

**Parents And Teachers Perceptions Concerning Education For Children With Fetal  
Alcohol Syndrome**

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**Parents And Teachers Perceptions Concerning Education For Children With  
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**BY**

**Toni Cascegna**

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

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**ABSTRACT**

Appropriate educational placement, and the combined supportive efforts of parents and teachers for children with Fetal Alcohol Syndrome (FAS), may make all the difference in their success. FAS is a permanent birth defect condition due to the effects of alcohol consumed prenatally and many of the children as a result, require special educational services due to significant learning disabilities, emotional, and behavioural difficulties.

The current qualitative study consisted of four in depth interviews; one foster parent and one adoptive parent who both have children with Fetal Alcohol Syndrome/Fetal Alcohol Effects, and the two respective educators who teach their children. Findings suggest that parents and teachers report similar behavioural, cognitive, and socio-emotional characteristics for these children as described in the literature (e.g., impulsiveness, and inability to understand abstract concepts). Teachers, and parents especially, were very supportive of teaching these children practical skills and social skills rather than academics at school. Three parents and 1 teacher also felt that current educational funding guidelines in Manitoba were not specific enough for children with FAS and as a result, makes it difficult to obtain appropriate supports needed to assist these children at school (e.g., paraprofessional assistance). In addition, very strong themes of advocacy and "goodness of fit" between the home and school were also found.

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## **Chapter I**

### **INTRODUCTION**

Children born with Fetal Alcohol Syndrome present a growing concern in Manitoba not only for caregivers, but educators as well. Statistics from the Canadian Centre on Substance Abuse show that Manitoba is requesting twice as much information on FAS/FAE per capita as the rest of Canada (MB FAS News, 1996/1997).

Fetal Alcohol Syndrome (FAS), and Fetal Alcohol Effects (FAE), are permanent medical conditions characterized by cognitive and behavioural dysfunction, a unique cluster of minor facial anomalies and prenatal or postnatal growth retardation resulting from heavy maternal alcohol consumption (Astley & Clarren, 1996). Our education system is only beginning to understand its implications in the classroom and it's a continuous challenge for teachers and caregivers to be able to meet the daily academic, behavioural and socio-emotional needs of these children. The intent of this study was to interview parents and teachers of children with FAS who could provide a more in depth look at the situation from a personal perspective.

## Prévalence

The true incidence of FAS is not accurately known due to milder cases (i.e., FAE), never being recognized (Chudley, 1991). It is currently estimated that 1-3 per 1000 live births in the western world is affected with FAS (Astley & Clarren, 1996), and one in 350 live births is affected with FAE (Gerring, 1992). The estimated incidence of FAS for the rest of the world is 0.08 per 1,000 live births (Abel & Hannigan, 1995).

There are currently no published Canadian statistics, however, American Indians and Aboriginal peoples of Canada are reported to be at very high risk for FAS (Burd & Moffatt, 1994). A study completed by Chudley and Moffat (1996), to determine the prevalence of clinically recognizable FAS/FAE in a Northern Manitoba community, indicated that approximately 10% of its school age population was affected by alcohol exposure. Chudley and Moffat made it clear that "this must have an enormous impact on both the educational system and community development".

## Fetal Alcohol Effects (FAE)

Many children with FAE go undetected in the education system due to the subtle characteristics of the syndrome. Children who are born to mothers who have consumed alcohol during pregnancy but do not fully meet the criteria for FAS

are termed FAE (or more currently termed Alcohol Related Effects). Children with Fetal Alcohol Effects may display many of the behavioural and learning difficulties of the FAS child (since the brain and central nervous system are highly affected by alcohol throughout pregnancy), but their growth and development may be near normal and they may not exhibit many of the typical facial features of the FAS child.

It is these children that often go misdiagnosed in the education system due to similar characteristics with other disorders (e.g., Attention Deficit Hyperactive Disorder) and/or the seemingly normal functioning level of many of these children. Fetal Alcohol Effects *is not* the lesser form of FAS, rather a child with FAE does not have all of the physical abnormalities of FAS. The cognitive and behavioural characteristics of FAS and FAE are similar. Therefore, alcohol "affected" children can also present with serious implications for educators and should not be ignored (Burgess & Streissguth, 1990).

How does alcohol affect the fetus?

While facing the challenge of educating children with FAS/FAE, we must also direct our efforts toward preventing the disorder from occurring in the first place. Since FAS/FAE is a *preventable* disorder, many expecting parents need to be warned of the dangers of drinking while pregnant.

There is a positive correlation between the incidence and severity of FAS and increasing daily alcohol consumption (Chudley, 1991). Heavy drinkers have a 30% to 50% chance of having children with FAS. Consumption of 2 to 4 ounces of hard liquor or 2-4 glasses of wine per day leads to a risk of FAS of 10% while lesser amounts may lead to more subtle adverse effects on fetal central nervous system development and/or function. It is also important to note that peak blood alcohol levels rather than total amount of alcohol consumption may represent the "critical dose" of alcohol above which an adverse effect may be detected (Becker, Randall, Salo, Saulnier, Weathersby; 1994). In other words, drinking large amounts of alcohol (or binge drinking), in a short period of time would increase the peak blood alcohol level faster than sipping on a glass of wine all evening.

An important characteristic concerning the pattern of effect that alcohol has on the developing embryo is the timing of alcohol exposure during pregnancy. Numerous studies have shown that the specific birth defect that occurs depends on the system(s) in the fetus undergoing development at the time of alcohol exposure (Becker et al.; 1994). Therefore, if there is alcohol exposure to the fetus during the time when the kidneys are developing, the kidneys may undergo some physical damage.

### **Associated Difficulties For the Child With FAS/FAE**

Not only are children with FAS/FAE faced with the cognitive and behavioural challenges that parents and teachers must adapt to, but many children diagnosed with FAS/FAE often have medical problems associated with the disorder such as; congenital heart disease, neurosensory deafness, and kidney defects. Visual deficits, typically nearsightedness and impaired visual acuity, are also common among children with FAS/FAE and can have substantial effects on learning if not diagnosed early (Becker et al., 1994). Children with FAS also show a high prevalence of hearing impairment related to the structural damage of the ear during its development. Furthermore, these children have a wide range of balance and motor coordination deficiencies, including problems with balance and gait and deficits in both gross and fine motor function which inevitably have impacts at home and in the classroom regarding their management.

There are numerous disorders that tend to overlap with FAS/FAE or can be mistakenly diagnosed instead of FAS/FAE. These include; Attachment Disorder, Attention Deficit/Hyperactive Disorder, Autism, Language-Learning Disorder, Oppositional Defiance Disorder, and Sensory Integration Dysfunction (Malbin, 1995). As well, when a child with FAS/FAE encounters difficulties with their ability to learn or socialize, they may develop secondary behavioural characteristics and/or defense mechanisms in order to deal with these difficulties (Malbin,

1995). Some of these behaviours include: defiance, withdrawal, low self-esteem, dependency, avoidance, fear, and isolation. Although these behaviours may be seen as intrinsic to the child with FAS/FAE, they are usually acquired over time and add to the challenge parents and teachers must face in meeting the needs of a child with FAS on a daily basis.

As children with FAS/FAE become adolescents and then adults, other secondary problems may occur such as: substance abuse, mental illness, school problems, troubles with the law, and homelessness. These potentially harmful secondary effects highlight the importance of early identification with the child who has FAS/FAE so they can be prevented or at least anticipated. Understanding that these children with FAS/FAE display particular behaviours and learning problems due to neurological impairment rather than intent, should facilitate greater understanding and compassion, and appropriate intervention with them both at home and school.

### Research Proposal

The purpose of this study was to explore the opinions of parents and teachers regarding some common behavioural, learning, and social issues of children with FAS/FAE. The drastic rise in the incidence of FAS/FAE, and the particular risk to our Native population is a significant issue for our education

system. The consequent lifetime impairment of the ability to function mentally, physically, and socially, is of particular concern to educators who must face the reality of serving these children in our schools. Common issues that are characteristic of these children include poor adaptive behaviours according to parents, and impulsivity, poor attention, and difficulty making transitions according to teachers (Burgess & Streissguth, 1990). Parents and teachers also note such problems as stealing, lying and inappropriate social interactions. As well, the combination of poor self-control and inadequate communication skills creates problems that leave teachers, parents, and students feeling frustrated and helpless.

An investigation of what parents and teachers feel should be the major focus of these children's school day was also of interest (i.e., academics or practical skills). Since many of these children are unable to understand many of the abstract concepts of such areas as math and history, it seems parents and educators must decide at what point the implementation of practical/life skills and social skills is necessary in order to foster individuals who will be functional adults as well as integral parts of their communities in the future. It was felt that their input would provide a first hand look at these issues, as well as ones that are not discussed in the literature (e.g., the time and effort spent in advocating for these children).

The research questions in this study include:

- Are descriptions of behavioural, cognitive, and socio-emotional characteristics by parents and teachers similar to those found in the literature?
- What efforts are expended on the part of parents and teachers in advocating and seeking supports for these children both in and out of school?
- What are some of the emotional aspects of raising/teaching a child with FAS/FAE?
- How do parents and teachers view the significance of academics versus practical skills and social skills in the classroom?



## **Chapter II**

### **LITERATURE REVIEW**

Although the literature on FAS/FAE reflect many of the behavioural and socio-emotional characteristics these children present, studies are only beginning to reflect an understanding of how these children with FAS/FAE learn best at home and in the classroom. There are no longitudinal studies to date describing the effectiveness of various programming strategies, so much work has relied on the observations and opinions of the caregivers and teachers who deal with these children on a daily basis. Various researchers discuss the importance of teaching these children practical skills (e.g., shopping), and socio-emotional skills (e.g., effective problem solving and communication skills) both at home and in the classroom (e.g., Burgess, 1994).

As well, there was no literature found that describes the efforts by parents and teachers to advocate and seek supports for these children both in and out of the classroom and the successes or failures they had in doing so. Another area of interest in this literature review that was unavailable, was to find other qualitative studies which reflect the more personal challenges and triumphs of parents and teachers in their efforts with these children. One main goal of this study was to describe such.

The focus of this literature review will be to describe what some common

academic, behavioural and socio-emotional characteristics are for children with FAS/FAE and what some proposed strategies are to effectively deal with them. As well, a look at *what* and *how* we should be teaching these children at home and in the classroom from the perspectives of caregivers and teachers will also be highlighted. One objective of this study was to interview caregivers and teachers to determine if their perceptions were similar or dissimilar to what the literature describes, as well as determining if there were any other interesting approaches or perceptions they could offer.

#### Behavioural and Achievement Characteristics Associated with FAS/FAE.

Behaviour and learning problems have been reported for all ages of individuals with FAS/FAE (Becker et al., 1994). It is difficult, however, to determine whether specific behavioural effects are actually due to alcohol exposure in the child, as many secondary environmental and emotional factors (e.g., anxiety), come into play when determining the origin of a problem (Coles, 1994). Despite the challenge in drawing conclusions from behavioural effects, some relationships can be observed. Early, heavy alcohol exposure during pregnancy, leads to the most severe outcomes and is associated with mental retardation, sensory deficits, and motor problems. Less extensive alcohol exposure may result in learning disabilities and attention problems, more subtle characteristics of the

syndrome. Regardless of where the child falls on the continuum, these deficits enter the home and/or educational environment and ultimately have the potential to create obstacles in many areas (i.e., learning and social situations).

Scientific studies have demonstrated that alcohol exposure during any part of pregnancy appears to be associated with poorer academic achievement of the child so affected (Coles, 1994). Coles reported that exposure in the third trimester was particularly associated with lower achievement scores and even though the I.Q. levels of many of these children fall within normal range, they still require special educational attention (Aase, 1994).

Functional skills of persons with FAS/FAE are also often classified in terms of chronological age and intellectual ability (Burgess & Streissguth, 1990).

Parents report much poorer adaptiveness based on educational assessments and vocational outcomes are usually poor. A large problem often is that there is a marked discrepancy between seemingly high verbal skills (e.g., the ability to have a conversation with someone), and the inability to communicate effectively (e.g., to understand social boundaries). The combination of the latter makes it very difficult for educators and families to teach social skills to these children.

Behaviourally, in the earlier years of school, children with FAS/FAE are frequently diagnosed with Attention-Deficit Hyperactivity, due to excessive hyperactiveness, short attention span, and poor short-term memory (Landesman-

Dwyer et al., 1981; cited in Aase, 1994). In addition, these children may present constant behavioural challenges in the classroom including; running around, climbing, and running into things (Project Care Newsletter, 1992), as well as aggressive outbursts. Unfortunately, it is usually only those children who aggressively act out that receive special supports (e.g., paraprofessional assistance), not for learning or socio-emotional issues however, but rather for safety issues in the classroom.

Additional behavioural problems observed in children exposed prenatally to alcohol, include: perseveration (repetition of a mental activity with an inability to switch to another activity), poor balance and co-ordination, difficulty in walking, and the inability to concentrate or to learn from past experiences (Becker et al., 1994). Socially, these children may exhibit poor judgement; particularly involving boundary issues with others (Gerring, 1992). Some children may seem to lack attachment with significant others, yet they run up to total strangers with affection. This behaviour has the potential to put them at greater risk for abuse of all types (e.g., sexual abuse).

As the child grows older and continues into later grades, progress is further hindered due to inadequate communication skills, impulsivity, and further difficulties with social interactions (Aase, 1994). Adolescents may exhibit poor judgement, trouble with abstract thinking, and limited problem-solving skills.

Many at this stage drop out of school only to encounter greater difficulties in trying to integrate into society. It has been reported that many of these individuals eventually have trouble finding and holding jobs due to their unreliability, lack of social skills, and lack of ability to maintain interpersonal relationships.

It is quite evident that there are serious consequences involved when we do not intervene early with these children. As well, the enormous amount of behavioural and socio-emotional challenges these children display raises the question of how much focus we should be placing in the classroom on programming that effectively deals with these issues.

#### What Should We Teach These Children?

Burgess (1994), states that until support for the efficacy of specific educational programs becomes available, it is very important to draw on the observations of educators and families with children affected by FAS/FAE, as well as other professionals who work in the area (e.g., psychologists and social workers). Burgess suggests several basic principles for educating these children based on personal expertise as well as parental and teacher perceptions.

In addition to academics, it is very important that we begin early to teach these students such functional skills as social interacting, problem solving, and decision making if we are to foster independent development in areas such as home

and work (Burgess, 1994). It is suggested that this functionality may be fostered by such things as offering an elementary child more physical involvement and planning community field trips to learn more about "real life" things. In high school, such tactics may include designing on-the-job training opportunities. Community based curricula are important and individuals with FAS/FAE should be able to have opportunities to practice new skills in situations in which they will use them, such as using money in the grocery store (Burgess & Streissguth, 1990). Burgess also stresses that the key is to make programs fit the needs of students rather than force the student into the confines of a certain program.

It is also very important to recognize that due to their organizational and problem-solving deficits, these individuals should not be labeled as lazy or unmotivated when certain expectations can not be reached (such as not finishing an essay). These characteristics are biological limitations of the individual with FAS/FAE and great care should be given by educational teams to balance the process of clear expectations with the opportunity for success. Educators and families should also be leery of programs that claim to fulfil all the needs of these children in one curriculum. Individuals with FAS/FAE vary greatly in their strengths and weaknesses and are all unique in their needs which means programs should be tailored to each situation.

A major focus of education should also be effective communication

(Burgess & Streissguth, 1990). Many of these individuals vary in these skills from apparently normal language to no verbal communication at all. Teachers must learn to recognize their students' communicative attempts (including facial expressions and body language), because without effective verbal language, these students will eventually learn to communicate in other ways (e.g. behaviourally). Programs should also view communication as "all the verbal, written, gestural, and behavioural skills that allow an individual to participate in a social environment" (pp. 3). Students need to be taught how to effectively communicate their needs to others and these skills should be developed in the context of social skills instruction. Burgess and Streissguth (1990), feel that since both are inseparable and essential sets of skills to live and work in the community, they should be major components of the educational process from pre-school through high school.

Burgess (1994), also stresses the importance of recognizing that challenging behaviours (e.g., stealing, lying, and sexual inappropriateness), are forms of communication. Parents and educators may become frustrated when punishment does not seem to work and often the behaviour is repeated with a seemingly lack of remorse and understanding of consequences. Communicative intent may be the key when planning behavioural intervention as these children may be expressing misunderstanding of rules or forgetfulness. Rather than punishing children for behaviours, parents and educators can teach them positive

skills relating to judgement and impulse control. For example, if a child tears up his/her work because it is too hard, they can be taught to ask for help instead. Consequences of their inappropriate behaviours should be a result of their poor choices in the first place and not on the actual behaviour. Therefore, the child who tears up his/her work would be consequenced not for tearing up the work, but for not asking for help when he/she needed it.

When living or working with a child who has FAS/FAE there are four strategies that can be implemented at all times to ensure manageability and promote positive developmental skills (Interagency FAS/FAE Program). Firstly, structure is important for these children. To provide consistency, one should reduce choices, prearrange environments to fit children's needs, and prepare them in advance for any changes that will occur. One should structure the environment around the child and change it so the *child* can function better (e.g., physical structures, and expectations of people around them). Secondly, less talk, and more visual/kinesthetic learning opportunities are beneficial. One should provide lots of visual cues and ask questions to ensure children understand what has been said to them. Thirdly, be concrete and do not assume anything. Children with FAS/FAE have difficulties generalizing and have poor problem solving abilities. Fourthly, be aware of the "time bombs". One should watch for over stimulating environments and difficult periods in the day to ensure the child does not become overwhelmed



and act out as a result of frustration. These are some useful key points to remember that has shown to be useful in the overall management of children with FAS/FAE according to the Interagency FAS/FAE Program in Winnipeg.

The current study will attempt to provide a more personal, first hand look at what 2 caregivers and 2 educators perceive as important issues regarding the children with FAS they deal with. The individual interviews reflect not only issues surrounding similar academic and behavioural programming needs for these children as described in the literature, but also the struggles each face with the education system (e.g., gaining paraprofessional assistance and appropriate training for staff), and the personal feelings of both frustration and devotion it takes to be able to meet their children's needs.

### **Chapter III**

## **RESEARCH METHODS AND DESIGN**

### **Population Sample**

A letter was sent to the Program Co-ordinator at the Interagency Fetal Alcohol Syndrome Program requesting assistance to identify 8-10 parents and 8-10 teachers who could be contacted to request their participation in the study (see Appendix A). The Program Co-ordinator works closely with teachers and parents of children with FAS/FAE and had volunteered to seek out participants for this study. Upon receiving a list of volunteers and their confirmation of participation from the Program Co-ordinator, interview appointments were set up and letters outlining the study and consent forms (see Appendix B and C) were sent out. Due to time constraints, only 2 parents and 2 teachers were able to participate in the study.

Participants included one adoptive parent, Norma Daun (pseudonym), and one foster mother, Jada Jones (pseudonym), who had children with FAS, and the two respective female teachers who taught them, Louise Fraber and Jane Braidmon (both pseudonyms). Both children; "Sophia" (pseudonym); 10 and "Kala" (pseudonym); 8, were diagnosed with FAS. Sophia had lived with her adoptive mother Norma since she was 5 and was in a segregated behaviour

program with paraprofessional assistance at the time of the interview. Kala had lived with her foster mother, Jada since she was less than 1 year of age and was in a regular kindergarten-grade 1/2 classroom with paraprofessional assistance at the time of the interview as well. This was Kala's teachers' first year teaching a child with FAS and Sophia's teacher had worked with her in the past.

### Data Collection

This research was conducted by using an interview questionnaire devised by the researcher and the Program Co-ordinator from the Fetal Alcohol Interagency Program of Winnipeg (as no related questionnaire could be found in past research) in order to interview parents and teachers individually (see Appendix D). It was originally intended that separate focus groups would be conducted with parents and teachers in order to generate topics and concerns that could then be organized into a more relevant questionnaire for individual interviews. The focus groups were not performed due to the end of the year time constraints for teachers (an important time to avoid in future research), as well as the unwillingness of parents to discuss these issues in front of others. Therefore, questions were chosen based on current issues for parents and teachers who are involved with these children according to what the literature made reference to (e.g., what we should be teaching these children in school), and based on issues

that have come up between the Program Co-ordinator, and parents and teachers in the past (e.g., "what do you feel are the top three educational needs of your child/student?" and "what do you feel is the greatest challenge in teaching/living with this child?"). Questions were also included to reflect personal feelings and opinions (e.g., What are your hopes for your child/student?). The questionnaire was developed to provide a systematic guide in the interview process but may also be used in future research for larger interview samples.

### Participation

Participants were interviewed for approximately 1 hour 45 minutes (Kala's foster mother at her home), 1 hour 30 minutes (Sophia's mother at her home), 1 hour 35 minutes (Kala's teacher at her school) and 55 minutes (Sophia's teacher; over the phone). Due to time constraints for Sophia's teacher, a phone interview was arranged as per her request. Each interview was guided by the questionnaire, and participants were also encouraged to discuss any issues that they felt were to be important (e.g., personal feelings). Each session was tape recorded (with written consent from the participant), in order to better analyze themes at a later time. All tapes were destroyed after transcription and pseudonyms were used for all participants and other individuals they were talking about. Each participant was also given a gift of appreciation for their participation.

## Data Analysis

Upon completion of the interviews, all were transcribed for analysis.

Firstly, each transcription was analyzed for the basic responses to the questions asked in the interview in order to compare similarities and differences in responses of parents and teachers afterwards. Each transcription was then analyzed by compiling the number of themes throughout (e.g., seeking community supports and advocating for segregated programs), and then clustered for more general and larger themes thereafter (e.g., advocacy). Each transcription was analyzed not only for information regarding the questions asked in the interview, but also for non-verbal information (e.g., defensiveness), and any issues that may have surfaced beyond the questionnaire format (e.g., personal feelings about parenting). The latter part will be discussed in more detail in the "discussion" part of the study. The second part of the analysis compared the parent and teacher of the same child for any similarities or differences in opinions/themes regarding questions asked on the questionnaire, taking into consideration all of the above factors in the initial individual analyses (e.g., desirability factors).

## **Chapter IV**

### **RESULTS**

#### **Theme and Cluster Analysis**

The following analyses consist of four separate analysis of the themes found in each of the four individual interviews. Following each theme will be the number of times each theme was identified throughout each interview. The themes were then further re-grouped to identify clusters of themes within each interview, and a discussion describing the findings and comparing them between the parent and teacher of the same child follows.

#### **Parent Interview #1 (Kala's Foster Mother)**

The interview with Jada Jones was informative and her nature seemingly caring. She appeared genuine and honest in her remarks and her dedication to meeting the needs of her foster child and her ability to discuss questions or concerns were elaborative and seemingly uninhibited. Kala had lived with the Jones' since she was an infant and their commitment to this child was strong. This was also reinforced by comments of the like by Kala's teacher (e.g., "she's become a real advocate for these kids"), and indicated to me that her attempt to advocate for Kala in numerous ways during the interview were likely reflections of her

advocacy outside the interview situation as well.

**Table 1**

Cluster and themes for parent interview #1A

	<b>Number of Responses</b>
<b>Cluster 1: Advocacy</b>	<b>41</b>
<b>Themes:</b>	
a) Increased education on FAS/FAE (e.g., for staff and other professionals working with these children)	11
b) Qualified and direct supports in class (e.g., paraprofessional aide)	13
c) Life skills and social skills training for Kala (e.g., shopping independently)	4
d) Segregated classrooms	5
e) Administrative/divisional supports (e.g., for increased funding)	8

In Table 1, advocacy was the strongest cluster throughout the interview for this foster parent (34% of total interview responses). Advocacy is defined here as "the act of pleading a cause". Jada advocated highly for "qualified and direct supports" in the classroom for not only Kala, but all children with special needs and stressed the importance of this for the success of these children (32% of cluster responses). "Increased education on FAS/FAE" for not only teachers, but all professionals working with these children was also reinforced repeatedly (27% of cluster responses). She felt that many professionals working in the school system with FAS/FAE children were not adequately trained to teach academic

basics to them and were not aware of the social, behavioural, and socio-emotional aspects of these children adequately enough to help them succeed through the academic years. Advocacy for social/lifeskills training (10% of cluster responses), segregated classrooms (12% of cluster responses), and obtaining divisional support (20% of cluster responses), were relatively less important in contrast to providing Kala with well educated and adequate supports in the classroom (e.g., full time paraprofessional aid).

**Table 2**

Cluster and themes for parent interview #1B

<b>Cluster 2: Proactive Themes:</b>	<b>Number of Responses</b>
a) In seeking community supports (e.g., from Society of Manitobans with Disabilities for management strategies for children with FAS)	8
b) In meeting Kala's academic needs (e.g., by communicating with teacher regarding abilities)	5
c) In gaining financial support (e.g., specifically level 2/3 funding for para professional assistance in class)	3
d) To educate staff/others/self about FAS and Kala (e.g., sending paraprofessional to an FAS workshop)	9

In Table 2, proactiveness was a moderately strong cluster in the interview (20.5 % of total interview responses). Proactiveness is defined as "in favor of



promoting change". Jada was very proactive in the persual of educating not only herself, but the educators around Kala in the school system (36% of cluster responses), including taking Kala's paraprofessional aid to an FAS workshop paid in full. Jada was also proactive in her persual of community resources (e.g., Society for Manitoban's with Disabilities) in seeking information and assistance in dealing with a child with FAS (32% of cluster responses). Jada's proactive efforts were also focussed on meeting Kala's academic (20% of total cluster responses) and funding needs (12% of total cluster responses). The latter two however, seemed secondary to the pursuit of educating herself and those around her in being able to understand, empathize and meet the needs of her foster child.

**Table 3**

Cluster and themes for parent interview #1C

	<b>Number of Responses</b>
<b>Cluster 3: Personal Rewards/Challenges for Parent Themes:</b>	<b>25</b>
a) In regards to Kala (e.g., personal feelings towards raising her)	15
b) For herself as a foster parent (e.g., being labeled as a "foster" parent)	10

In Table 3, Jada was also reflective in her personal feelings of rewards and challenges with Kala and being a foster mother (20.5% of total interview responses). Although Jada had encountered many trials and tribulations with the

education system in trying to meet the needs of her foster child, she was generally quite positive about fostering Kala and felt she was a positive addition to her family's life. She commented on how Kala's "love of life" made fostering her all worth it (60% of total cluster responses). Jada also described many of the "real" challenges she faced on a daily basis with Kala, herself, and the supports around her (40% of total cluster responses). Among some of the challenges included: trying to manage a household of 4 special needs foster children, dealing with the struggles of limited access to medical/social services information about Kala, and trying to decrease ignorance in society about foster parents "not really knowing anything about these children".

**Table 4**

Cluster and themes for parent interview #1D

	<b>Number of Responses</b>
<b>Cluster 4: Goodness of Fit Between Home and School</b>	<b>31</b>
<b>Themes:</b>	
a) Match between school and home/Kala (e.g., parent feels school is meeting Kala's academic/social needs)	12
b) Mismatch between school and home/Kala's needs (e.g., instructional and social needs in previous school settings)	19

In Table 4, "goodness of fit between home and school" was the second strongest cluster throughout the interview (25% of total interview responses).

Much of the discussion centered around how the education system and its professionals "were or were not" meeting the educational, socio-emotional, and behavioural needs of Kala. Jada seemed to feel very positive about Kala's current school and supports that were in place (39% of total cluster responses were a match between home and school). Among some of her comments, she felt the paraprofessional was highly knowledgeable and "in tune" with Kala's needs and that the teacher was very accepting. She also felt that both kept a good line of communication open between themselves as well as with Jada (e.g., with the use of a daily communication book).

Jada more strongly reflected on how the education system had failed not only her and her foster child, but also a majority of special needs children in the system (61% of total cluster responses were a mismatch between home and school). Not only did Jada face numerous challenges at the classroom level (e.g., prior teacher's who would not adapt to Kala's learning needs), but also at the administrative and divisional level (e.g., fighting the division to exercise her right to school of choice for Kala). Jada felt she knew what it took to help Kala "be the best she could be" outside her home environment (e.g., low stimulation environments and constant repetition of instruction) and aside from the current paraprofessional and school, it was a constant battle trying to get others to take a vested interest as well.

**Table 5**

Cluster summary for parent interview #1

<b>Cluster</b>	<b>Total Response (out of 122 total)</b>	<b>Weight of Response (% out of 100)</b>
<b>1. Advocating</b>	<b>41</b>	<b>34</b>
<b>2. Proactive</b>	<b>25</b>	<b>20.5</b>
<b>3. Personal rewards/challenges</b>	<b>25</b>	<b>20.5</b>
<b>4. Goodness of fit between home and school</b>	<b>31 (12-"match") (19-"mismatch")</b>	<b>25</b>

Table 5 summarizes the clusters, their totaled responses in each one, and their weight of response throughout the interview with Jada Jones, Kala's foster mother. "Advocating" was the strongest cluster for this foster parent (34%), followed by the "goodness of fit between home and school" (25%), and then followed equally by "proactiveness" (20.5%) and the "personal rewards/challenges" of fostering Kala (20.5%).

**Teacher Interview #1 (Kala's Teacher)**

The interview with Jane Braidmon was less relaxed than with Jada Jones'. I had to alleviate Jane's concerns for confidentiality and had to clarify that I was not there to learn more about FAS literally, but to simply hear about her

experiences as a teacher to Kala. Despite these concerns, Jane was reasonably relaxed throughout the interview and was able to answer for the most part, in elaborative detail in response to the questions asked.

**Table 6**

Themes and clusters for teacher interview #1A

	<b>Number of Responses</b>
<b>Cluster 1: Advocating Themes:</b>	<b>27</b>
a) FAS/FAE education (e.g., taking workshops on FAS for herself)	7
b) For special supports (e.g., funding for Kala in the classroom)	10
c) Independence for FAS/FAE children (e.g., teaching Kala life skills)	10

In Table 6, "advocating" was the strongest cluster in this interview (35% of total interview responses). Kala's teacher advocated equally highly for obtaining "special supports" and fostering "independence for FAS/FAE children" (37% for both of total cluster responses). Special supports and fostering independence included things like: more stable funding for the classroom to obtain paraprofessional assistance and teaching children with FAS/FAE the proper social skills to cope and make them feel successful as individuals; respectively.

Kala's teacher also advocated for increased education by the division on FAS/FAE for those educators working with children like Kala, especially herself (26% of total cluster responses). Although her attitude about special needs

children was positive and adapting in the classroom, she felt unprepared with the knowledge she thought she needed to truly understand how to be able to teach these children. Therefore, she was attending workshops and consulting with others in order to be able to feel more knowledgeable in the area, but she did feel the school division should better prepare teachers for incoming special needs student before hand.

**Table 7**

Cluster and themes for teacher interview #1B

	<b>Number of Responses</b>
<b>Cluster 2: Professional Growth</b>	<b>18</b>
<b>Themes:</b>	
a) Persual of learning Kala's needs in the classroom (e.g., through observation in class)	11
b) Awareness of cognitive/physical limitations of children with FAS/FAE (e.g., long term memory deficits)	7

In Table 7, "professional growth" constituted 23% of total interview responses. Although Jane felt the division had not prepared her to meet the educational needs of Kala, she was quite compelled to persue such on her own. "Persual of learning Kala's needs in the classroom" included such strategies as classroom observation to figure out what worked best to provide an optimal learning environment for Kala (61% of total cluster responses). For example, by allowing Kala to wander slightly during story time allowed Kala to cope with her

impulsive tendencies (i.e., lack of ability to stay seated for a whole story), while still noting she had understood some of the story along the way (e.g., Kala could answer questions about the story afterwards).

"Awareness of cognitive/physical limitations of children with FAS/FAE" was the least weighted theme of this cluster (39% of total cluster responses). However, Jane had learned in the past year working with Kala, of the specific deficits Kala had and was learning to adapt her teaching style to them. For example, she knew Kala had difficulty with abstract concepts, therefore when it came to teaching the history section on "Long Ago" she would simply provide her with other learning materials that were related, but more easily comprehensible to compensate.

**Table 8**

Cluster and themes for teacher interview #1C

	<b>Number of Responses</b>
<b>Cluster 3: Empathy</b>	<b>7</b>
<b>Themes:</b>	
a) <b>Admiration for foster parent's efforts in raising Kala (e.g., feels parent endures a lot to manage at home)</b>	<b>5</b>
b) <b>Hopes Kala will be a productive adult in the community (e.g., as an adult helping other children with FAS)</b>	<b>2</b>

In Table 8, "empathy" was the least weighted cluster in this interview (10%

of total interview responses). Empathy is defined here as "imaginative apprehension of another's condition". Jane's "admiration for foster parent's efforts in raising Kala" constituted 71% of total cluster responses. She noted on several occasions her admiration for Jada's efforts to provide for Kala and empathized with the struggles that came along with those efforts (e.g., always battling the school system, as well as the day to day managing of a child with such high special needs).

Jane's hopes that Kala will be a productive adult in the community was also a theme in this cluster (29% of total cluster responses). She projected her hopes for Kala in the future and felt that with adequate supports and understanding, Kala could be a successful and emotionally healthy adult (e.g., Kala could one day work with other FAS/FAE children).

**Table 9**

Cluster and themes for teacher interview #1D

	<b>Number of Responses</b>
<b>Cluster 4: Goodness of Fit Between Home and/among School Themes:</b>	<b>24</b>
a) Match between:	
i) School meeting teacher's educational needs (e.g., sending her to workshops)	3
ii) Kala's safety/social/ current funding needs (e.g., Kala is accepted by staff and peers)	14
b) Mismatch between school not meeting:	
i) Kala's special educational needs (e.g., funding is only based on safety issues and not educational needs)	4
ii) Teacher's educational needs (e.g., feels staff should be better trained)	3



In Table 9, "goodness of fit between home and/among school" was the second strongest cluster in this interview (32% of total interview responses). Goodness of fit in this study is defined as "one's perception of whether or not there is a satisfactory meeting of expectations between the home and/or within school systems". In contrast to Kala's foster mother, Jane felt more strongly about the school being able to meet her needs as well as Kala's (71% of total cluster responses were a "match between home and school"). She felt that although unprepared to accept a special needs child in the classroom, the division did support her efforts to seek out the information she needed (e.g., attending workshops). A stronger theme was Jane's comments on how the school was trying to meet Kala's safety, social, and current funding needs. For example, she felt that due to heightened awareness and education of students and the community at large, Kala's peers in the classroom were very accepting of her. Jane also felt that due to the current funding in place, the instructional assistant was able to provide the necessary safety and educational supports needed to deal with Kala.

A less weighted theme was the inability for the school/division to meet Kala's and Jane's educational needs (29% of total cluster responses were a "mismatch between home and school"). For example, Jane felt that current funding application guidelines should be better tailored for children with FAS.

Kala was currently funded due only to her safety needs in the classroom (e.g., she would run out of the school impulsively), and not for her the additional supports she required for her cognitive deficits.

**Table 10**

Cluster summary for teacher interview #1

<b>Cluster</b>	<b>Total Response (out of 76 total)</b>	<b>Weight of Response (% out of 100)</b>
<b>1. Advocating</b>	<b>27</b>	<b>35</b>
<b>2. Professional Growth</b>	<b>18</b>	<b>23</b>
<b>3. Empathy</b>	<b>7</b>	<b>10</b>
<b>4. Goodness of Fit Between Home and/or among School</b>	<b>24</b> (17-"match") (7-"mismatch")	<b>32</b>

Table 10 summarizes the total clusters, the number of responses for each cluster, and the weight of response in each cluster for the entire interview with Jane Braidmon, Kala's teacher. "Advocating" was the strongest cluster in the interview, and comprised 35% of total interview responses, followed by the "goodness of fit between home and school", which comprised 32% of the total interview responses. The remaining two clusters, "professional growth" and "empathy" comprised 23% and 10% respectively, of total interview responses.

**Parent Interview #2 (Norma Daun; Sophia's adoptive mother)**

The interview with Norma was informative. She was relaxed and seemingly comfortable in discussing all of the topics and was very open to her personal feelings towards the issues at hand, as well as those regarding herself (e.g., "I always have to qualify she's [Sophia] doing well, so that's hard").

**Table 11**

Cluster and themes for parent interview #2A

	<b>Number of Responses</b>
<b>Cluster 1: Advocating Themes:</b>	<b>27</b>
a) For increased educational standards for Sophia (e.g., teachers being more knowledgeable about FAS/FAE)	5
b) For segregated programs	8
c) Home-school connection (e.g., parent-teacher interviews)	6
d) Social/emotional/practical skills training (e.g., learning to get along with other peers)	4
e) Appropriate funding for children with FAS/FAE (e.g., based on educational needs rather than behavioural)	4

In Table 11, "advocating" was the second strongest cluster throughout the interview (26% of total interview responses). Norma advocated for continued segregated programming in the school system (30% of total cluster responses). She felt that being able to meet the needs of Sophia in a smaller, more specialized

setting with specialized supports, far outweighed the benefits of mainstreaming. She also advocated for a positive home-school connection (22% of total cluster responses). With the school and home working together to meet the needs of a child, Norma felt that Sophia would receive more consistent attention from both areas and progress would be gained if there was a vested interest on both parts. Norma also advocated for "increased educational standards for Sophia" (19% of total cluster responses). She felt that professionals in the school division who working with FAS/FAE children were lacking much of the knowledge needed to understand and teach them and they should be educating themselves more to be able to do so.

The latter two themes in the cluster were equally weighted in responses (both 15% of total cluster responses). Not only did Norma advocate for more appropriate funding guidelines for children with FAS/FAE (i.e., since funding for Sophia was based on behavioural safety issues rather than learning deficits), she also felt that schools should be delineating the stress on academics for children like Sophia, and concentrating on more practical and social life skills to be able to get them through their adult years (e.g., how to grocery shop, and how to be respectful of others). Norma felt it was far more important for Sophia to "be liked" by others and respect herself, as well as being able to be independent, rather than pushing her to be academically successful.

**Table 12**

Cluster and themes for parent interview #2B

	<b>Number of Responses</b>
<b>Cluster 2: Proactive Themes:</b>	<b>18</b>
a) Seeking initial diagnosis for Sophia (e.g., requesting a cognitive assessment)	4
b) Seeking supports for Sophia and self (e.g., utilizing grandmother support in child rearing, seeking therapeutic advice from professionals)	5
c) Seeking funding/safety/socio-emotional needs for Sophia (e.g., fostering extra-curricular activities such as joining a soccer team)	18

In Table 12, being "proactive" was the least weighted cluster in the interview relative to the others (18% of total interview responses). Within the cluster however, Norma was very proactive in her attempts to seek out the various funding, safety, and socio-emotional needs Sophia needed to succeed in the school system (50% of total cluster responses). For example, at the time of the interview, Norma was attempting to obtain level 3 funding for Sophia (who was in grade 5 at the time of the interview), so she would be prepared for grade 7 when there would be a large transition for her and the supports would be greatly needed.

When Norma adopted Sophia, she was also proactive in her attempts to determine what her issues were, as she did not know at the time of adoption that Sophia was FAS (22% of total cluster responses). She approached various medical professionals, and even requested psychological assessments to seek out

an appropriate diagnosis. On a more personal level, Norma was also proactive in seeking out the necessary supports needed not only to help out with Sophia, but also to provide respite for herself (28% of total cluster responses). For example, Norma would seek out the advice of a therapist to determine developmental appropriateness of Sophia's behaviours, as well as utilize the support of her mother for child rearing when needed.

**Table 13**

Cluster and themes of parent interview #2C

	<b>Number of Responses</b>
<b>Cluster 13: Personal Rewards/Challenges for Parent Themes:</b>	<b>19</b>
a) Personal hardships needed to raise Sophia (e.g., dealing with thoughts that everyone thinks Sophia's behaviour problems stem from her bad parenting)	6
b) Rewards for raising Sophia (e.g., feels gratified that has been able to give Sophia a chance to succeed in life and make her an addition to their family)	2
c) Ability to recognize Sophia's behavioural/developmental needs (e.g., knows when and in what situations Sophia can handle herself without going out of control; better in 1-1 settings with friends rather than "birthday parties")	11

In Table 13, Norma revealed many of the personal rewards and challenges for a parent (19% of total interview responses). Although Norma discussed many of the hardships she endured in the child rearing process with Sophia (32% of total cluster responses), she also commented on the very rewarding experience of being

able to give Sophia a chance at life that Sophia's mother or grandmother never had (11% of total cluster responses). For example, it was difficult and draining to deal with Sophia's day to day behavioural issues at school and home, but being able to provide an environment where Norma feels Sophia had no reservations about being who she wants to be and feeling unconditionally loved was quite rewarding to her as a parent.

Since Sophia was not diagnosed with FAS when adopted, Norma was faced with constant challenges of understanding Sophia's behavioural and developmental needs (58% of total cluster responses). Even after the diagnosis, it was, and seemingly still is, a challenge to understand what works best for Sophia at home and school. For example, Norma learned that typical behaviour modification strategies to redirect behaviour were ineffective for Sophia because she was unable to understand "cause and effect" of implementation, a typical characteristic feature of children with FAS/FAE.

**Table 14**

Cluster and themes for parent interview #2D

	<b>Number of Responses</b>
<b>Cluster 14: Goodness of Fit Between Home and School/Society</b>	<b>38</b>
a) Match between home and school (e.g., feeling that academic needs are being met for Sophia by the school)	18
b) Mismatch between:	
i) Home and school (e.g., school not meeting Sophia's emotional/Educational needs)	6
ii) Home and society (e.g., feels community alienates Sophia from Community - wants to feel "normal")	14

In Table 14, "goodness of fit between home and school" was the strongest cluster in the interview (37% of total interview responses). Norma stated she felt fortunate to have such a good experience with Sophia's school. She felt that Sophia's LAC program was well suited to her needs, and she was well connected and informed with not only the teacher, but administration as well. She did state however, that not all parents would report the same experience but that she worked very hard at achieving that relationship with the school primarily due to intense involvement in meetings and accessing supports.

Norma also commented on the mismatch between home with not only school, but society in general (53% of total cluster responses). Although Sophia's current educational placement was satisfactory, Norma commented on the



concerns she had once Sophia entered middle years (33% of total cluster responses). She felt that specialized programs (like an LAC program), for children like Sophia no longer concentrated on mental health issues and the like, but were more geared to segregate and control many of the students with severe behavioural concerns (e.g., gang members). Therefore, she felt that middle years education was not adequately prepared to take in children like Sophia.

Norma also stated her disappointment with society's general attitude about special needs children, especially with Sophia (37% of total cluster responses). Norma commented a great deal on her personal feelings about the difficulties with others in the community that caused her great distress as a parent. She felt that others thought Sophia's behavioural issues were due to her "bad parenting" and that although people would appear to be sensitive to Sophia's disability, they really were not.

**Table 15**

Cluster summary for parent interview #2

<b>Cluster</b>	<b>Total Responses (out of 102 total)</b>	<b>Weight of Response (% out of 100)</b>
<b>1. Advocating</b>	<b>27</b>	<b>26</b>
<b>2. Proactive</b>	<b>18</b>	<b>18</b>
<b>3. Personal Challenges/Rewards</b>	<b>19</b>	<b>19</b>
<b>4. Goodness of Fit Between Home and School/Society</b>	<b>38 (18-"match") (20-"mismatch")</b>	<b>37</b>

Table 15 summarizes the total clusters, the number of responses for each cluster, and the weight of response in each cluster for the entire interview with Norma Daun, Sophia's adoptive mother. The "goodness of fit between home and school/society" was the strongest cluster in the interview (37% of total cluster responses), followed by "advocating" (26% of total cluster responses). The "personal rewards/challenges as a parent" and "proactive" clusters were almost equal in their weights within the interview (19% and 18% of total cluster responses; respectively).

#### Teacher Interview #2 (Louise Fraber; Sophia's teacher)

The interview with Louise was not as powerful as the others. Time restraints for Louise warranted a phone interview and the personal engagement

established in the other interviews was not encountered here. In addition, when the interview started, there was some ambiguity towards the interview as Louise claimed she knew nothing about the study (whereas Norma Daun had assured me she had already spoken to her prior, in order to gain consent). The tape recording of the interview was also faulty, therefore the validity of the responses may have been somewhat compromised as questions had to be reconstructed from notes taken during the interview.

Although Louise was willing to participate in the interview, the tone was somewhat negative (e.g., short, choppy answers), and it was hard to establish a positive flowing discussion. There also seemed to be a negative flavor to the entire discussion regarding Sophia's current situation (including behaviour), and her outlook towards Sophia's future (e.g., "she will end up in a lock up facility", "dedication will make no impact here"). These characteristics can however, be attributed to the fact that the phone discussion left little room to become more personal and probing, however caution should still be exercised in interpreting the data.

**Table 16**

Cluster and themes for teacher interview #2A

<b>Cluster 16: Advocating Themes:</b>	<b>Number of Responses</b>
a) Independence (e.g., teaching Sophia life skills so she can be functional in the community)	6
b) Segregated programs	4
c) Communication between teachers and parents	2

In Table 16, "advocating" comprised 31% of total interview responses. Louise advocated for teaching basic skills of "independence" (e.g., lifeskills), to children like Sophia (50% of total cluster responses). She felt that it was very important for these children to be a functional part of the community as adults and teaching them such skills early, were equally if not more important than an academic focus.

Louise also advocated for segregated programs for children like Sophia (33% of total cluster responses). She felt that the LAC program in particular provided the optimal environment for children like Sophia to adapt. As well, Louise felt that it was important that a line of communication between teachers and parents be constant if the child is to have consistent successes (17% of total cluster responses).

**Table 17**

Cluster and themes for teacher interview #2B

<b>Cluster 17: Goodness of Fit Between Home and/among School Themes:</b>		<b>Number of Responses</b>
a) Match between home and school:		27
i)	In school meeting Sophia's educational/behavioural/emotional needs (e.g., feels staff is highly trained to deal with Sophia)	4
b) Mismatch between:		
i)	School not being able to meet Sophia's need (e.g., her aggressiveness in class)	7
ii)	Teacher and views of administrators/policies (e.g., teacher disagrees there should be special funding for all children with FAS)	6
iii)	Teacher and Sophia as a student (e.g., teacher feels Sophia is too aggressive to be in the public school system)	10

In Table 17, "goodness of fit between home and/among school" comprised 69% of total interview responses. The match between "school meeting Sophia's educational/behavioural/emotional needs" comprised only 15% of total cluster responses. Louise did feel that the staff working with Sophia were highly trained and competent to be working with her.

Louise's comments however, tended to focus on how the school and Sophia "did not match". She felt the school in some ways was not able to meet Sophia's needs (26% of total cluster responses). She felt that since Sophia's aggressiveness was in the extreme end of behaviour (e.g., self-mutilation and physical assault of staff), the school setting was not an adequate facility to be

"holding" her.

In terms of funding, Louise disagreed with Norma Daun (Sophia's foster mother), and some the general administrative staff that all children with FAS should receive special funding (22% of total cluster responses). She felt that since all children with FAS presented with such varying degrees of symptomology (i.e., ranging from mild to severe), that it would be unfair to grant all children the same funding if it wasn't needed. Funding should be evaluated based on need of resources for the child.

Another prominent theme in the cluster was the "mismatch between teacher and Sophia as a student" (37% of total cluster responses). Louise tended to comment a lot on the extremity of Sophia's aggression in school. Although she was personal friends with Norma, it still seemed to appear that her classroom (and the school system in general), was not an appropriate setting for Sophia. She had stated that Dr. Hildal, child psychiatrist, felt that the school setting had done all it could. Louise predicted that due to Sophia's extreme physical aggressiveness, that the ultimate placement for her will be in a locked up facility where supports could better deal with her violent tendencies in a smaller group situation. She stated that at the school level "dedication is not going to make any impact here".

**Table 18**

Cluster summary for teacher #2

<b>Cluster</b>	<b>Total Response (out of 39 total)</b>	<b>Weight of Response (% out of 100)</b>
<b>1. Advocating</b>	<b>12</b>	<b>31</b>
<b>2. Goodness of Fit Between Home and/or among School</b>	<b>27 (4-"match") (23-"mismatch")</b>	<b>69</b>

Table 18 summarizes the total clusters, the number of responses for each cluster and the weight of response in each cluster for the entire interview with Louise Fraber, Sophia's teacher (caution should be noted as the number of responses throughout the entire interview was low, only 39, compared to the other 3 interviews in this study).

"Goodness of fit between home and/among school", with emphasis on the "mismatch" (85% of total cluster responses), was the strongest cluster in the interview and comprised 69% of total interview responses. "Advocating" was the weakest cluster of the two, comprising only 31% of total interview responses.

## Chapter V

### CONCLUSION

The purpose of this thesis was to investigate and document important issues and concerns for parents and teachers who live with or teach children with FAS. In addition to exploring whether or not parents and teachers in this study described similar behavioural, cognitive, and socio-emotional characteristics to the literature, a more in depth look at personal issues for them was also of interest (e.g., mainstreaming views and the emotional challenges of raising a child with FAS).

#### Discussion of Findings

Based on the four research questions that were set out to be investigated in this study, the following section will discuss aspects of all four interviews which reflect such.

*Research Question 1: Are descriptions of behavioural, cognitive, and socio-emotional characteristics by parents and teachers similar to those found in the literature?* The results found in this study indicate that many of the behavioural, cognitive, and socio-emotional characteristics of children with FAS/FAE found in the literature, were also expressed to be typical characteristics found with Kala and Sophia by both parents and teachers. Both children



demonstrated cognitive difficulties in areas such as; abstract reasoning, cause and effect, and long term memory retention. These deficits required increased assistance in the classroom by both teachers and paraprofessionals to accommodate learning (e.g., the use of visual aids with Kala, and using different techniques to "re-learn" previously learned material for Sophia).

Jane, Kala's teacher, often referred to Kala's impulsive behaviour in the classroom and her frequent wandering out of the classroom. It seemed Kala could not understand the "cause and effect" of the potential danger of running out onto the road unsupervised and as a result is one of the main reasons she requires paraprofessional assistance at all times. Cognitively, Jane also noted limitations in the classroom with abstract reasoning. Kala had difficulty with topics such as history, as she could not grasp concepts such as "long ago". Therefore, accommodations in the class had to be made to teach her alternate material during that time.

Norma, Sophia's mother, also commented on the lack of "cause and effect" her daughter exhibited. Interestingly, she stated that for this reason, traditional behaviour modification techniques (which frequently rely on cause and effect theory), typically do not work for students with FAS/FAE as methods for distinguishing unwanted behaviours. As a result, individuals living or teaching these children need to use alternative methods of action to re-direct behaviour.

Alternatively, Burgess (1994), suggests that rather than punishing these children for undesirable behaviour, one can teach positive skills related to judgement and impulse control. As described in the literature review, an example of such may be that if a child tears up his/her work because it is too hard, they can be taught to ask for help instead. Consequences of their inappropriate behaviours should be a result of their poor choices in the first place and not their actual behaviour. Therefore, the child who tears up his/her work would be consequence not for tearing up the work, but for not asking for help when needed.

Louise, Sophia's teacher, also commented on classroom issues for Sophia related to learning, such as knowing material one day and not remembering it the other, but her focus was primarily on the extreme aggressive tendencies that were frequently exhibited in the classroom. As described in the literature, aggression may or may not be primary to FAS/FAE, however it is a potential issue that must be addressed in the class, home, and community setting, sometimes with limited success. The literature did not directly address how to deal with those children exhibiting extreme aggressive behaviours, and from the interview with Louise, it seems that the safety of those around (i.e., students), and for Sophia was of primary consideration. If Sophia became aggressive, she would often be physically restrained and removed from the area until she regained control and was able to be reintegrated into the classroom setting.

Boundary issues were also of concern for Kala by both her foster mother and teacher. Kala was described as overly affectionate and would approach anyone without reservation, which had both concerned about the potential danger of this issue in public with strangers as she became older. Both also described Kala's seemingly high verbal skills, particularly by her teacher Jane, but yet Kala's lack of understanding during a conversation. This characteristic was also highlighted in the literature and the inability to communicate effectively (e.g., understand social boundaries), is one of the ongoing challenges faced in teaching social skills to these children.

Therefore, both parents and teachers were able to comment on how Kala and Sophia demonstrated similar behavioural, cognitive, and to a lesser extent, socio-emotional characteristics to those described in the literature. Kala was described to be impulsive and lacking in cause and effect reasoning skills. Cognitively, her abstract reasoning abilities were not developmentally at the same level as her classroom peers and classroom instruction had to be modified to meet those needs as such. Sophia was also described to have weak cause and effect reasoning skills, as well as memory issues in the classroom in which the teacher had to accommodate in her teaching. The focus of Sophia's difficulties however, seemed to lie in her extreme aggressive behaviour in the classroom and the management techniques used to provide safety to herself and others around her.

*Research Question 2: What efforts are expended on the part of parents and teachers in advocating and seeking supports for these children both in and out of school?* Appropriate funding for assistance in the classroom was strongly advocated for. Unfortunately, one of the current struggles both parents and teachers reported was that these children with FAS/FAE are not funded based on the learning disability they have, rather, they are funded due to behavioural issues of safety to themselves and others (i.e., Kala's "wandering" out of the school, and Sophia's extreme aggressive tendencies to herself and others). Therefore, if these children did not demonstrate some behavioural need for paraprofessional assistance in the classroom, both children would not receive any funding. Norma commented on how "fortunate" she was that her child *was* "behaviourally challenged" in some sense, because then Sophia met the criteria for funding support.

Kala's foster mother, Jada not only advocated for funding in the classroom, she actively sought support for such by petitioning Kala's former school division with other parents. She and other parents of special needs children wrote letters for increased supports, however were unsuccessful in gaining more funds. Jada felt that it was not enough for parents to have sought support but that greater impact may have come if educators in the division would have also supported them. Jada also stressed the concern by herself and other parents that if they

pushed too hard, negative attitudes may have been passed down to their children as a result. Therefore, they could push only so far.

Norma also was in the process of trying to obtain level 3 funding for her daughter 2 years in advance. She stated that grade 7 was a big transition period for Sophia and she was going to be proactive in trying to get that funding early just in case it was denied. In such a case, alternate plans would then be considered in order to meet Sophia's needs (e.g., home schooling).

While Jada, Jane, and Norma, felt that funding should be redefined to include those children with FAS, Louise, Sophia's teacher, felt it should not. Louise stated that due to the wide range of deficits and characteristics in FAS/FAE individuals, it would be unfair to automatically grant all students the same funding. She felt each student should be evaluated individually based on need. The literature however, indicates that FAE is not the lesser extreme of FAS (i.e., individuals with FAE still exhibit many of the learning and cognitive difficulties as those with FAS), rather the individual with FAE simply does not demonstrate the physical characteristics of FAS (Burgess & Streissguth, 1990). Therefore, when an individual is diagnosed with FAS or FAE, it would seem still warranted that funding should be reconsidered to include both due to the learning and cognitive issues that persist regardless of which diagnoses is made.

The topic of mainstreaming was also addressed in the study. Interestingly,

while advocacy to mainstream special needs children has been a seemingly strong issue for educators and teachers, both parents in this study surprisingly did not feel this way. Jada, Kala's foster parent, felt that when the education system first implemented the idea, it appeared theoretically sound, however, lack of funding to adequately mainstream children over the years has made it unsuccessful.

Educators are not provided with assistance in the classroom to be able to provide the adequate attention needed to educate and manage these special needs children amongst a class of "regular" children. Therefore, she advocated segregated classrooms for children with FAS/FAE so that they could at least receive the individualized attention they require and deserve.

Norma, Sophia's mother, advocated for segregated classrooms, but in her case the reasons were quite different. Due to the extreme aggressive tendencies Sophia exhibited, she felt that segregated classrooms (in Sophia's case and LAC program), not only provided the appropriate environment for Sophia to cope (i.e., low stimulation and greater one to one attention), but it also segregated her from the rest of the school when she became aggressive to herself and others. This seemed to be more of an issue for Norma as her insecurities about how others would "perceive" her daughter if they saw her react made her quite uncomfortable. Although labeling was somewhat of an issue for Norma, she thought it would be easier for Sophia to be accepted by her friends and those in the community if she

told them she was in a special program due to brain damage, rather than let them see her become violent if she was mainstreamed in a regular classroom. This however, seemed to be more of a concern for Norma than for Sophia (i.e., Norma never stated Sophia did not want to be in a segregated classroom). Throughout the interview, it was apparent that Norma's personal feelings about "acceptance" for her daughter by others was an extremely sensitive and important area for her. She became very emotional (e.g., anxious) when discussing the issue and wanted only for others to be empathic and unprejudiced towards Sophia both in and out of school.

Outside of the school environment great efforts were also made to advocate for Kala's and Sophia's acceptance in the community and parents actively sought the resources of outside agencies for support. For example, Kala's foster mother sought the support from The Society for Manitoban's With Disabilities to assist her with behavioural and developmental strategies to care for Kala. Both parents also actively involved their children in extra curricular activities (e.g., swimming and soccer), to promote increased physical strength and more importantly, community integration and acceptance. Kala's teacher also advocated for peer and community involvement. She felt that by informing the students and their parents of Kala's special needs that it would foster greater acceptance and understanding which in turn would only benefit her self-esteem and confidence.

Since the school was located in a small community, this may have heightened the ability to promote such.

It seems that each parent and teacher interviewed expended efforts to advocate and seek supports for these children in their own way. With the exception of Louise, Sophia's teacher, one of the largest efforts seemed to be in advocating for a separate funding category for FAS/FAE children, as currently both Kala and Sophia were funded based on behavioural rather than learning disability issues. Both parents and teachers also advocated for segregated classrooms as opposed to mainstreaming, as providing a better environment to meeting the children's needs and lastly, community integration was seen as being an integral part in both fostering self confidence and acceptance for both Kala and Sophia.

*Research Question 3: What are some of the emotional aspects of raising/teaching a child with FAS/FAE?* An interesting cluster in the interviews with both the foster parent and adoptive parent was the issue of “personal rewards and challenges” for raising a child with FAS. Although I expected more “informative” findings based on issues found in the literature, the degree of emotional content that surfaced throughout, especially for Norma, was unforeseen. As the interviews progressed, it quickly became apparent that such issues as funding, accessing supports, and the relevant characteristics associated with FAS;



were not the main “feel” of the interview for me (especially for Sophia’s mother). As the interviews went on, they began to take on a more personal and “heart-felt” tone that created the feeling that not only did these parents highly advocate and support these children both at home and school, but that these children were truly loved.

Although both Jada and Norma expressed many of the positive feelings around raising these children (e.g., Kala’s “love for life”, and the ability to give Sophia a second chance for good life), the topic of interest in this study seemed to be discussion around the emotional hardships that were endured on a personal level. Jada expressed the difficulties with how others portrayed her as “just a foster mother” who really did not know anything about Kala. Not only did this frustrate her (i.e., when trying to get medical documentation on the status of Kala’s health and the doctor telling her she could not have it because it was confidential), but it also pained her when she truly knew what Kala needed to succeed outside of her home and many of those around her would not take her suggestions to heart (e.g., telling a previous classroom teacher to take an FAS workshop to better understand Kala’s needs and feeling like the teacher ignored her).

Another emotional issue was for Norma and the sensitivity around parenting Sophia. The tone was apparently sincere when Norma discussed some

of the difficulties for her around how *others* perceived Sophia's aggressive issues to be a result of her "bad parenting". Although cognitively she knew this wasn't the case, it pained her to think that others didn't understand that as well. She wanted so much for her daughter to be accepted by others and for Sophia to grow up and "just be happy" that it seemed to be hierarchically more important than any educational or administrative issues Norma was dealing with. It began to take on a real parental quality, rather than just someone who was discussing the challenges of battling the education system for the adequate supports for a child. Although Jada discussed some similar feelings and did appear to be genuinely concerned for Kala's well being (e.g., she hoped Kala would grow up to be happy), I felt this parental sincerity more from Norma. The fact that Norma had actually adopted Sophia as her own may have had some effect on these issues.

The emotional aspects for teaching a child with FAS/FAE seemed to be more intrinsic to the teacher rather than extrinsic to the child in both teacher interviews. Jane for example repeatedly expressed her desire to have been more prepared to teach a child with FAS prior to Kala's entry into her classroom. She felt she did not know enough about FAS and therefore was not at a level she felt comfortable with in meeting Kala's needs. Although she felt divisional support in obtaining such knowledge (e.g., taking workshops), she was very appreciative having the current paraprofessional in place to assist in informing her on FAS as

she was knowledgeable and had experience working with Kala. Even though discussion around any emotional comments for Kala was limited, Jane did empathically comment on the everyday trials and tribulations Jada must endure to raise Kala at home.

The emotional aspects of teaching a child like Sophia were portrayed somewhat differently with Louise than with Jane. Granted Sophia appears to have severe behavioural and aggressive issues, Louise seemed to radiate a sense of animosity on the topic. She indirectly commented several times that the classroom setting was inappropriate for Sophia. Her aggressive levels were far beyond what should be expected of a school environment to tolerate. She felt that Sophia would likely end up in a lock up facility due to her aggression and stated that even dedication at the school level would have no impact on Sophia's education and well being. It was unclear whether Louise's comments were objectively reflective of Sophia's current inability to adapt or integrate in the LAC class, or whether it was a subjective feeling about her intolerance to continue having Sophia in her classroom.

Emotional aspects, in raising both Kala and Sophia was evident from both parent interviews and labeling issues on behalf of both were strong. Jada, Kala's mother, expressed sensitivity towards others perceiving her as "just a foster mother", whereas Norma expressed such over other's perceiving Sophia's

behavioural issues to be a result of her "bad parenting". Both expressed a enormous desire for their children to be accepted and understood by all those around them. Emotional content in the teacher interviews were not as personal in nature, rather focus seemed to center on the disservice the education system had done them in ill-preparing them to teach and deal with the behavioural issues these children brought into the classroom.

*Research Question 4: How do parents and teachers view the significance of academics versus practical and social skills in the classroom?* Another important issue in this study was the degree of practical/social skill implementation that should be incorporated into Kala's and Sophia's school day. At the primary level, Jane (Kala's teacher), felt that much of what is taught in her classroom already incorporates a lot of practical and social skill simply due to the age level of her students (K-2). Jane did however comment positively on the importance of teaching proper social skills to children with FAS/FAE in order to promote independence and help them feel successful as individuals. Louise also felt her classroom incorporated a lot of practical and social skills into her academic focus and she also felt it was important for these children to be functional parts of their community as adults.

Although both parents felt their children should be taught basic academic skills to be able to function practically in the community (e.g., number concepts for

banking skills), they felt that life skills and social skills training/awareness were far more important in their children's success as adults. They stated that due to the cognitive limitations their children possessed, they would never go on to pursue any academic venues, therefore being successful adults in all other areas was a more important pursuit for them. Norma also commented on the importance of fostering self-esteem in the process of teaching these children independent lifeskills and social skills, so that they grow up feeling proud of themselves as well. This finding corresponded with findings in the literature review, in that parents would like to see more practical/social components as the focus to their children's school day. The literature also stresses that these functional skills should also be taught early to foster independent development in the home and at work (Burgess, 1994).

Both parents and teachers seemed to express slightly different opinions when it came to the importance of teaching practical and social skills in the classroom over academics. Teachers felt that both areas were important to focus on in the classroom throughout the educational years. Parents on the contrary, felt that although it was important to learn the basic academic skills to succeed independently (e.g., basic math skills to do banking and shopping), greater emphasis should be placed on the implementation of practical and social skills in the classroom to promote success in adulthood.

In conclusion, it seems parents and teachers in this study were able to

describe many of the behavioural, cognitive, and socio-emotional characteristics for Kala and Sophia that were similar to the literature. The interesting findings in this study however, seemed to be the strong personal feelings describing the challenges faced in raising and supporting these children, by parents and to a lesser extent, teachers.

Funding was also an important issue. Our education system does not recognize FAS/FAE as a distinct handicapping condition nor as a separate funding category, which leaves many parents and teachers feeling helpless in their efforts to gain additional supports in the classroom (e.g., with instructional assistants). In addition, many of these children have debilitating academic and behavioural deficits that remain undetected at most and unserved by schools do to the lack of appropriate diagnosis, programming and training of staff in the area of FAS/FAE. Greater consideration should be given to support funding for FAS/FAE students in our education system.

"It takes a village to raise a child", and the efforts described in this study to do so were evident. Parents, teachers, paraprofessionals and other community members all play a major role in fostering the healthy social, behavioural, and educational needs of not only children with FAS/FAE, but other children with special needs as well. These children need to be programmed appropriately in order to give them practical skills to function in the community as well as adaptive,

social and communication skills to effectively and confidently integrate into society. With continued support for these children and their families or caregivers, and access to growing knowledge on FAS/FAE, these children have a fighting chance to succeed.

### Limitations

A limitation of this study may have been the manner in which the questionnaire was used. Although many of those interviewed were able to comment for long periods of time on issues while expanding those questions asked of them, it may have restricted greater spontaneous thoughts and comments and limited the overall quality of the interviews. Future research may consider using the questionnaire in a more open-ended format.

Due to the time constraints during this study for participants and the researcher, a larger sample population was unobtainable. A greater number of participants would have added more information, opinions, and variability to this study. It must also be cautioned that since there were only four participants, the results should not be generalized beyond this study. The present research was more of a preliminary, exploratory study to a potentially larger one in the future.

### Recommendations For Further Research

Future replication of this study may be strengthened by taking into consideration several factors. Findings suggest that administrators (e.g., principals) and especially paraprofessionals, play a significant role in these children's lives. Interviewing the senior administrators who must decide or at least delegate such important issues as funding and instructional assistant designation may have provided the reader with a less biased outlook on the current situation. We must not forget that the education system not only serves this relatively small population of children with FAS/FAE, but also its greater population of other special needs and regular students who are also deserving of its attention in other ways.

The invaluable efforts of the paraprofessionals with these children (especially Kala's paraprofessional) is perhaps an even stronger link to fostering communication between parents than with teachers. The paraprofessionals spend a greater amount of time with these children, in most cases, and they develop a better understanding of the child's needs simply because they spend more physical time with the child during the day. Therefore studies in the future may find it beneficial to interview these individuals as well.

The child with FAS is also an important individual to gain insight from. In many instances, these children are capable of describing their own difficulties and



attitudes towards their own lives. It would be interesting to determine how similar/different the attitudes are between the child and his/her caregivers/teachers.

It may also provide some information as to oversights the child may notice, but perhaps not the other significant individuals in the child's life.

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*Appendix A*

May 4, 1998

Toni Cascegna  
139 Dobrinsky Drive  
Winnipeg., Manitoba  
R2P-2N5

Ms. Kathy Jones  
Interagency Fetal Alcohol Syndrome - Effects Program  
49-476 King St.  
Winnipeg, MB

Dear Kathy,

As you know, I am currently conducting research at the University of Manitoba for my Master's Thesis in Educational Psychology. The title of my research is "How Parents and Teachers Can Work Together to Educate Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects". My focus is to assess the current issues for parents and teachers of children with FAS/FAE and discuss strategies beneficial to their management and education.

I am aware you are in frequent contact with such parents and educators through telephone and personal involvement, and I wonder if it would be possible to obtain a list from you of names and phone numbers of approximately 10-12 teachers and 10-12 parents who may be willing to participate in this study. Upon receiving a list of possible interview candidates, I will then contact them to discuss my study and their possible participation. My study will involve a two stage process. I would like to initially hold 2 separate focus groups (in which I will facilitate discussion); one for approximately 4-5 parents and one for 4-5 teachers, in order to stimulate and discuss relevant issues regarding FAS/FAE. Some of the topic issues include: educational and behavioral needs of these children, focus on academics or functional skills in school, etc. The groups will meet for approximately 30-45 minutes and the time and location will be arranged at a later date. I will send a letter to the principal of the school(s) in which the participants are involved, requesting approval to conduct both the groups and individual interviews at the school itself. This may make it easier to arrange times for teachers to meet as well as provide a more comfortable environment for parents

Following the focus groups, I would like to separately interview an additional 4-5 parents and 4-5 teachers, (for approximately 20-30 minutes), who have not participated in the groups, in order to obtain a more personal, first hand look at the issues. The intent of the initial focus group is exploratory, and it is hoped that, by initially investigating the issues with the focus groups, a more relevant guideline will be devised for the subsequent individual interviews with parents and teachers. Both the focus groups and individual interviews will be tape recorded for the sole purpose of facilitating data analysis, and the recordings will be destroyed upon completion of this study. All information collected during this study will be confidential and anonymous and participants may withdraw from the study at any time.

Upon receiving a list of volunteers from you, I will contact them to explain my study and plans. Following verbal acceptance by each participant, I will send out a consent letter describing the study and its expectations, including a consent form to be filled out prior to commencement of the study. Each participant will also be told beforehand if they are included in the focus group or individual interview, and optional dates and times will be made available to them. Enclosed is also a sample of the consent form each participant is required to sign prior to commencement of the study.

I would greatly appreciate any support in helping me gather information for this study. If you have any questions or concerns, please feel free to call me at 697-4407, or my thesis supervisor, Dr. Riva Bartell at 474-9048. Thank you for your time and consideration.

Sincerely,

---

Mrs. Toni Cascegn

*Appendix B*

May 4, 1998

Mrs. Toni Cascegna  
Department of Educational Administration and Psychology  
Faculty of Education, University of Manitoba  
Winnipeg, Manitoba R3T 2N2

**Subject: How Parents and Teachers Can Work Together To Educate  
Children With FAS/FAE:**

**Interview Participation**

Dear Participant,

This is a follow up letter our discussion regarding your participation in my study, "How Parents and Teachers Can Work Together To Educate Children With FAS/FAE". As you already know, this study is a University of Manitoba Master of Education Thesis project conducted to explore issues at home and school for parents and teachers of children with FAS/FAE.

I will begin by looking at the literature in the areas of education, behavior and social programming which is thought to be helpful in the management of these children. Recent literature in the area of education for children with FAS/FAE has suggested we teach these students such things as practical skills (e.g., grooming), communication skills, and learning how to do things while in the community. My intent is to see how parents and teachers actually feel about these areas, which ones should be focused on in our schools, and what practices are actually helpful.

My study will be done in two stages. In the first stage, prior to our interview session, I will hold 2 focus groups; one for parents and one for teachers, in order to discuss these relevant issues in a group setting (you will not be required to participate in the focus groups). The information gathered from the focus groups will serve to form a general questionnaire for the individual interviews in the second stage of this study.

The second stage will involve individual interviews with 4-5 parents and 4-5 teachers, to obtain a more personal viewpoint on the issues discussed in the



focus groups. The interview will last approximately 20-30 minutes, and I will contact you to set up a convenient date, time, and location for it. Your participation in this study is voluntary, and all information will be anonymous and confidential. The interview will be tape-recorded in order to help interpret more accurately the conversations at a later date, and recordings will be destroyed upon completion. A consent form has been attached to this letter for your signature prior to commencement of this study. Please bring the signed consent form to the interview.

Your participation in this study will be greatly appreciated. Should you have any questions or concerns, please feel free to call me, Toni Cascegna at 697-4407, or my thesis supervisor Dr. Riva Bartell, at 474-9018. A summary of the results from this study will be made available should you request one.

Sincerely,

---

Mrs. Toni Cascegna

## Consent Form For Participant

### **How Parents and Teachers Can Work Together To Educate Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects**

I, \_\_\_\_\_ agree to participate in the study "How Parents and Teachers Can Work Together To Educate Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects". I understand that I will be interviewed and tape recorded (approximately 50-60 minutes), regarding my opinion on issues concerning children with Fetal Alcohol Syndrome/Effects who are currently attending school. All tape recorded information is for the sole purpose of facilitating data analysis and will be destroyed upon completion of this study. I also understand that all information is confidential and anonymous and my participation is fully voluntary. I may withdraw from the study at anytime should I choose to do so.

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

Signature of Participant: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_

This study is being conducted by Mrs. Toni Cascegna, a Master of Educational Psychology graduate student at the University of Manitoba under the supervision of Dr. Riva Bartell. If you have any questions regarding this study or would like the results upon completion, please feel free to contact one of us at: 474-9048 or 697-4407.

\*\* Yes, I would like a copy of the results upon completion of this study \_\_\_\_\_ (please check)

Appendix D

**Perception of Parents and Educators Concerning Current Educational Support For Children With Fetal Alcohol Syndrome/Fetal Alcohol Effects**

1. Do you feel that current special educational supports meet the needs of a child with FAS? **Y/N**  
Why or why not? \_\_\_\_\_  
\_\_\_\_\_
  
2. What do you feel are the top 3 educational needs of a child/student with FAS/FAE?  
i) \_\_\_\_\_  
ii) \_\_\_\_\_  
iii) \_\_\_\_\_
  
3. What do you feel is the greatest weakness in the current educational support system? \_\_\_\_\_  
\_\_\_\_\_
  
4. What do you feel is the greatest strength in the current educational support system? \_\_\_\_\_  
\_\_\_\_\_
  
5. What are two common long term goals for most children with FAS/FAE (aside from unique differences)? \_\_\_\_\_  
\_\_\_\_\_
  
6. a) What percentage of the curriculum do you feel should entail academics? \_\_\_\_\_  
b) What percentage of the curriculum do you feel should entail functional skills? \_\_\_\_\_  
c) Are there any other areas you feel should be emphasized? \_\_\_\_\_
  
7. In your opinion, is special educational funding adequate for children with FAS/FAE? Why or why not? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*Appendix D*

8. What do you feel is the greatest challenge in [teaching/parenting] a child with FAS? \_\_\_\_\_

\_\_\_\_\_

9. Do you feel there is strong communication between parents and educators in the development of appropriate educational programming for these children? Please briefly comment on your situation. \_\_\_\_\_

\_\_\_\_\_

10. What do you perceive as a positive to [living/working] with this child? \_\_\_\_\_

\_\_\_\_\_

11. What are your hopes for this child? \_\_\_\_\_

\_\_\_\_\_

12. What do you perceive as some challenges your child's [parent/teacher] faces on a daily basis? \_\_\_\_\_

\_\_\_\_\_