationship with them. I believe that ultimately, we all want to be cared for by our mothers and want to care for her. Tina's reflections indicate her emotional struggles about her relationship with her mother, acknowledging this as the source of her longings . She said, "I used to think… that she didn't love me and that's why she drank… My hole in my heart was always about my mom and me."

In their efforts to make sense of themselves and their relationships with others, this first and primary relationship rupture and loss of their birth mother seemed to accompany them in their future relationship losses and in their quests for friendships and connections with others.

Loss - A Way of Life

These relationship ruptures and losses became a way of life for many participants during their childhood and adolescence. Leslie described the craziness and ongoing multiple losses from the many moves she underwent within the adoptive and foster care systems. She recounted, "I don't know how many foster homes and group homes I've been in. I lost count. For a while every weekend I'd be at one home, and then on the weekdays I'd be in another one. It was crazy." She provided an example to paint the reality and extent of her losses, when she said, "I didn't know the neighbourhoods, I'd get lost just trying to go for a walk to the store for smokes." Leslie used the word "lost" in multiple ways to describe her experience and conveying the multiplicity of her losses. Like Leslie, Erika moved from foster home to foster home. Erika pointed out that all the foster home and community moves she went through also meant that she left and entered many different schools. She lacked stability both in her family and home life as well as in her education and peer groups. She explained, "I went to so many schools cuz I was in so many foster homes in [another city] and then over here."

Erika sometimes retained hope that she will have a "long-term" home and family, but then experienced multiple changes again. One such situation she described was, "[I] moved here with one of the foster moms who said that she would keep me for long-term. But then when I was 15 and got pregnant, it didn't work out." Similarly Justin described feeling positive about leaving one situation to go to the next but then his negative and lonely experiences would be repeated when he changed the people in his life, negating his hope that he would be cared about and understood. He related, "Often the foster home people got mad and then I just ran from them too… I would be happy to change schools when I changed foster homes, but then it would be the same thing again."

Although Michelle and Sara did not experience as many moves as other participants did, they both failed a year of school and each spent a year on their own in home school with their (adoptive) mom. Michelle told a story of "losing contact" with her friends, and "dying, because I wasn't on any sports teams". She wondered, in retrospect, why she did not participate in the sports teams since she was still eligible to do so, which she had described as an important link to having friendships. When Michelle returned to school the following year in a lower grade level with "a whole different set of kids I did not even know", she discovered that her disruption in school attendance had also disrupted and altered her friendships and her class membership. She described her sense of alienation she initially experienced saying, "I felt like I was coming into a new town. … Like not that friends weren't there but …, you're with the class, you hang."

Jen related a story of her experiencing painful loss and confusion when her childhood illnesses and hospital stays caused long absences from elementary school. When she returned, she didn't understand her classmates response to her. She recalled, "they just looked at me and said you are a completely different person. I was really the same person, ... I just hadn't been there."

Relationship ruptures and losses became a way of life for many participants. In their efforts to make sense of themselves and their relationships with others, the first and primary relationship rupture and loss with their birth mother seemed to accompany them in their future relationship losses and in their quests for friendships and connections with others. For most, their childhood life experiences of multiple displacements and losses created upheaval in themselves, their family, school, community and peer relations, as well as barriers to opportunities for friendships. Who was in their lives, such as whom they called family, with whom they lived, went to school, and might play, and therefore might have developed friendships, often changed.

People Were Mean

They Write You Off

Intertwined within participants' stories of their life experiences, and in particular of relationship losses and longing/searching for friendships, was their pervasive experience and conclusion that, "people were mean". For many participants, this belief came from feeling written off, discounted, given up on, abandoned and being shown no belief or faith in their capacities.

Erika described being "written off" by virtually everyone in her life in her childhood years. Erika related a particularly poignant story of her experience of being regarded as a misfit object, and thus rejected, by her adoptive parents. She related, "When I got to be about 9 they turned me in. They gave up on me, they returned me for a refund like I was a pair of jeans - I didn't fit them anymore and wasn't their style." Erika continued to explain that despite her intensive efforts to please her adoptive family, she did not receive what she was longing for, love. She emphasized, "No matter how hard I tried, and I tried and I tried, they didn't love me… I just couldn't be who they wanted me to be."

Erika recalled being written off at her schools too, with the variety of labels she acquired, even at a young age. She reported, "Even at elementary school they write you off - as retarded, special needs, learning disabled." At that time, Erika did find one person who acknowledged and believed in her, and to whom she longed to be closer. She related, "my favorite teacher, Mrs. Whitely, gave me a diligence award… for working so hard. I kept it…. I used to want to live with Mrs. Whitely, she seemed to really like me and believe that I could do the work." However, as Erika changed schools after her adoption break down, that positive connection with her teacher was lost.

Being written off stayed with Erika. When she achieved what others thought she couldn't, such as graduation, she wanted to return to her schools to prove her capabilities. She remarked, "When I got my grade 12 grad I wanted to go back … and say, 'Look … You never thought that I could do it, but I did.'"

Leslie also found that her capacities were underestimated by most others, pointing to the conclusions people draw about her and Erika, "We're called special needs and so everyone thinks that we're stupid and retarded." Erika agreed, saying that she would inform people, "I'm human" and that she deserved more respectful treatment. Similarly, Justin recalled feeling regarded by all as, "Just a problem. To everyone. Not a person." Tina also described feeling written off and regarded as something she wasn't. While describing how she tried to deal with her overwhelming feelings and experiences, she reported that others only saw her as a "bad kid".

Jen described being constantly attacked, or "slammed in the face" by Joe, her ex-boyfriend, about her disability, which he called "having a mental capacity of an eight year old." She also described her disappointment and hurt about his lack of belief in her. She cited her thoughts in response to this was, "Oh, gee, thanks, you have a lot of faith in me." She did reach a point where she had enough of this treatment, realizing, "I don't want that."

For most participants, their childhood experiences of being written off and rejected by most, if not all, people in their lives left them longing for love, acceptance and someone who believed in them and their capabilities. For some, such as Jen's experience with Joe suggests, these negative experiences continued into early adulthood.

I Was Always Really Picked On

Each participant told stories of being "picked on" and bullied throughout their childhood/youth. Often their stories involved feeling targeted, violated, being unheard and not understood. Justin, like almost all participants concluded that "people were so mean". They described the severity of the meanness of their tormentors and its lasting impact on how they felt about themselves and others.

Tina spoke about her skin sensitivity and how other children ignored her protests to their teasing, and "meanness". She related, "They [would] tickle me and tease me and I'd be shouting and crying and saying that it hurts and they would laugh and call me crybaby." Justin related similar stories of torment, explaining, "I was always really picked on. I hated going outside at lunch cuz I knew that I would be beat up." Sara also concluded that kids in her community were really mean. She, too, described the teasing and exclusion she experienced because of her differences, "they just totally snubbed you, … like name calling and snobbish with all their little groups and cliques… they'd talk behind your back." Jen also recounted experiences of being called "every name in the book, stupid, retard, everything", and being the target of meanness, which made "growing up hard". Jen explained that she was laughed at because she couldn't accomplish what others could, recalling that, "just cuz I didn't know it, they all looked at me like, 'look at her, she can't do it, ha ha ha'."

Jen added that she was not what they called her and that neither her classmates nor her teachers understood her differences. She stated, "it wasn't because I was a retard, it's cuz I was slower than they were. And they couldn't understand it." Being called what they were not was a familiar experience to other participants as well. Tina recalled being assigned aboriginal status, by teachers, human services workers and other children when they learned of her FAS. She recounted that, "Some of the kids at the group home used to call me "The Little Indian"… I wouldn't mind if I were Native but I'm not." She also explained her response to this disrespect was to become more private about herself, like her mom, " because people will do and say things to you that are very mean and not respectful."

Tina expressed empathy for another child in her group home who was aboriginal, when she reflected upon her treatment. She said, "I now wonder what she must have thought about herself when she would call me a little Indian." Jen also expressed that her experience of being the target of this meanness provided her with greater empathy for others in a similar situation. She vowed, "I would never do that to anybody... If I saw somebody who couldn't do it or was trying to… figure it out, I would always try to help them if I could, or get somebody to help them."

The pain of childhood teasing and exclusion stayed with Jen into adulthood. When, as a young adult, she underwent cognitive and medical assessments related to her FAS, she wanted to be informed and included in the case meeting. She asserted, "I wanted to be treated as an adult, as a person. I wanted to hear what other people had to say about me, not behind my back. Cuz it hurt too much as a kid."

Michelle also spoke about teasing and the different groups or "classes" at school. She reported, "There was times where, like, 'I don't want to be here and some people are such idiots'..." However, she explained that she was buffered from the negative treatment she saw others, such as her sister Sara, receive. She explained, "but I never really experienced that problem", because her involvement in sports teams gave her a "link", or ways of getting to know and make friends with variety of people. She explained, "because… I had that link to everybody… I was involved with everybody, because with sports teams… there's a whole range and so you got to know people that way."

When some participants spoke about their choices and behaviours, such as theft, that brought them consequences from the juvenile justice system, they attributed their behaviours to getting picked on or being intimidated. Justin explained that he "took a car" because he just wanted to be free from the pressure from other youths. He explained, "I don't know why I did it I just wanted them off my back – they kept razzing me." Leslie provided a similar explanation of being intimidated and threatened for her and Erika's actions in a shoplifting "team" of other youths. She related, "We were told what to take and if we didn't then we would have gotten beat up really bad - they were bigger than us."

Experiences of being picked on, bullied or targeted by peers and teachers stood out for participants in telling their life story. They explained it had a lasting negative impact on their beliefs and experience of others and themselves. With the exception of Michelle and Sara, participants also explained that this meanness was not buffered by a positive home and family connection. Most participants described feeling alone and uncared for a great deal of their lives.

I Was All Alone... I Had No Friends… No One Cared About Me

A core theme within participants' life experiences and central to their experiences of longing and searching for, finding and having friendships was, for either the majority of their lives, or at particular times in their life, feeling alone, friendless, and that no one cared about them and their difficulties.

Justin spoke about having "no friends" throughout his childhood. In addition to feeling "like a problem, not a person", Justin's aloneness involved feeling different and unsupported "everywhere". He expressed, "Nobody asked me how I was doing… I never felt like I fit in or felt like I was liked by anyone." Tina echoed feeling this solitude, and a sense of absolute difference from and non acceptance by others, especially by those who were supposed to be her peers, for most of her life. She recalled, "I was so lonely and there was no one like me or that liked me." Tina's poignant words captures the immensity of her loneliness and void. She expressed, "I felt lonely… I've had 2 holes in my heart, one that the doctors sewed up and one that has never been filled up, the hole in my feelings and … in my spirit or soul."

Jen also felt "all alone" and different for most of her childhood and adolescence; "no matter how hard [she] tried", she could not be like other young people, or match their achievements. She contrasted her peers to herself recounting that, "other kids just seemed to have it easier - they could do everything, they had it together." Her aloneness included being unheard and not understood, once again pointing out that, "no one listened to me." Tina also expressed trying to be and do like others and perform the school work, but only feeling incapable, unheard and unworthy. She recalled, " I tried to explain.... No one at school would listen to what I wanted to say. I felt so stupid and so bad…" Justin related similar experiences of solitary struggles, adding that he had no one explain his experience to him. He reiterated, "I used to wonder why things were so hard. I had no one to tell me that I wasn't stupid. I had no real family or friends. No one really cared…"

Michelle also experienced being different and without friends at her first year of college, in contrast to her positive stories about school and being linked to friends through her sports involvement. In college, she described losing her excitement and motivation, and failing her course, when she felt intimidated by her classmates' commonalities that she lacked. She recalled, "there wasn't any friends … The age range in the classes were quite different… like older students. … and so you feel intimidated to approach them."

Jen recalled that her loneliness, being friendless but still looking for love was her motivation for getting pregnant at age 15. She explained, "… even though I had my mom and my dad and my little brother and his friends, I had no friends of my own. I felt so lonely that I wanted someone else to love me back." Jen described being alone and isolated again, with an additional loss of freedom when she was parenting her second child at age 17. She recalled, "I felt like I was always at home with just her…I wanted my freedom back… I just wanted to go out and party and I wanted to go out and have friends…"

For most of the seven participants, much of their life experience so far had involved an ongoing sense of aloneness and isolation. They felt alone, having no one whom they shared commonalities, understanding or acceptance. Only Michelle and Sara spoke of the caring they experienced in their home, from their (adoptive) mom and sisters, in particular.

Longing and Searching for Friendships

All participants spoke about trying to make friends. They also spoke about longing for and searching for friends and friendships. Their searches for friendship were driven by their life experiences including being different, and not different; ruptured relationships beginning with their birth mother, and continuing as a way of life; being written off and picked on by "mean people"; feeling alone, friendless, unliked and unloved. These experiences, losses and voids made their efforts for friendship seem all the more important and difficult, and their find all the more elusive.

I Tried to Make Friends, But…

Tina recalled that she "tried to make friends" throughout elementary and high schools but confronted barriers such as moving, changing schools, and entering into situations where no one seemed available to befriend. She explained, "all the kids had their own friends and fun after school and I moved around a lot anyways." This left her with the familiar feelings of being overwhelmed, seen as "stupid and weird" and that "no one cared". Justin also expressed that he, "just wanted to be part of things" and tried to be included in peer activities. However, instead he would receive the familiar attacks; he recalled that he would be, "jumped by 2 or more guys… they'd beat me up." This then led him to withdraw, "then I would skip the rest of school."

Jen spoke about the efforts she made to prove herself worthy of friendship when she returned to school from her long-term absences due to illness. She recalled. "I went to the point where I was trying to prove myself to these people." But then, like Justin, Jen ended up responding in ways that further excluded her from others. She described her behaviour as, "I was harsh, insulting them back like they did it to me."

I Wished I Had Friends, But….

Jen recalled that throughout her childhood and adolescence she wished to have the commitment and support of a "real friend", defining this to be "someone who sticks with you in the long haul. " She recalled that she "wished I had friends to support me, to help me out when I needed it." "But", she lamented, " I didn't have it." Justin also wished to "have someone to do stuff with to have fun with", which he thought would ameliorate some of his troubles, and projected that, "school probably wouldn't have been so bad." Tina also recounted her intense longings for friendship and acceptance. She professed, "I wanted so much for so long, to have friends or … a special friend that … I could just be me, not have to try so hard, who really liked me and we could talk and do things together."

Tina had longed for friendship to assuage the profound loneliness she experienced. She was, "just trying to fill that hole in my heart any way I knew how." Upon reflection years later, she saw that she dealt with this void by taking other's possessions to feel close to them. She recalled, "just wanting to feel friends or close to them and having something of theirs… like a letter they wrote or a picture of them or a picture they made. [This] made me feel like we were friends." She also wanted to show others that she did have friends, recalling, "I would tell my foster mom Mabel that Melanie made the picture to give to me." Tina spoke about how both she and others had not understood her longings and the reasons for her behaviour then. She recalled that, "no one would ever understand that I wasn't trying to be mean or bad when I took things. I wish people had seen that about me and helped me see that then. "

Looking For A Real Best Friend But Ending Up With….

Many participants recounted that they did not find the friends or friendship experiences they were longing for when they did connect with someone. Five of the seven young people spoke about having sex by age 14 or 15, with a motivation to be loved, cared about and attended to, be it through their sexual partner or by having a baby. Jen, Erika and Leslie became pregnant twice, between the ages of 15 and 18, and Tina at age 16. Tina described trying to fulfill her longings, but ending up still feeling empty after having sex, getting pregnant and miscarrying at age 16. She expressed that, "having sex with Mike sure didn't… fill my feelings hole, and now after losing my baby I feel like it made my heart hole bigger." Similarly, Jen described finding Joe, aged 37, with whom she lived and had her second child, as a parental figure, rather than the more equal and reciprocal "real best friend" she had been looking for to "go through things together".

Even With Friends, I'm Still Looking For Someone Exactly Like Me

Sometimes, this longing and searching for a particular type of friendship, continued after these young people had found positive and significant friendships. Despite finding her good friend, Amy, at age 16 (just after Tina's miscarriage), who connected her to other friends, Tina spoke about still wanting "a friend with FAS too." This friend with FAS, a connection she likened to sisterhood, would be someone who would know through their own experience, "exactly what it's like to have a body and brain like mine... someone who goes through the same thing as I do everyday". In addition to sharing their everyday experience, Tina's searching had functional attributes, looking for someone to share practical strategies for living with FAS. She explained, "and then we could talk about it and figure out how we can work through our memory problems or problems with too much noise or people or activity."

Participant's longing and searching for friends and their unsuccessful attempts at initiating and having the friendships they were looking for, included or resulted in certain behaviours and choices. These included skipping school, insulting others, taking other's belongings, having sex, becoming pregnant, and becoming involved with someone twice their age. Others may have seen these actions as acting out, poor impulse control or irresponsible. However when participants reflected upon their experiences, sometimes years later when they were young adults and after they had found a significant friend, they saw how they were trying to fulfill their unmet needs. These needs included, feeling liked, truly understood, accepted, cared for, loved, and having someone to go through things together.

In addition, Tina's continued search for a friend with FAS underscores the importance for her to have someone who she shared specific commonalities, someone with whom she could have a sisterly connection, who, through their own experience of having FAS, would be able to understand her and her experience, and with whom she could explore and learn together practical strategies for living with FAS.

Finding and Making Friendships

Participants spoke about the significant moments when they actually found what they had been longing and searching for - friendship, either by finding a special friend or being part of a crowd or group. For some, this experience did not happen until their late teen years.

I Got in With a Crowd

Sometimes the finding and making of friends involved or began with finding a group or crowd. Jen recalled finding in her early teens, "the older crowd", who offered her refuge from maltreatment by those her own age. She described this older group as "into having fun"; "so that's what I was into too", she recalled. However, she also described this older group of youth's anticipation of grade 12 graduation, a position which she did not share as she was much younger. This and other differences from this group due to her age and life experience may provide insight into her continued loneliness. Despite Jen's involvement with this older group, at 15, she recalled that she still felt all alone, with "no friends of my own", and became pregnant. After giving birth, and giving the baby for adoption, she came back to her community and her parent's home. But she soon left home, and again found people she felt she fit with, "the older crowd". Upon reflection 5 years later, she wondered why she chose this "older crowd" and went to the streets: "I just look back at it now and I just go, "NO, why did I do that?"

For a few years of her teens, Jen lived in and out of foster care, a youth shelter and the downtown streets. She described her friendship experiences of this time to be more of group or "crowd" friendships than the close friends she developed later, which will be explored later in this chapter. As Jen's experiences of her group friendships at that point in her life provide some illuminating similarities and contrasts to her later experiences and to other participants' friendships, we will explore a bit more here.

Jen described the simple companionship, or "a way to spend a couple of hours", she received from the other kids living in her foster home as being one of the most useful aspects of foster care. She also explained that she would "stay out of trouble" when she was with these friends, as they could report her actions to her foster parents. She then explained that she then had a different group of friends who she would engage in the "trouble" behaviours. She qualified her behaviours, though, explaining, "[I] never went to jail though. ... a lot of my friends were thrown in jail at 17 or 16. I didn't do too much though. " She added that her intentions had been positive, reinforcing that she, "tried to stay out of trouble." Jen then further explained that her choices and actions depended on the influence of others, at times. She stated, "It depends who you're hanging with and what they're doing. If they're doing something that looks interesting, then I'm gonna try it."

Often, the influence of others living on the street, was positive and useful for Jen. Despite leaving her parent's home because she "didn't want to follow their rules", Jen credited her friends at the Youth Shelter in helping her follow the curfew rules of the shelter, and keeping her on track. She recalled, "At [the] Youth Shelter, if you miss a curfew, you can't come back, so I think it helped when I had friends who were okay, we need to go back, it's 10:00... and [we'd] just run down the street." In addition to this guidance/keeping on track function, Jen's friendships on the street served protective functions.

Jen again credited her friends on the street for her being "OK" and surviving the various dangers of "scary" street life, pointing out her vulnerabilities, "as a female you wouldn't be by yourself... or [you]'re gonna be dragged into bad stuff." She reported her discovery that, "if you got friends, like I had friends on the street ... if you stuck with them you were OK." Jen recounted that her friends on the street helped her escape a potentially life threatening situation where she had been forced into working in the sex trade for a night. Again she concluded that if you had friends who knew the people with power in that setting, then you escaped the serious dangers. She recalled, "I had friends, who knew this person, and they helped me get out... If you have friends that know the people down there, then you're all right. But if you don't, you're totally messed. That's it, you're gone."

Other participants described their experiences of first finding attention from groups of peers, which then led to finding one-one friendships.

Justin found that his school experience improved when, "all of a sudden at high school I had friends". He began to get attention from girls and he no longer felt alone. He recalled, "I don't know what happened but, in grade 8 it started that all these girls would always call me, and it made me feel good, I guess." He also found himself getting attention from males when he gained popularity from reputation of being sexually active. He continued his story of his new-found wave of attention, recalling, "And then the guys would say, 'You're doing it, eh?' So I just did it, like sex, whenever and wherever I could." He continued this sexual behaviour within his reaction to this "crazy" time, until meeting his important friend, Kyla. He concluded, "I've calmed down now, once I met one girl - Kyla."

Michelle spoke about finding herself in the unfamiliar place of not knowing many people around her when she first returned to high school after a year's absence. She pointed to Sara's role in her return, "But Sara knew all the kids… I [said], 'I'm actually Sara's twin sister'." Michelle remarked that she "got over" not being known, and, still referring to Sara in her process of making friends, reported that, "we got new friends." Michelle once again recalled how her "outgoing" nature and involvement in sports teams and activities gave her important ways to meet, get to know new people and make new friends. She explained, "I was involved in everything you know. I had that link to everybody cuz I was involved… and there's a whole range and so you got to know people that way."

Michelle related successful experiences of finding friendship(s) by meeting a whole range of people through her sports crowds. Justin also related a positive outcome to his new-found attention, albeit "crazy", from a variety of other youth, by meeting Kyla, who had a calming effect on his behaviour and friendship search. Jen's experiences of "getting in with the older crowd", in some ways provided her with ways of having companionship, keeping on track with the youth shelter curfew and staying safe from street dangers. However this proved to not to satisfy her quest for friendship, which she realized years later, and thus she continued her search for different friendship experiences.

A Good Find for a [Close] Friend

Finding and making friends, especially best or close friendships, was an important and memorable event for all participants. What made these moments particularly significant and meaningful for most, was the long road they had travelled, the long search they had done, and the heavy load of their past experiences of multiple ruptures, disruptions and losses within their family, homes, and schools, of feeling alone, written off and picked on that they carried before finding these friendships.

Tina described the moment she found Amy as a friend, at age 16, two years prior to our interview. Playing in a treasure hunt at her church, Tina was approached in a positive, friendly way by Amy. Tina experienced "a match" with Amy, both for the game and for a friend. She recalled, "She came over to me and we were a match and we laughed about the joke and she was just so nice and friendly." Tina called Amy "a good find for a friend", illuminating her long process of searching for friendship and the treasureable nature of her discovery experience.

Justin, too, had the moment that he met Kyla clear in his mind, identifying it as the highlight in his life story. Like Tina's experience with Amy, he was also greeted with warmth by Kyla, who initiated conversation. He recalled, "She was just sitting by a tree by herself and she smiled and said hi." Sara also vividly recalled first meeting Vanessa, whom she called her best friend, when she repeated grade 6 and was unfamiliar with her classmates. Similar to Justin's experience of friendly invitation, Sara recalled, "Vanessa came over and said hi and asked if I wanted to play."

Sometimes the meeting and making of close friends occurred through sharing important commonalities in situation and/or experience. Leslie and Erika recalled "being in the same boat" in their life when they met 5 years prior, both aged 15 and pregnant. Erika related, "I went to the group home and met Leslie who was also pregnant."

Jen described how she made connections to others at a women's transition house after she left her ex-boyfriend Joe. "We all introduce ourselves and by the end of the week you know everybody there and you're ... having a great time ... going out for walks with each other." She recalled feeling "so good to be at home", noting that she made "serious friends" at the house, "especially Stacey." Jen explained that she and Stacey became good friends as they had commonalities, including separation from an abusive boyfriend and their disabilities, as well as a common understanding of each other's experience. She said, "We became good friends cuz we can get what the other has gone through... Stacey is ... going through the same thing I am. "

Participants recalled and described specifically the moment they met and made their best/close friend. Their first meeting of this friend happened through either a friendly approach by the other or through important commonalities in their experience and/or life situation. This occurred through what, for all except Michelle, had been an elusive event and experience - a friendly approach by another and/or meeting someone who shared important commonalities with them. Although Michelle did not describe specifically meeting a particular friend, she did describe how important her sports teams were in finding new friends.

I Know How to Make Friends Better

Another aspect about finding and making friends for participants was gaining a greater sense of self confidence and ability to deal with challenges they confronted, including their ability get to know people and make friendships. Tina identified these self-gains after becoming friends with Amy. She reflected, "I learned how to get to know people at church… and… I know how to make friends better." She also saw how her self development has increased her communication and coping skills and provided her more stability. She explained, "I feel more able to tell people when it's not working for me, rather than just disappearing like I did before."

In many ways, participants spoke about how their lives and experiences changed when they found and experienced significant friendships. As Jen put it, when she explained that it was necessary for her friend Stacey to get new friends to move past her abusive boyfriend, "It's almost like a new life."

Finding friends and friendship, close friends in particular, was a memorable event for participants. Tina identified this finding and making of friends as a skill she improved through her experience. Jen compared this event to getting a new life and as a necessity to move forward in living life. Tina's metaphor of "a good find" and "match" underscores their long anticipation, extensive search, hard work and appreciation of the treasureable nature of their friendship discoveries. This appreciation is also inherent within their reflections about their experiences of having and being in these friendships.

Participants' Experiences of Having and Being in Close Friendships

Each participant spoke about having a best friend or someone that they had a very close one-one friendship. For several, this experience was relatively recent in their lives. Aspects of the meanings and qualities of their close friendship experiences included: companionship - someone just to be with; shared qualities/experiences and understanding - she's got the exactly the same thing ; acceptance/unconditionality - She accepts me the way I am; confidante and confidentiality; help/support - she helped me –believed in me and then so did I; Mutuality/reciprocity in helping - I've helped her too; Going through it together; Co-worker/partnership: we work best… together; and; links to others - she invited me to things where I met other kids.

The Company of Friends - Someone Just to Be With

Some participants spoke about finding companionship, someone to hang out with, with their close friend(s). Until his friendship with Kyla, Justin doubted that he would have companionship, someone to share his time and thoughts. He expressed, "I didn't know that I would have friends, someone to just be with, like sit on the grass and just talk about whatever, until Kyla." Justin's reflections of doubting whether he would ever have this simple shared experience underscores the significance of this companionship, given his and many other participants' stories of feeling and being alone for the majority of their childhood.

Sara, also spoke about having companionship with friends, when not at home, "hang[ing] out by myself." She explained, "I have a couple close friends and I hang out with them quite a bit." Michelle spoke about her active lifestyle as including the company of her friends. She reported, "I'm very much into sports and doing something… with my friends." Jen had also spoken about the companionship she experienced in her group friendship experiences, however there were other aspects of her close one-one friendships, such as the following reflections of having commonalities that provided a sense of being understood, for all participants.

Shared Qualities/Experiences – She Understands Me

For all participants a key aspect of these close friendships involved having commonalities in "qualities" of themselves and in life experiences. These commonalities played a key part for them in feeling like their close friend really understood them. These commonalities relate to their life background; another aspect, "going through it together" is examined later in my analysis.

Tina identified her commonalities with Amy, noting that they both had had "hard stuff happen" to them. Similarly, Justin expressed that he and Kyla were the same age and that, "she has problems too." This shared experience of enduring difficulties ended feeling that they were "the only one", as Justin had previously believed.

Erika introduced Leslie and herself to me by describing some important commonalities they had, including, FAS, age, knowing the other's experience of life and ways of thinking and speaking. Erika stated, "We both have FAS and... [are] same age... and know what it's like for the other one. No one else knows how I think but she does; we finish our sentences for each other." In our interview, Leslie demonstrated their co-expression by completing Erika's sentence, "all the time" and as did Erika, by chiming back in return, "like that!"

Jen also described the "cool" commonalities she had with Stacey, including their disability and the "qualities" that came with having FAS. Jen explained, "Her mom was an alcoholic... So [Stacey]'s got the exactly the same thing... like she's smarter in certain ways than I am, but, ...we can still see the same qualities in ourselves." Although Jen noted that she believed her friend to be smarter than her, she related that as she and Stacey more specifically explored their commonalities, such as learning styles and comprehension/listening retention difficulties, Jen reported that she could say, for the first time, "That's the exactly the same with me." Jen described their exploration of "the way we are", by asking each other, "do you do this and do you do that, and do you do this?". With satisfaction they were able to say, "yeah, I do." Similar to the mutuality of Erika and Leslie, Jen described the mutuality of her and Stacey's experiences, their dialogue with each other and the totality of their mutual understanding. Jen reflected, "It's so neat cuz we can totally understand what we're talking about. She can say something to me and I'll go, isn't that . . and we just make comments back and forth about it, and we both agree."

According to Jen, this mutuality provided significant fulfillment as she projected an empty experience of life for both her and Stacey without their friendship. She resolved, "If we didn't have each other, we'd be so depressed, we'd be so bored.... she'd have no life."

Despite their commonalities, Jen also contrasted how they both dealt with, and the severity of, their disabilities. Jen believed that only her birth mother, with whom she had no contact, could explain to Jen the actual causes and nature of her FAS. Without this information, she struggled to make sense of her difficulties and measured herself against her friend. Jen concluded, "But [Stacey's] learned how to deal with it a lot easier than I have. I don't think her mom was that harsh on her alcohol. … And I think I have it worse than she did." Jen's evaluations about her mother, her FAS, her abilities and life being "worse" than Stacey also reflects the extent to which Jen sees herself struggle to make sense of herself and her experiences.

Twin sisters Sara and Michelle both identified each other as friends; Sara, described themselves as "best friends". Michelle likened her relationship with Sara to a friendship, describing Sara as "like a friend I can talk to and stuff like that." Similar to other participants, friendship experiences, Sara and Michelle expressed that each felt understood by the other, due to their relationship. Sara described feeling understood by Michelle, expressing, "She knows me so well - without having to explain." What differed in the friendship between Sara and Michelle to the close friend(s) of other participants, included that they saw each other not as similar in nature but, as Sara stated, as "absolute opposites". She summed their differences as, "I like just staying at home some times and she's like, 'I have to like go out, I have to go out'." Michelle also pointed out some of their differences, "We have our different friends… and our different likes.… so we still got our own identities." Michelle's differentiation of their identities may have also related to the twin aspect of their relationship, where often each twin's individuality is not as recognized as their similarities by others, and therefore twins must call attention to their differences as well. What provided Sara and Michelle's sense of mutual understanding included their shared experience within their twin sister relationship.

Having commonalities in experience, and in qualities of themselves, was a significant component of participants' experiences of friendship. Most expressed that feeling understood without having to explain and interpret was an important component of these commonalities. Given most participants' previous life experience of feeling so different than others, and feeling unheard and misunderstood, many participants expressed highly valuing this sense of commonality. Furthermore, Jen, Erika and Leslie identified that an important commonality for their significant friend was having FAS. In addition to having this commonality and feeling understood, this allowed them to explore more specifically their experience and find strategies to deal with their FAS. This need and value was also expressed by Tina, who was still searching for "a friend with FAS too." In addition, the complexities of understanding and being understood regarding experiences of having FAS, are apparent in Jen's reflections. Despite valuing her shared experiences with Stacey, Jen also spoke about still having differences to Stacey and having unresolved questions and feelings about aspects and origins of her disability.

Links To Meeting Others: I Met Other Kids

Participants' close friends also provided opportunities for them to meet, get to know and become friends with others. Their close friend provided access to other young people, and acted as a liaison between participants and these potential friends. Tina described Amy's invitations to join her in activities where she met others to befriend. She recalled, "she invited me to things where I met other kids of the youth group, like Linda, who I go swimming with." Sara assessed that Michelle was "good for me" because she encouraged and provided opportunities for Sara to "get out… meet people… play pool… watch movies, … like do normal stuff."

Sara had other links as well. After explaining that she saw less of Vanessa, now that Vanessa was busier with events such as working and getting married, Sara also commented about meeting and hanging out with friends of her other friend, Kim. She added, "Kim… Lynn and Liz, we hang out together quite a bit." Similarly, Jen identified the mutual friendships that she and Stacey had developed, "we also met and became friends with Tami … and Rob."

Although most participants specified one person as their best, close or most important friend, most also spoke about one or more others as close friends. Often they met these friends through the facilitation of their close friend, who invited them to meet and interact with others. Sara's assessment of Michelle as being "good for me" and that this got her out to "do normal stuff" reflected her appreciation of these connections and the benefits she experienced. These were important opportunities and experiences, given most participant's (previous) life experiences of exclusion and isolation from their peer groups.

Acceptance and Unconditionality

She's My Best Friend - She Accepts Me the Way I Am

One of the first things most participants said about their own "best" or close friend was that their friend accepted and liked them for who they were. This acceptance was in great contrast to their stories of meanness, rejection and blame they had experienced from others, such as classmates, teachers and family.

Sara stated that Vanessa, with whom she'd been "best friends" for over 6 years, "accepts me the way I am." Justin indicated how elusive this acceptance had been for him. While describing his experience of friendship with Kyla, he proclaimed that, "For the first time I felt understood and accepted for who I am."

Sometimes this sense of acceptance by another also came from other close friends whom they met through their close friend. Sara spoke about other close friends who "accepted her right away". Tina described the acceptance she gained from her friends whom she met through Amy, pointing out that her FAS was not important to their view of her. She said, "I feel like they like me for who I am. Lots don't know about my FAS and it doesn't matter. I'm just me to them." There is a simplicity to her words – "just me" - and yet there is also a profoundness to them as well. When I consider her life experience of feeling rejected, alone, with "holes in my heart" and longing to be liked and accepted, as well as the complexities and contradictions of her experience of being "me", I can appreciate the importance and profoundness of her words and experience of friendship.

Jen described the support that her new boyfriend, Rob, provided her, rather than blame and non acceptance she had experienced from others throughout her life. She said, "Rob, …he's not there to judge me, … he's more there to support me." She specified that this non judgement gave her freedom to express herself more openly. She said, "I can communicate with him. I can share whatever I want with him."

With this experience of acceptance, these participants expressed that they felt understood, that they could be themselves and share what they wanted within these friendships, or the freedom to be "just me". Their experiences of being accepted regarding who and how they were in these friendships contained an aspect of unconditionality. This was also true for Erika and Leslie's experiences of their friendship.

True Family - Unconditional

Erika and Leslie's friendship had been longer than most friendships participants described. Erika and Leslie had met over 5 years prior and had lived together in a variety of situations: foster home, group home, on the street and shared apartment. Their reflections about their friendship showed the integrity and depth of their caring and regard for each other and their relationship.

Erika and Leslie both described the special friendship they had with each other as being the one and only authentic family either of them had - unconditional, permanent, without limits, and with primary commitment to one another. Erika proclaimed that, "We will always be here for each other." Erika's unconditional spiritual and primacy descriptions of their relationship reflect the profoundness of her friendship experience with Leslie. She expressed, "I think we are really sisters in the spirit and soul sense. She is ... my only family who really cares if I live or die or if I'm happy or not." Contrary to her adopted sister, Erika described Leslie as "my true sister."

Their friendship had not been entirely without struggles, at least for Erika. Erika expressed that for part of the time that Leslie was pregnant with Erik she struggled with her own feelings and needed to "[take] off for a while". She recalled, "it was really hard for me, remembering what happened to me before in my two pregnancies... and I think now I see how I was mad at Leslie in some ways." Erika's reflections about being "mad at Leslie" and needing to temporarily leave suggest that they still had their individuality and difficulties within their friendship. At times one person's (at least Erika's) experience of the other was different than their expectations of their friendship and/or they were overwhelmed by their own individual needs. However, Erika's separation was temporary and she returned to support Leslie before and after Erik, her namesake, was born.

Erika saw the reciprocity within their familial relationship. She explained the importance of her familial commitment to Leslie by describing her "Auntie Erika" role, in which she had a role and responsibilities in helping Leslie and Erik. She explained, "Like getting help for Leslie to have Erik and getting help to care for Erik. I love Erik like any auntie does. I'm Auntie Erika." Leslie echoed Erika's sentiments about their relationship, demonstrated by naming her son after Erika. Leslie saw it as her responsibility to provide an authentic family connection to her son through Erika. She explained, "I named him after her because she's my only true family and Erik needs to have true family."

This unconditional, authentic, permanent and primary family connection within both Erika's and Leslie's experience of their friendship was in considerable contrast to their stories about being written off by their past birth and adoptive families. Erika described being "given up on" and "returned like a pair of jeans" by her adoptive family and Leslie related being "lost" by all the foster home moves she endured. Erika and Leslie's relationship could be seen as fulfilling many different needs that many of us meet through relationships with more than one person, such as family of origin members, spouse, close friends, advisors. However, for the most part, Erika and Leslie only have each other. The reciprocity and primacy of their friendship is reflected by Erika's assurance that, "We will be ok and with love and caring we will have a good life and we will give love and caring to others too." She has found the love and caring she needs through her relationship with Leslie, which makes its authenticity and unconditionality all the more important.

Confidante and Confidentiality

Another important aspect of participants' experiences of close friendship was having a confidante and confidentiality. They spoke about confiding aspects of themselves that they didn't share with others. They trusted that their disclosures were kept private and within their friendship. This sharing and trust was in sharp contrast to their previous choices of withdrawal and distrust, in response to their experience of exclusion, bullying, teasing and blaming by the "mean people" in their lives.

Sara described the confidante nature of her friendship with Vanessa and what they exchanged when they "hang out together". She described sharing private aspects of her life experiences with Vanessa, trusting that Vanessa would keep these disclosures private. She explained, "we tell each other things… that go on in your life… and talk about things that I wouldn't tell anyone else… and I know that she won't tell anybody." Sara expressed that this confidance was "really good".

Tina echoed this sense of confidance within her descriptions of friendship with Amy. She remarked, "We talk about lots of stuff I wouldn't say to anyone else, like Mike and the baby and feeling so lonely and confused." Another component of the confidance exchanges for Tina involved sharing activities and expressing emotions. "and then we do something and laugh and cry." This sharing of intimate thoughts, experiences and emotions was markedly different for Tina, than her previous resolve to "keep things private" after the mean and disrespectful treatment she received from others throughout her life.

Erika spoke of her confidante trust that she had with Leslie. Erika recounted how she went to Leslie when in great pain after miscarrying in her second pregnancy. Leslie kept her in confidence until they recognized that Erika's serious condition needed outside help. Erika related, "I ran away to Leslie's foster home and she hid me in her room for over 3 weeks… it was only because I was so sick … and needed to go into the hospital that we told." Their commitment to each other and one another's well being, was evident in their actions and decisions to help and seek help when beyond their means.

These confidante experiences of sharing and trust were also related to the helping and support aspects of their friendship experiences.

Help and Support

Helped Me, Believed in Me and Then So Did I

The experience of being helped by their close friend(s) was a consistent theme for all participants. In conjunction with the companionship, shared qualities and experiences, and understanding, acceptance, confidante, they experienced and the help and support they received, many participants also experienced their friend(s) believing what they expressed about their experience and having faith/belief in them, and in their capacities. Many reported that this faith/belief from their friend(s) then had participants believing in themselves.

Sara described Michelle as "a really good support" who "helped me with problems that I'm going through." Jen also described the support she received from her new boyfriend Rob, describing him as "more like a comforting friend", who was "a shoulder to bawl my eyes out", which, she added, was "what I needed". Jen contrasted her support from Rob to the non supportive treatment she'd received from others. She explained, "It wasn't like 'Jen, you're not allowed to cry', or .. shrugging me off, or 'I don't want to listen to it', it's more like, 'what's wrong?, are you okay?... Talk to me'."

Support, help, and contact from "buddies... like a big sister, or big brother" was seen as essential by Jen. When I asked Jen what would be helpful for young people with FAS, she replied that, "it really helps" her to have Tami (who was about 5 years older than Jen) and Stacey (who was 3 years older than Jen), "to call upon and say, I need help." She emphasized the importance of this support by proclaiming emphatically, "If you don't have that, you're gonna be totally lost. That's all I'm gonna say. You're gonna be lost." Jen further explained the importance of having this support by expressing, "I think it's just knowing that I have someone out there... cuz I'm scared to be on my own." For Jen, her buddies provided not only emotional security but also practical help and support, which she saw as essential for keeping her from losing her way.

Besides the support and assistance participants received from their friends, many also described the confidence that their friends had in them, which led to a increase in their self esteem and self confidence. Tina found that Amy "helped me feel more comfortable with ... people. And with myself." Justin expressed that Kyla provided him with hope and motivation for a good life, despite his difficulties. He explained, "She's what makes me think that I can have a good life, even though I have FAS." Justin's assertion that "Kyla's important" indicates the significance, value and influence of this relationship and positive outlook for Justin. Knowing and feeling the genuineness of Kyla's belief in him, in his capacity and diligence, Justin found it easier to confront the challenges that lay before him. He reported, "Kyla thinks that I can finish school and get a good job, and I believe that I can do it now too." Similarly, Jen accounted for her gain of happiness by the change in her life of having "really good friends". In contrast to her past experiences with her ex-boyfriend Joe and others such as classmates and teachers, Jen now found from her friendships a sense of encouragement and belief in her capabilities. She expressed, "they're like 'Jen, you can do anything you could possibly want, and I know you could do that.' Like Stacey. So, it's good to have friends like that."

In addition, Jen described feeling included, acknowledged and treated with respect by Rob. She emphasized that he would never exclude her, in sharp contrast to her childhood experiences of exclusion and disrespect from her peers. She remarked, "He would never leave me out. He'd always introduce me, [saying], 'This is my girlfriend, Jen', … he would treat me with respect."

Jen connected her new found experience of being treated with respect to her new found ability to speak more openly with others about her point of view. She explained that if she or Rob wanted to bring up a concern or a point of difference between them, they asked the other, "What's your problem today?" She further described the newness of this self-assertiveness and conflict resolution within relationships for her, expressing, "I am slowly actually starting to realize that I can do that now. I never did it with Joe, I'm now doing it with other people." Similarly, Justin attributed Kyla's respect for him and belief in his abilities and diligence to his increased willingness and confidence to "speak up for myself more", in his efforts to complete school and secure employment. He forecasted that these achievements, "won't be easy", but expressed that "she makes it easier, knowing that she believes me ...that I am hard working. "

The experience of being supported and helped by their close friend(s) was a common and important theme for all participants. They described their friend(s) as a valuable support and comfort. Jen spoke of the necessity of having someone to call upon to talk with and to say that she needed help, adding that without this, she, or other young people with FAS would be "lost". Jen further explained the importance of having this support by expressing her fears about being on her own and the importance of knowing that she had "someone out there".

Tina, Justin and Jen spoke about finding a new sense of esteem and confidence in themselves, leading to an increased capacity to express themselves more openly with others about their views, emotions and needs, by their experience of being respected and believed in by their friend(s). These qualities were also inherent within Erika and Leslie's friendship experiences which are explored further below in '"going through together" and co-worker/partnership stories.

Reciprocity in Helping: I've Helped Her Too…

Another common aspect of participants' friendship experiences was the caring and help they also provided to their close friend(s), demonstrating the reciprocity of support within their friendship experiences.

Tina remarked that Amy acknowledged their reciprocal support of one another. She reported, "she says that I have helped her too." Tina also identified both their improved happiness as another reciprocal benefit from their friendship. She stated, "[Amy] says she feels happier since we've been friends too." Similarly, Jen described how Stacey acknowledged the positive changes in herself and her social network she had gained from her friendship with Jen. Jen recounted that, "[Stacey] said, she's met me, I've totally taken her out here and… there, like I've introduced her to people." Michelle also described the reciprocal support between Sara and herself. She declared, "Sara, of course… we support each other." Similar to Jen's contribution to Stacey's social life, Michelle identified that she provided Sara that valuable "link" to others that she had through her involvement in group sports activities. She explained, "I know Sara's a bit different from me, she's not as active as me and outgoing as me, so I support her by dragging her out and introducing her to people."

Justin explicitly expressed that he enjoyed, and experienced rewards in, helping and giving to Kyla. He expressed, "I like doing things for her too. Like cheering her up when she's down." He recognized his strengths, talents and goodness in his caring and giving. He continued, "I am good at telling her jokes to make her laugh and she likes my drawings… I even did one for her mom … and she laughed, in a nice way, and put it on their fridge."

Some participants described their sense of responsibility to their friends. Michelle was taking her support role to Sara into consideration in her choices of post secondary education institutions. Michelle expressed knowing that her sister Sara did not want Michelle "to go too far", and appreciated Sara's anticipatory loss of her and her support.

Reciprocity in caring, giving, helping and support were important aspects of participants friendship experiences. Most participants expressed that they were acknowledged by their friends for their caring, giving and support, and that they enjoyed this appreciation. Helping their friends provided them with a sense of being valued and specific ways of being appreciated and liked. This was in sharp contrast to many of their previous negative experiences of others.

These qualities of mutual and reciprocal help were also inherent within Erika and Leslie's friendship experiences, which are explored below in "going through it together" and co-worker/partnership stories.

Going Through It Together

"Going through it together" was an important part of participants' friendships. Similar to the theme of shared qualities and experience, which referred more to their life background, "going through it together" meant accompaniment, sharing and support through an experience. When participants described difficult events or experiences such having an abortion, ruptured relationships, the meanness of others that was so predominant in their school years, or the ongoing living of their lives, they also described the difference in their experience when they had their close friend to "go through it together". The notion and experience of "through it" seemed to be important to participants, both the going/being (process of the experience) and gone/went/been (surviving/exiting/over, being in a different place) the particular event/experience.

Sara emphasized the totality of what she and her long-term best friend Vanessa had been through together. She declared, "through everything we've been together – everything". Erika provided a similar description of the depth and volume of the life experiences that she and Leslie had gone through together, summarizing, "we've been together through a lot of stuff and a lot of places." This resembled Leslie's characterizations of their friendship. In addition to "true family", Leslie also likened their relationship to that of "Thelma and Louise", women in a movie who fought to be together and survived many harrowing obstacles and dangers, and who were, as Leslie identified, "buds forever through anything."

Leslie described her and Erika's decisions and experiences of having an abortion at age 15, stating, "we went through it together." They both credited the other for making it through and surviving this ordeal. Leslie asserted, "I never would have made it without Erika." Erika agreed with, " Me neither." Once again, their descriptions of their friendship contains elements of primacy, interdependence and being essential, serving their basic needs for survival.

At the time of our interview, Jen reported she was pregnant, "for a third time." She also explained that together she and Stacey she were "going through" her decision and anticipation of an abortion, and described the importance of Stacey's support Jen valued Stacey's previous experience with abortion, and stated, "she's been through it before, when she was younger… you have to talk to someone who's done it." Key to Stacey's support of Jen was that she would stand by her and "hold my hand all the way through it". Jen's experience of Stacey's support "all the way through it" can also be related to her reflections about when she met Joe 3 years prior, while looking for a "real best friend to go through things together", but had not found this in her experience of Joe, who she described as a parental figure.

For these participants, the depth and totality of their shared experience of company, support, and commitment while dealing with particular or ongoing experiences, events or difficulties was important part of their friendship experiences. The notion and experience of "through it" seemed to be important to participants, and entailed both the process and exit of the particular shared event/experience.

Erika and Leslie's Co-Worker Partnership: "We Work Best… Together"

In addition to "going through things together", and their reciprocal support, Erika and Leslie's friendship involved a co-worker partnership as they lived their lives and dealt with the challenges they faced. Living their day to day lives involved a great deal of work for Erika and Leslie, as they dealt with their disabilities, their series of relationship losses, negative treatment from others, and navigated through human services systems. When describing the assistance that she and Erika needed from an advocate, Leslie emphasized that their friendship needed to be understood from their perspective and experience. She expressed, "we need this support person to really understand and support Erika's and my friendship." She explained that, through their experience, they "know that we work best when we're together."

Over their 5 years together, Erika and Leslie had experienced several successes with this co-worker approach. Leslie spoke of how positive her learning experience was when she and Erika were able to work together at home. She recalled, "It was the first time that I actually liked doing school. We could work together…. at home … it was so much better." Erika, agreed, "yeah and … we both graduated"

Leslie also recounted how others, such as human services workers, did not understand nor support their friendship, and attempted to separate them when they were involved in the foster care, social services or justice systems. She remarked, "everyone was always trying to break us up, saying that we spend too much time together." This led to unsatisfactory results for all. For example, Leslie described their difficulties at their probation office. She related, "Even though we asked for the same day and time so we could help each other remember…. Our appointments were different days… So we'd forget whose appointment was when, then we both got in trouble." These workers, Leslie said, did not see the necessity of, and successful strategies that came with, the co-worker aspects of their friendship. She explained the difference when the probation office and youth justice system utilised Leslie and Erika's "system" of partnership. This allowed them to be able to fulfill their responsibilities. She said, "Finally we had a system where we'd each bring in a calendar to … write down the next appointment, … same day and time for both of us, and then that worked."

Leslie related another story where their approach to working and doing together was again met with disapproval and non-cooperation by workers. At age 18, Leslie became pregnant again, and she and Erika planned to take care of the baby together, "because it felt like both of ours." They confronted barriers by workers who "freaked" at their plan, as they tried to navigate through the human services systems together. She recalled, "All the workers freaked at that thought and we just couldn't find anyone to help us do what we wanted." After Erik was born, Leslie and Erika once again co-navigated through service systems when Leslie needed help re-gaining custody of one year old Erik, who was being cared for by his paternal grandmother. Leslie expressed the reassurance she felt that "Erika will always be there" for her and her son. Erika reported that their co-worker approach to temporary employment was also successful for them. She relayed, "We were selling big pretzels and fruit ice … It was great." Leslie also referred to their co-worker approach to getting training and employment needed to demonstrate their capacities to provide for Erik. She stated, "we'll look at what school we need to go to."

The co-worker/partnership aspects of Erika and Leslie's friendship was their strategy and approach for successfully completing high school, navigating through a variety of human services systems, temporary employment and preparing them to live their lives as mother and auntie. Most often, their message that they "work best… together" was not understood nor supported by others in the youth justice and social services systems. When they were able to utilise their co-worker "system", such as finally at the probation office, that allowed them to be able to fulfill their responsibilities and experience success.

Summary

All seven participants reflected upon the complexities of their experiences, often explicitly referring to their FAS or FAE. These include both being different and not being different from everyone else, from how they appeared or how others assumed, and feeling one way and the contrary. These complexities provide a useful frame for understanding their friendship experiences, the meanings friendships have for them, and their views of friendship experiences as they face the challenges of FAS or FAE.

All participants' reflections and expressions about their birth mother hold many conflicting feelings and expectations of their past and future connections with her. These young adults saw the complexities of their birth mother's role in the origins of their FAS or FAE and in the rupturing of her relationship with them. Some acknowledged that the void they experienced and longed to fill related to their emotional struggles about their birth mother. This first and primary relationship loss of their birth mother seemed to accompany them in their future relationship losses and in their quests for friendships and connections with others. Loss became a way of life for many participants. For most, their childhood life experiences of multiple displacements created upheaval in themselves, their family, school, community and peer relations, as well as barriers to opportunities for friendships. Who was in their lives, such as whom they called family, with whom they lived, went to school, and might play, and therefore might have developed friendships, often changed.

Much of participants' messages and advice about understanding them arose from not being understood. Often these negative interactions took over their experience of school, and interfered with their opportunities for developing and experiencing friendships for much of their childhood. Intertwined within their stories was their pervasive experience and conclusion that, "people were mean". For most participants, their childhood experiences of being written off and rejected by most, if not all, people in their lives left them longing for love, acceptance and someone who believed in them and their capabilities. In addition, experiences of being picked on or bullied by peers and teachers stood out for participants in telling their life story, explaining that it had a lasting negative impact on their beliefs about others and themselves. Most also explained that this meanness was not buffered by a positive home and family connection. They felt alone, having no one whom they shared commonalities, understanding or acceptance. Their longing and searching for friends, and their unsuccessful attempts at initiating and having the friendships, resulted in certain behaviours, including skipping school, insulting others, taking other's belongings, having sex, becoming pregnant. When they reflected upon their experiences, they saw how they were trying to fulfill their unmet needs for friendship.

Some participants found connections and friendship through being part of a crowd or group. Finding and making friends, especially best or close friendships, was a significant and meaningful event for all participants, given their past experiences. Their first meeting of this friend happened through a friendly approach by another and/or meeting someone with whom they shared important commonalities. Some compared this event to getting a new life. Some spoke about finding companionship, someone to hang out with, with their close friend(s). Participants' stories of feeling and being alone for the majority of their childhood underscores the significance of this companionship. They appreciated that their close friends also provided opportunities for them to meet, get to know and become friends with others.

Having commonalities in life experience, and in qualities of themselves, was a significant component of participants' experiences of friendship. Feeling understood without having to explain was important to them. Given most participants' previous life experience of feeling so different than others, and feeling unheard and misunderstood, many participants expressed highly valuing this sense of commonality. Furthermore, it was important to Jen, Erika and Leslie that their significant friend has FAS. In addition to having FAS in common and feeling understood, they could explore more specifically their experience of, and find strategies to deal with, their FAS. Tina was still searching for "a friend with FAS too." In addition, Jen showed the complexities of understanding and being understood regarding having FAS. Despite valuing her shared experiences with her friend, Jen also expressed being different than her friend and having unresolved questions and feelings about the causes and nature of her FAS.

One of the first things most participants said about their own "best" or close friend was that their friend accepted and liked them for who they were. With this experience of acceptance, they felt understood, they could be themselves and share what they wanted within these friendships, or have the freedom to be "just me". There is a simplicity and also a profoundness to their experience of friendship, when we consider their life experience of feeling rejected, alone, empty and longing to be liked and accepted, as well as the complexities and contradictions within their experiences. They experienced unconditional acceptance regarding who and how they were in these friendships. Erika and Leslie's reflections about their friendship showed the integrity and depth of their caring and regard for each other and their relationship. Their unconditional, authentic and primary family connection within both Erika's and Leslie's experience of their friendship was in considerable contrast to their stories about being written off by their past birth and adoptive families. Erika and Leslie's reciprocal and primary relationship could be seen as fulfilling many different needs that many of us meet through relationships with many others.

Another important aspect of participants' experiences of close friendship was having a confidante and confidentiality. These confidante experiences of sharing and trust also relate to the helping and support aspects of their friendship experiences. The experience of being helped and supported by their close friend(s) was a common and important theme for all participants. They also experienced their friend(s) as respecting them, believing what they expressed about their experience and having belief in them, and in their capacities. For many, this belief from their friend(s) then had participants believing in themselves. They gained an increased self esteem and self confidence, and an increased capacity to express themselves more openly with others about their views, emotions and needs. They described their friend(s) as a valuable support and comfort. Jen spoke of the necessity of having someone to call upon to talk with and to tell that she needed help. Without this, Jen reported, she, or other young people with FAS would be "lost". Jen expressed her fears about being on her own and the importance of knowing that she had "someone out there".

Reciprocity in caring, giving, helping and support were also important aspects of participants' close friendship experiences. Most were acknowledged by their friends for providing caring, giving and support to their friends, and they enjoyed this appreciation. Helping their friends provided them with a sense of being valued and specific ways of being appreciated and liked. When participants described difficult events or experiences such as having an abortion, ruptured relationships, the meanness of others, or the ongoing living of their lives, they also described the difference in their experience when they had their close friend to "go through it together". The depth and totality of their shared experience of company, support, and commitment while dealing with particular or ongoing experiences, events or difficulties was important part of their friendship experiences. The notion and experience of "through it" seemed to be important to participants, both the process and exit of the shared experience.

Erika and Leslie's friendship involved a coworker partnership. Living their day to day lives involved a great deal of work for Erika and Leslie, as they dealt with their disabilities, their series of relationship losses, negative treatment from others, and navigated through human services systems. Through their experience, they "know that we work best when we're together". Most often, this was not understood nor supported by others in the youth justice and social services systems. When they were able to utilise their co-worker "system", such as finally in the probation office, it allowed them to be able to fulfill their responsibilities and experience success. This success included completing high school, navigating through a variety of human services systems, temporary employment and preparing themselves to live their lives as mother and auntie.

Leslie's message that they needed us to understand and support their friendship from their experience and perspective can be related to her request that we listen and believe what she says about what she needs and how she must go about doing things. She articulated that people such as herself who have FAS, want the same as others but may need to think and do differently. "Working together" worked well for Leslie and Erika, and demonstrates the importance of understanding the perspectives of these young adults about their experiences, relationships, friendships, and how they want and need to live their lives. Without this understanding, our actions and interactions, even if done with positive intent, will not be respectful nor useful in supporting these young people "to have a good life".

CHAPTER SIX: CONCLUSIONS

Further Discussion

This study's findings about the experiences and meanings of friendship for seven young adults with FAS or FAE provide some valuable insights into the experiences and perspectives of some people with FAS or FAE. It is useful to note here that the sampling of Study I has a direct influence on the findings of this study. Every sample has particular characteristics that contextualize the findings and implications. In this study, these characteristics include the following. The seven (six female, one male) young adults ranged in age from 16 to 20 years, and five were diagnosed with FAS and two with FAE. All were separated from their birth mother in their infancy or very early years and only one had reunited with her birth mother. Four of the young women had become pregnant once or twice between the ages of 16 to 18 and had either experienced loss through miscarriage, abortion or giving their baby for adoption. Two had given birth and had some involvement in parenting their child.

Study I

This study adds to and builds upon the findings of Study I (Copeland & Rutman, 1996). This study into experiences and meanings of friendship allows for a more in-depth analysis of friendship-related experiences and perspectives provided by the five young adults with FAS and two with FAE. Study I utilises information gained from the interviews with the seven young people with FAS or FAE, and also from interviews with eight parents of people with FAS or FAE and seven human services professionals. Often the testimonies from all participants were similar, however, in some instances, such as diagnostic issues, independent living and parenting as a young adult with FAS or FAE, the three groups of Study I participants demonstrated differing perspectives. The differences are informative and raise questions about the issues, experiences and perspectives related to FAS and FAE. These contrasts and contradictions, and some of the experiences and achievements, challenges and barriers, found in Study I provided useful entry points for more in-depth analysis of participant's stories.

A major finding of Study I is, "contrary to previous literature on fetal alcohol syndrome, the young adult participants are quite reflective about themselves, their relationships with others, and how having [FAS or FAE] does and does not impact their lives" (Copeland & Rutman, 1996, p. 7). This finding provided a basis for this study's narrative analysis of their reflections about their friendship experiences. Furthermore, Study I provides an overview of what participants described as "FAS/E feels like…" (Copeland & Rutman, 1996, p. 7). This includes living with a continuous experience of contradiction. This study provides more in-depth stories and narrative analysis of this by examining their experiences of both being different and being not different. The complexities and contradictions of both being different and not being different from everyone else, than how they appeared and how others assumed, feeling one way and the contrary, and their assertions that their individuality needs to be recognized, informs this study's analysis of their experiences and meanings of friendships.

Study I provides an overview of achievements, challenges, barriers, specific support needs/strategies, and recommendations for human services providers, related to learning, transitions to independent living, pregnancy and parenting as a young adult with FAS or FAE, and interactions with human services. Within Study I's findings and recommendations regarding these issues, individualised and peer supports are identified as important needs and strategies. This study concurs with this identification of peer supports and provides more extensive examination of this relationship; within participants' experiences of having and being in close friendships reciprocal help/support figured prominently in their stories, extending to the experiences of "going through it together" and "we work best together".

Moreover, Study I found that the starting point for its discussion about pregnancy and parenting as a young adult with FAS or FAE needed to be about the young women's profound sense of loneliness and desire to have a baby so they could experience love and being loved. Similarly, this study found that participants' stories, experiences and meanings of friendships are intertwined with their life experiences, which included, being different and being not different, negative experience of school, ongoing ruptured relationships, beginning with birth mother and continuing as a way of life, being written off and picked on by mean people, being all alone and longing and searching for friendships. This study provides more specific and complex detail and analysis of their "road to friendship", which also includes some of their pregnancy and parenting experiences. This study also uncovers more complexities to the significance of birth mothers in participant's experience of themselves and others, including the severing of their relationship and their connection to participants' FAS or FAE. This finding, and participants' stories of their quests for fulfilling maternal love, offers an additional complexity to add to Study I's examination of pregnancy and parenting with FAS or FAE.

In addition, as an appendix, Study I provides stories of Tina and her birth mother, as well as Leslie and Erika. These stories were effective in conference presentations about Study I and inspired me to use narrative analysis and expand the use of participants' stories in this study. Although there are similarities to Tina's and Leslie and Erika's stories of Study I and this study, the emphasis and inclusion of material differs due to the different analysis foci of the studies. Participants' stories in this study focus on their experiences of longing for, searching for, finding and having friendships as well as related experiences, such as their experiences of their disability, family relationships, schools, and home(s). It is my hope that this study's stories and narratives provide meaningful understandings for all readers about the young adults' experiences and meanings of friendships, which will somewhat differ depending upon the individuality of the reader's interests and experiences.

The Literature

This study relates to and can inform the literature on FAS and FAE and friendship. The following discusses key aspects of the literature in relation to this study.

As in other recent works, such as FAS/Support Network of BC, 1997a; 1997b; Kleinfeld et al., 1993; 2000; and Rutman et al., 2000, I believe that this study shows the value in seeking, sharing and understanding the experiences and perspectives of people with FAS or FAE. The young people in FAS/E Support Network of BC (1997b) briefly explain their perspectives on their misunderstood behaviours and motivations to maintain friendships, showing that there is a difference between how they see their behaviour and how others see it. Similarly, for many participants in this study, their quests for friendship included or resulted in behaviours such as skipping school, running away, insulting others, taking other's belongings, criminal theft, having sex, becoming pregnant, and becoming involved in street life. These young adults' perspectives and reflections on their behaviour as attempts to find and have friends, or in response to their profound loneliness, provide important information. This information differs from the explanations of particular deficits or disorders of FAS or

FAE provided by most pathology oriented studies, such as Streissguth et al.'s (1991) "lying and defiance conduct disorders" (p. 1966), and the still popular portrait of those with FAS or FAE as "boys who get locked up" or "girls who get knocked up" recited by Loock (1990). This study concurs with the conclusions of other recent literature, such as Kleinfeld (2000), that this pathology oriented portrait must be revised.

Moreover, we can see from this study what Mills (1959) meant by describing people's experiences as being located in particular historical and societal contexts. Participants' negative experiences of how others viewed and treated them may be traced back to some of our common (mis)perceptions regarding people who have FAS or FAE. Through their words and stories about being written off and picked on by "mean people" we see how they have lived the consequences of our pathology oriented and "100% preventable" foci on FAS. This study supports other recent works, such as FAS/Support Network of BC, 1997a; 1997b; Kleinfeld et al., 1993; 2000; and Rutman et al., 2000, as evidence that we must alter our views about, and interactions with, people with FAS or FAE to be more acknowledging and respectful. This study's narrative analysis and participant's stories about both their struggles that have arisen from their lives and disabilities, and their positive experiences and achievements, also joins with the above recent literature as evidence to uphold efforts to change the societal contexts and views about FAS and FAE. This would achieve a more balanced perspective which acknowledges the very humanness of people with FAS or FAS and understands their strengths, capacities, challenges, barriers and individualities.

When this study's participants reflected upon their experiences and behaviours, they saw how they were trying to fulfill their unmet needs such as to feel liked, truly understood, accepted, cared for, loved, and having someone to go through things together. Their life experiences of being different and not different, multiple home and school displacements, ongoing relationship losses, profound loneliness, being written off and picked on by "mean people", friendless, unloved and searching for positive, fulfilling connections with others provide a different perspective and different explanations from what many researchers and practitioners have identified as deficits associated with FAS or FAE, such as superficial verbal abilities and deficits in cognitive functioning, as reasons for their relationship and socialising problems (LaDue & Dunne, 1997; Malbin, 1990). Stories of this study's participants show that they lacked the "protective factors" (living in a stable home for most of one's life, early childhood diagnosis, and receiving appropriate developmentally disabled support services) that Streissguth et al. (1997) identified as needed for reducing what they termed "secondary disabilities of FAS". Participants' stories and the narrative analysis in this study add the complexities to, and appreciation of, the lived experience of these difficulties. In addition, this study also underscores the negative impact of being without positive, affirming and meaningful relationships, including friendships.

Finding and having friends, especially best or close friendships was a momentous and long sought after experience for this study's participants. Given the totality of their life experience, this primal and spiritual quest for friendship was all the more essential and difficult, and their "find" of friendship was all the more elusive and vital. Participants held a high appreciation of their friendship experiences since these were previously missing from their lives. In contrast to some literature that did not seek the experiences and perspectives of people with FAS or FAE, such as LaDue and Dunne (1997), this study shows that young adults with FAS or FAE are capable of having friendships; friendships can be a viable, important and meaningful part of the lives of people with FAS or FAE. This finding, and this study's stories and narratives, support and provide more detail and complexities to what the young people of the FAS/E Support Network of BC (1997b) tell us about how their friendships are important to them.

Participants' experiences of friendship in this study have thematic similarities to adolescent and young adult friendship literature, in particular with Laursen's (1996) model of interdependence for adolescent and young adult friendships. Laursen's (1996) model of interdependence involves intimacy, reciprocity, companionship, loyalty, commitment and equality; this model is similar to the significant components of participants' experiences of friendship found in this study. Significant components of participants' experiences of friendship include, companionship and links to befriending others; shared commonalities in experience and qualities, including FAS, which led to feeling understood; acceptance, which led to authenticity, unconditionality and having a confidante; help, comfort, support and being believed in, which was reciprocal; "going through it together", and for at least two, extended to a co-worker partnership, "working best… together". For this study's seven participants, these qualities of interdependence appear to have a high intensity and importance, given their previous life experiences and negative relationships with others, and, in particular for most, the lack of other supportive relationships, such as family, in their lives. Their positive and fulfilling connection with their friends also had a positive influence on their experience of themselves and on their self expression. Participants expressed that they felt understood, that they could be themselves within these friendships, and they valued the simple yet profound freedom to "just be me".

Moreover, the interdependent nature of this study's participants' experiences of friendship has the added complexities found in Mulderij's (1997) inquiry into the "life world" of young people with disabilities, which emphasized an explicit component and valuing of reciprocal helpfulness. The seven participants of this study described their friend(s) as a valuable support and comfort. Jen concluded that this support is essential since without this, she, or other young people with FAS would be "lost". Reciprocity in caring, giving, helping and support and "going through it together" were very important to them and their experience of friendship. Helping their friends provided them with a sense of being valued and specific ways of being appreciated and liked. This study supports and provides examples of experiences, and meanings of these experiences, to Kleinfeld's (2000) conclusion that people with FAS or FAE value having empathy for and helping others, and that this is important to their self-worth.

This study provides detailed stories and meanings of the experiences of "going though it together", which includes the depth and totality of their shared experience of company, support and commitment while dealing with particular or ongoing experiences, events or difficulties. This was a highly valued part of their friendship experiences. Furthermore, Erika and Leslie's friendship involved a co-worker partnership as they lived their lives and dealt with the challenges they faced. Through their experience, they "know that we work best when we're together." These findings are consistent with FAS/E Support Network of BC's (1997b), Kleinfeld et al.'s (1993; 2000) and Rutman et al.'s (2000) findings and discussion about the importance of friends, peers and other supportive relationships in successfully "resolving problems-in-living"(p. 1).

In this study, Erika, Leslie and Jen identified the shared experience of having FAS was important to their friendship experiences. In addition to feeling understood, this allowed them to explore more specifically their experience and find strategies to deal with their FAS, a need and value shared by Tina, who was still searching for "a friend with FAS too". This valuing of shared experience, including having the same disability, is also consistent with friendship literature regarding young people with or without disabilities. Shared membership in any group tends to be correlated with choice of friends (Bukowski et al., 1996), including having the same disability, because of a shared understanding of their life experience (Detweiler, 1987; Harry et al., 1998; Romer et al., 1998). I also hold Harry et al.'s (1998) caution that this finding is not intended to encourage a return to the position that people with disabilities are "better off with their own kind", but a call for more attention to and support for "friendships of many kinds" for people with disabilities, and to understand their friendship needs and choices.

This study's participants' valuing of their shared experience with FAS or FAE also relates to Tanya's (FAS/E Support Network of BC, 1997b) message to her peers, that, "You are not alone. Many people have FAS/E". The isolation that most participants of this study recounted experiencing prior and during their peer relationships informs us about the considerable importance of Tanya's (1997b) message. These findings also relate to Rutman et al.'s (2000) finding that knowing that they have FAS or FAE, and understanding this disability, had positive impacts on their participants' understanding of themselves, their relationships with others, community participation, and involvement in FAS education activities. Moreover, this study provides an appreciation of the complexities of understanding and being understood regarding experiences of having FAS, which are apparent in participants' reflections. For example, despite valuing her shared experiences of FAS with Stacey, Jen also experienced having differences to Stacey and having unresolved questions and feelings about the causes and nature of her disability.

Further, Leslie's message that she and Erika needed us to understand and support their friendship, from their own experience(s) and perspective(s), is consistent with Harry et al.'s (1998) call for interest, acceptance and support of "friendships of many kinds". This study and its participants echoes Leslie and Harry et al.'s (1998) advocacy for supporting, respecting and valuing the choices and individuality of young people with disabilities. This respect for the choices and individuality of friendship is in keeping with Krappman's (1996) philological finding of voluntary choice embedded within the meaning of friend.

Participants' experiences of friendship, and the meanings friendships have for them, demonstrates the importance of understanding the experiences and perspectives of these young adults and the value of including people with FAS or FAE as informants of research and practice. This study's participants provided many messages and advice about how others must understand them and others with FAS or FAE, their lives, and how best to support their efforts "to have a good life". Messages from this study's participants are consistent with Morse's (2000) call to people with FAS or FAE to participate in research and her belief that they have valuable contributions to make in informing our knowledge and actions.

Further Implications for Informing Policy and Practice

This study and its findings have relevance for informing policy and practice in a variety of services and authorities, including child protection, family and social services, services for people with disabilities, personal counselling, education, youth justice, health care, recreation, employment and employment training.

Respect and Inclusion of People with FAS or FAE

This study underscores the importance of seeking and understanding the voices, experiences and perspectives of people with FAS or FAE to inform our policies and practices. First, this study's participants advise us to acknowledge their worthiness as humans. Participants' messages that "we are here - see us, believe in us" speak volumes about their experiences of being unseen and unheard. Rather than writing them off as something that should not have happened, this study's participants provide compelling insights into human experience. Their extensive quests for friendship are congruent with Uditsky's (1993) view of what defines us as human. Although prevention of FAS and FAE is an important objective, we must ensure that our dramatic and simplistic declarations of FAS being "100% preventable" (Fetal Alcohol and Drug Unit, University of Washington, 1996; Health and Welfare Canada, 1992; Society of Special Needs Adoptive Parents & Ministry for Children and Families, 1999) or "entirely preventable" (BC Children's Commission, 2001) do not overshadow the very real existence and very humanness of people who do have FAS or FAE.

This begins with acknowledging the complexities to preventing FAS and FAE and identifying and addressing the complexities in the origins of FAS and FAE, including addictions, poverty, violence, reproductive health issues and societal and personal relations to alcohol. This has been undertaken, for example, by Vancouver's Sheway Project (British Columbia's Centre of Excellence for Women's Health, 2000). In addition to prevention, our policies and practices must have more balanced focus on supports and strategies for inclusion for people with FAS or FAE and their families. The Canadian Centre on Substance Abuse National Working Group on Policy (1996) and Federal Government of Canada's (1999) Fetal Alcohol Syndrome/Fetal Alcohol Effects Initiative provide valuable opportunities, and they include goals for prevention, treatment and "FAS/FAE activities". This study and its participants emphasize that we must extend beyond identifying "the most effective professional treatment"(Canadian Centre on Substance Abuse National Working Group on Policy, 1996) to acknowledge and utilise the strengths, capacities, challenges, barriers and individualities of people with FAS or FAS in our development of support strategies.

In addition to respecting people with FAS or FAE, this study highlights the need, and the participants' desire, to include their voices and perspectives in the decision-making of designing and providing human services. FAS/E Support Network of British Columbia's current project *FAS/E: A Manual for Community Caring*, is an important opportunity for collaboration that includes people with FAS or FAE and their families. Given Doe's (1996) and Campbell, Copeland and Tate's (1998) cautions, consideration must be given to understanding and addressing the power, access and perspective differences within collaboration among people with disabilities and professional stakeholders. Rutman et al. (2000) discuss their concerns about, and strategies to support, participation by people with FAS or FAE at their project's Action Round Table. These participation strategies include, personal invitations, individualised preparation support for presenters, fostering a sense of identity and connection among all participants with common t-shirts, photos and social time. Campbell, Copeland and Tate (1998) describe how they and their research team (composed of people with disabilities, health care providers and researchers) used their ongoing discussions about their experiences, challenges, barriers and achievements of participation in the project to inform their analysis, findings, recommendations, and policy and practice change actions. By examining the differences of power and perspectives within the work of the project, the research team was better able to understand and address these issues in the project's findings and actions. Although there may be additional considerations for collaboration with people with FAS or FAE, the principles of awareness and commitment to attending to collaboration issues are relevant.

Furthermore, this study shows that we also need to understand the complexities of the experiences of people with FAS or FAE - some that relate to having FAS or FAE - which involve being different and being not different from others. There must be flexibilities within our policies and practices for human services that allow for individual needs and approaches to living with this disability. In addition, rather than solely looking to possible deficits from their disability, we must also understand how the life experiences of people with FAS or FAE may influence their behaviours, needs, abilities and interests. Given this study's participants' experiences, this seems to be particularly relevant to our schools where individual educational plans and general welcoming and inclusion of young people with FAS or FAE require more individualised attention, with input from the young person, than what participants related. Lasser's (1999) handbook for teachers of students with FAS or FAE would have been a useful resource for the teachers and schools of this study's participants, however I do not believe that this kind of resource was available in those years. Given this study's participants' emphasis on understanding their experiences and perspectives, one aspect of Lasser's (1999) compilation of strategies that I recommend revising is to have more explicit discussion, and inclusion in the recommended strategies, of how the students themselves can be problem solvers and planners in their individualised education and peer relations.

Three of this study's seven participants related that they were involved with the youth justice system. Justin's, Leslie's and Erika's stories reveal their perspectives and motivations (such as intimidation by others, attempts to address loneliness, prohibition to use peer support/co-worker strategy for keeping appointments) for their behaviours that led to criminal charges or that interfered with fulfilling their probation responsibilities. Their stories also reveal that they had strategies that would have addressed some of their conflicts with these systems. Once the justice system adapted to Leslie and Erika's "co-worker" system, they successfully completed the requirements. This information is useful for efforts to prevent involvement in criminal systems and for strategies to support people with FAS to fulfill their responsibilities within the youth justice system, including following probation and court appearance orders. This study's findings that individual consideration and peer/mentoring supports for people must be given within the criminal justice systems is consistent with Fast et al.'s (1999) and Rutman et al.'s (2000) findings and recommendations.

Supporting Relationships and Continuity

Participants' experiences of a series of ruptured relationships, beginning with their birth mother and continuing throughout their youth, raise some critical issues to address. This study's participants reveal how the severing of their relationship with their birth mother can extensively impact their understanding of themselves and their relationships with others. The maternal origin and associations of FAS and FAE may influence the significance people with FAS or FAE place on their birth mother. Although there are many individual variations in circumstances, needs and interests of all parties involved in foster and adoption families, we must better understand the lives of birth mothers of people with FAS or FAE. Also, we must provide more effective supports to enable some kind of connection between the birth family and the young person with FAS or FAE. Outreach programs such as the Vancouver Eastside's Sheway Project, which provides "women-centred" holistic services to pregnant and parenting mothers with substance use problems until their children are aged 18 months, have relevance here. This program is a useful step in preventing birth mothers separating from or losing their children and in supporting birth mothers' increase in well- being to enable them to have a relationship with their child(ren) – who may have FAS or FAE (British Columbia's Centre of Excellence for Women's Health [BCCEWH], 2000). BCCEWH (2000) found in their evaluation of the Sheway Project that women accessing Sheway's services were more likely to keep custody of their child(ren), and for those who had their child(ren) apprehended, over one third had their child(ren) returned to her or her family's custody. BCCEWH (2000) recommends expansion of these services and support networks, which could also strengthen the likelihood that healthy birth mother-child relationships continue. This study shows the importance of such efforts for young people with FAS or FAE.

Participants' experiences of adoption breakdown and constant disruptions and moves in foster care indicates the serious attention needed to provide more stability and caring for some adopted children and children in care. This study supports British Columbia's Children's Commission (2001), the Child, Youth and Family Advocate of British Columbia (2001), adoptive parents support groups' (SNAP, 1999), Foster Parents Associations' (BCFPA, 1998) and the FAS/E Support Network of BC's (2001) recommendations for increased resources and support for children with FAS or FAE, and their adoptive or foster families, to prevent adoption or foster placement breakdown. Child welfare authorities must provide more effective care planning and supports for long term foster placements for the young person to have stable attachments related to family, school, friends and community.

Participants explained that they not only moved from foster home to foster home, but these disruptions also triggered many other losses and changes relating to schools, peers, and sometimes communities. This study shows that opportunities for developing and maintaining friendships were destroyed by this instability. Moreover, many of participants' stories involved being overwhelmed by their feelings and experiences of loss, loneliness and other difficulties, but lacked support, including counselling. Some participants had gained counselling support just prior to their interview for this study, and spoke positively about their counselling experience. Affordable, accessible and individualised counselling opportunities must be more available to young people in these circumstances. Baxter (2000), an adolescent counsellor, reports that, "traditional therapy can help alcohol affected adolescents. The key is to link talk therapy to concrete, physical representations of the issues… role playing, practice dialogues, play therapy, scrapbooks" (p. 170).

Further, care planning by child protection workers must include opportunities for the young person to have ongoing connections and relationships with significant others, such as friends, family, child and youth care counsellors, school teachers, and recreational leaders, in their life and community. This study's findings regarding the lack of ongoing relationships with significant others relates to Raymond and Belanger's (2000) project and evaluation of five "support circles" aimed at helping five young adults with FAS or FAE cope with transitions to independence. Raymond and Belanger report that the most successful support circle was for a "34 year old who was well aware of her problems and welcomed the help her group provided" (p. v). They also describe the difficulties the other four support circles encountered, including burnout by support circle members and disinterest or objection by the young adult with FAS or FAE. Given their outcomes, and this study's findings about the importance of understanding the perspectives and experiences of people with FAS or FAE, people with FAS or FAE must be involved in the decision-making of efforts such as support circles or other opportunities for relationships, connections and friendships with others. This recommendation is consistent with Lutke's (1997) paradigm shift from "doing to" to "doing with" people with FAS or FAE.

As previously indicated in above discussion related to Study I, peers with FAS or FAE may be one group for their ongoing significant connections. This study highlights the needs, strategies for living, and benefits of friendships among people who have FAS or FAE. Providing opportunities for young people with FAS or FAE to meet, such as through peer support groups, can be beneficial for mutual understanding and emotional and practical support. Human services professionals could provide valuable liaison and resources for these peer support groups. Although it is important that the young people themselves are involved in the ongoing development and activities of these peer support groups, key professional groups such as human services government ministries, schools, and community services organizations should provide funding resources to cover the nominal costs, such as transportation, meeting space and some activities. This study's findings about the value of peer relationships and peer support is consistent with the findings and recommendations of Rutman et al. (2000) and programs such as the FOCUS Employment Program in Burns Lake, British Columbia, which offers "personal management and pre-employment skills" (FAS Connector, 2000, p. 3), to adults with FAS or FAE. The FOCUS program encourages their participants to build "personal support networks" and, among the many skill-building opportunities the program offers, provides communication and personal development/emotional mastery skills support. A vehicle for peer connections includes the program's catering business in which some participants cooperatively train, organise and work. Project evaluation of the program found that peer supports and peer learning have been an important aspect of the program's and participants' positive outcomes (College of New Caledonia Lakes District Campus, 2001).

Supporting Friendships

Peer support groups or other supportive relationships may provide opportunities for, but may also differ from, friendship. Participants' fulfilling experiences of friendship highlights the importance of supporting young people with FAS or FAE in their efforts to meet, develop and maintain friendships with others. Given that this study shows that young people with FAS or FAE are capable of having friendship and that these friendships can be a meaningful part of their lives, parents, family members, human service providers, and others are encouraged to support and foster opportunities for friendships for people with FAS or FAE. This study finds that participants wanted their friendship(s) to be supported and understood from their own experience and perspective. By listening to and understanding the meanings those friendships have for the young person, what they gain from these friendship experiences, and what supports for these friendships they would find useful, we will be better able to support their choices in friendship. Sometimes others, such as parents or service providers, who are concerned about the young person's safety and well being, may have a different perspective about the friendships. They must balance this with the young person's perspective and experience. For example, Lutke (2000) speaks about how she sorted out her feelings and concerns about her son's friendship choices and prioritized what her son got out his friendships:

> We did not always like everything about these friends, particularly the lack of home supervision and some of their attitudes towards school. However, they were not bad kids and we recognized the importance of these friendships to Ken. They meant he had someone to talk to and hang out with. He listened to their advice, and since they were not into illegal activity or drugs or alcohol, that had to be good enough (p. 27).

Moreover, these friendships may be seen by the young person as a source of support that may complement the 'professional' support services for people with FAS or FAE. Education and training services, support services, or mandatory programs such as those in youth justice, should have flexibility to include the resources of the young person's friendship(s), such as Leslie's and Erika's partnership motto "we work best together", as an integral component of program design and delivery.

Further Research Recommendations

In addition to the above discussion of, and recommendations to, the literature in relation to this study, there are some more general areas where this study suggests further research is required.

Perhaps the most unexpected finding of this study is the young adults' experiences of their ruptured relationship with their birth mother, and the significance people with FAS or FAE may place on their birth mother due to the maternal origin and associations of FAS and FAE. This was true for all participants, and while this finding may directly relate to the characteristics of the sample, it bears further investigation. There is a substantial body of literature on attachment (see Ainsworth, 1973, 1993; Bowlby, 1969, 1973) which links the mother-child relationship to the child's development. Ainsworth (1973) defines attachment as, "an affectionate tie that one person… forms between himself and another specific one – a tie that binds them together in space and that endures over time" (as cited in Berger &Thompson, 1995, p. 277). The depth of connection between mother and infant has been shown to be linked to the child's development, in particular the child's development of further relationships (Ainsworth, 1973, 1993; Bowlby, 1969, 1973; Sroufe, Fox, & Pancake, 1983). This study suggests this may be a particularly important area for further study, given that people with FAS or FAE may not only experience ruptures in relationships with birth parents but also that mother and child may have complex emotions related to the development of FAS or FAE. Further exploration and understanding of these issues are important for researchers, practitioners and families.

In addition, friendship literature lacks exploration of, and understanding from, the experiences and perspectives of people with disabilities. More studies are needed to explore friendship experiences, and the meanings friendships have for them, from an increased diversity of young people, including people with FAS or FAE. This would provide more diversity in our basis for knowledge about friendship. This study found thematic similarities to Laursen's (1996) and Mulderij's (1997) findings regarding interdependence within friendship experiences, including reciprocity in caring, helping and support. Further research into this experience of interdependence, including what each person of the friendship regards as interdependent, the commonalities and differences of the friends' experiences, lives and abilities, and how the friends utilise their interdependence in living their lives, may also give further insight into the human values and needs connected with friendship.

Moreover, with some recent influential exceptions, FAS and FAE literature lacks exploration of, and understanding from, the experiences and perspectives of people with FAS or FAE. This study reveals the negative influence of the pathology orientation of FAS and FAE on the life experiences of people with FAS or FAE. People with FAS or FAE need to be recognized and included as valuable informants and participants in the design and conduct of research into FAS and FAE. Their life experiences and insights must be utilised to provide revised explanations of their behaviours, abilities and endeavours. Research issues and interests must also be revised to include examination of, and knowledge about, issues that are of concern to people with FAE or FAE. These may include friendships and peer supports among people with FAS or FAE, improvement of their experience of their birth, adoptive or foster family; improvement of their experience of school; and improvement of their experience of peers and community living.

Final Conclusion

Finally, without understanding young adults with FAS or FAE, from their own perspective, we would not be able to enrich our lives by, as Leslie invites us to, "See me as someone that you'd like to get to know, to talk with and maybe learn something from". We have much to learn from getting to know, working with, and being friends with people with FAS or FAE. This study's seven young adults have given us an understanding of where to start.

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APPENDIX A: CONSENT FORM FOR PARTICIPATION IN STUDY

"Young People With Fetal Alcohol Syndrome/Effects: Experiences, Needs and Support Strategies"

I understand that this research project is exploring the experiences of families affected by fetal alcohol to try to understand your experiences, support needs/strategies. I understand that I will be asked in an interview about my personal experiences and opinions about dealing with issues related to fetal alcohol. I understand that this research is conducted by Brenda Copeland and Dr. Deborah Rutman through the Family and Child Welfare Research Program, a joint program of the School of Social Work, University of Victoria and the Ministry of Social Services.

I understand that my participation is completely voluntary and that I can refuse to answer any question and can withdraw from the interview or study at any time, without giving any reasons.

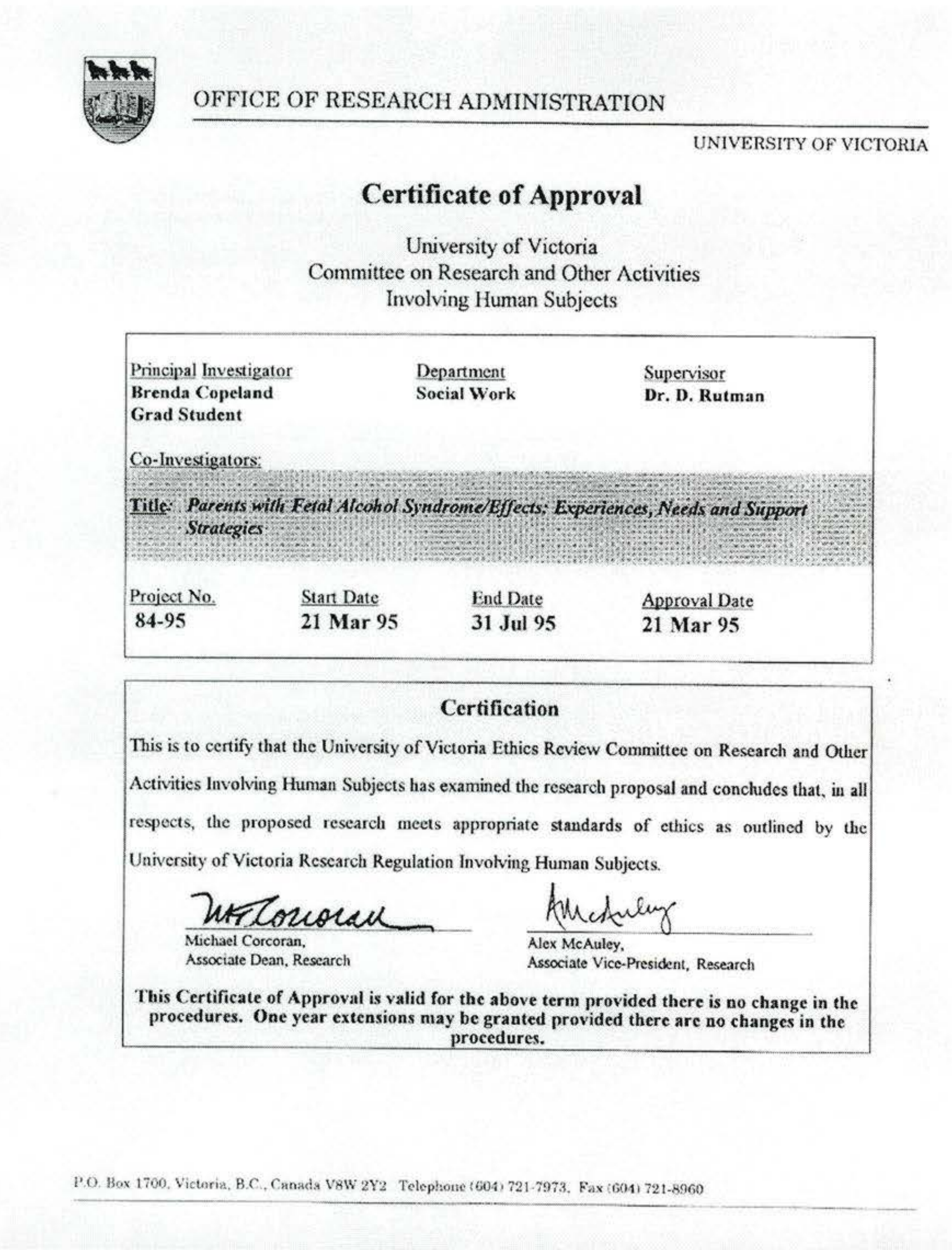
I understand that any data collected in the study will remain confidential. Interview results will be kept in a locked filing cabinet in a locked room and only the researcher will know my name. I understand that anonymity will be guaranteed, and my name will not appear in any research study documents, and that anonymity will be protected by using code numbers to identify the results obtained from individual participants.

I understand that my interview will be audio taped and that the tape will be erased immediately after the interview is transcribed. If they do not want their interview audio taped, I can refuse to do so.

I understand that whether I participate or choose not to participate will have no bearing on my services, job or school and that their workers/employer will not have access to any of the data collected in this study.

Participant:______________________ Researcher:______________________
Date:____________________
As guardian, I consent to ________________'s participation in this study,
Guardian:_______________________

APPENDIX B: CERTIFICATE OF APPROVAL ETHICS REVIEW



OFFICE OF RESEARCH ADMINISTRATION

UNIVERSITY OF VICTORIA

Certificate of Approval

University of Victoria
Committee on Research and Other Activities
Involving Human Subjects

Principal Investigator **Brenda Copeland** **Grad Student**	Department **Social Work**	Supervisor **Dr. D. Rutman**

Co-Investigators:

Title: ***Parents with Fetal Alcohol Syndrome/Effects: Experiences, Needs and Support Strategies***

Project No.	Start Date	End Date	Approval Date
84-95	**21 Mar 95**	**31 Jul 95**	**21 Mar 95**

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and Other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulation Involving Human Subjects.

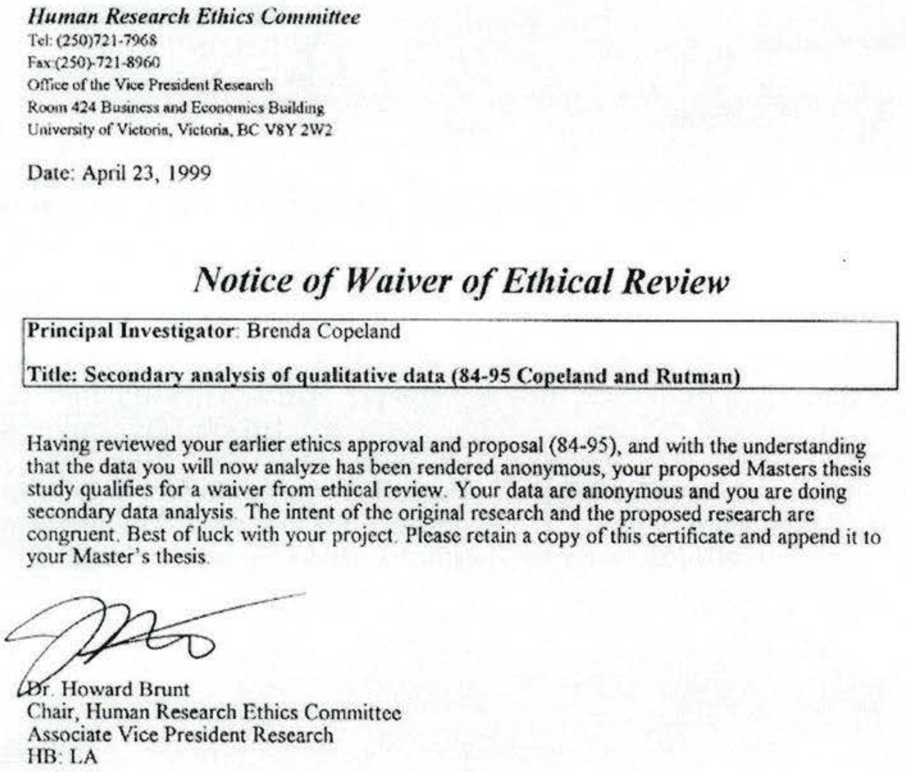
M.F. Corcoran
Michael Corcoran,
Associate Dean, Research

AMcAuley
Alex McAuley,
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. One year extensions may be granted provided there are no changes in the procedures.

P.O. Box 1700, Victoria, B.C., Canada V8W 2Y2 Telephone (604) 721-7973, Fax (604) 721-8960

APPENDIX C: NOTICE OF WAIVER OF ETHICAL REVIEW



Human Research Ethics Committee
Tel: (250)721-7968
Fax:(250)-721-8960
Office of the Vice President Research
Room 424 Business and Economics Building
University of Victoria, Victoria, BC V8Y 2W2

Date: April 23, 1999

Notice of Waiver of Ethical Review

Principal Investigator: Brenda Copeland

Title: Secondary analysis of qualitative data (84-95 Copeland and Rutman)

Having reviewed your earlier ethics approval and proposal (84-95), and with the understanding that the data you will now analyze has been rendered anonymous, your proposed Masters thesis study qualifies for a waiver from ethical review. Your data are anonymous and you are doing secondary data analysis. The intent of the original research and the proposed research are congruent. Best of luck with your project. Please retain a copy of this certificate and append it to your Master's thesis.

Dr. Howard Brunt
Chair, Human Research Ethics Committee
Associate Vice President Research
HB: LA

VITA

Surname: Copeland Given Name: Brenda Copeland

Place of Birth: Nanaimo, British Columbia, Canada

Educational Institutions Attended:
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Degrees Awarded:

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Campbell, M., Copeland, B., & Tate, B. (1998). Taking the standpoint of people with disabilities in research: Experiences with participation. Canadian Journal of Rehabilitation, 12(2), 95-104.

Copeland, B., Armitage, A., & Rutman, D. (1996). Preparation for responsible community living. In B. Galaway & J. Hudson (Eds.). Youth in transition: Perspectives on research and policy. (pp. 270-275). Toronto: Thompson Educational Publishing.

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Title of Thesis: Searching for, Finding, and Experiencing Friendship: A Qualitative Study of Friendship Experiences of Seven Young Adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects.

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Brenda Maureen Copeland
July 03, 2001