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# Family Faculty Perceptions: Sharing Their Story

Erin Jarry

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**FAMILY FACULTY PERCEPTIONS: SHARING THEIR STORY**

**BY**

**ERIN M. JARRY**

B.S., Criminal Justice, New Mexico State University, 1989  
M.A., Special Education, New Mexico State University, 1995

DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy  
Special Education**

The University of New Mexico  
Albuquerque, New Mexico

**December, 2009**

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**DEDICATION**

This manuscript is dedicated to my husband Jeff, and my daughter Kaci for their continuous encouragement and support.

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**ABSTRACT**

This qualitative study examines the experiences of family members who participated as Family Faculty in the Families as Faculty program. All of these family members were primary caregivers for students with disabilities. Families as Faculty is a part of some of the teacher preparation programs at universities in New Mexico. Three research questions were explored. First, why do families choose to participate in this program? Second, what are the benefits and challenges they experience as participants in the program? And finally, what about their experience influences their decision to continue or terminate their participation in the program? Data were collected through telephone interviews utilizing open-ended questions. Results indicated that Family Faculty chose to participate in the Families as Faculty program because they believed that by sharing their stories, they can influence students in teacher preparation programs thus positively impacting classroom practice. Family Faculty report many benefits and no challenges from participating in the program. Overall the participants reported that their experiences were extremely positive and they expected to continue their participation in the future. Implications for future research are discussed.



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## CHAPTER 1

### Introduction

#### *Background*

Henderson, Johnson, Mapp, and Davies (2007) stated “partnerships among schools, families, and community groups are not a luxury – they are a necessity” (p. 1). Parent involvement in education is a critical component of a child’s overall educational success. When parents are involved in a child’s education, there are extensive benefits for students, families, and schools. Student success, and academic achievement, the expression of a positive attitude and improved behavior can all be linked to parental involvement (National PTA 1997; Henderson, Johnson, Mapp, & Davies, 2007).

Henderson and Berla (1994) noted, “When schools work together with families to support learning, children tend to succeed not just in school, but throughout life” (p. 1). They went on to make an argument for the importance of family contribution to student achievement. They suggested efforts to improve children's outcomes are much more effective if the efforts encompass the children's families. Henderson and Berla (1994) also noted that when parents are involved in their children's learning at school, not just at home, children do better in school and they stay in school longer. Additionally, when parents are involved at school, their children go to higher performing schools. They went on to explain that children do best academically when their parents are encouraged to play four key roles in their children's learning: teachers, supporters, advocates, and decision makers. In summary they noted that a comprehensive, well-planned family school partnership fosters high student achievement. Finally, they stated families, schools, and community organizations all contribute to student achievement.

Over the last several years, the focus on enhancing a child's development through a focus on parent involvement has transitioned to focus on family outcomes and supports for families in other areas. In addition to building the family's capacity to assist their child's developmental progress, focusing on other family outcomes allows for an increase in the family's perceived ability to work with professionals. It also allows families to develop a strong support system, as well as increase their quality of life through envisioning an optimistic view of the future (Bailey et al., 1998).

Parental involvement in education has been scrutinized as a help or a hindrance in the educational process (Fylling & Sandvin, 1999; Soodak & Irwin, 1995). When parents and teachers are working well together, there is a sense of collaboration, camaraderie, and successful communication. When the communication fails between parents and teachers however, the ability to collaborate disappears and there is a feeling of discontent on both sides. Fylling and Sandvin (1999) found that parents play two roles, that of "implementer" and/or "client." The "implementer" role implies that parents and family members are, without influence, to "follow-up" on any directions or activities set forth by the school. The "client" role occurs when the parent is viewed as part of the "problem" by the teacher. They went on to note that whether a parent is viewed as an "implementer" or a "client" places them in a secondary and powerless role. They suggested that this "power play" could impede a school or teacher's ability to develop parental partnerships.

When a child receives special education services, parental involvement becomes even more critical. Henderson, Johnson, Mapp and Davies (2007) noted students with parents who are actively involved in their education at home and school are more likely to earn higher grades, higher test scores, enroll in higher-level programs, graduate from

high school, and go on to post-secondary education. Collaboration and communication between parents and education professionals are the essential pieces to the puzzle of educating a child with disabilities. Developing and maintaining relationships and partnerships with schools and education professionals is crucial for the academic success of a child with disabilities; and they cannot be created without parental involvement.

The notion of parental involvement in special education was not a priority in federal education legislation until the mid 1970's. As time has passed, several laws have re-iterated the importance, and strengthened the role of the parent in a child's education. Research has indicated that parental involvement is central to the successful education of any child and Congress is taking a stance on its importance as well.

*Education for All Handicapped Children Act (Public Law 94-142)*

In 1975 the Education for All Handicapped Children Act (PL 94-142) was signed into law by President Gerald Ford. It was the first of a series of legislative acts that would serve to increase and strengthen parental involvement in the education of children with disabilities. It established parents as important agents of accountability by defining safeguards and parental rights. The Act also established parents as critical members of the team responsible for designing and carrying out a child's educational plan.

In 1983, amendments to PL 94-142 provided funding for parent education and training centers as well as financial incentive to expand services for children birth to age three. Initiatives to implement transition planning from school to adult living were also added. 1986 amendments enabled parents to recover reasonable attorney's fees should they win their court case.

*Individuals with Disabilities Education Act (Public Law 101-476)*

In 1990, the amendments to the Education for All Handicapped Children Act (PL 94-142), changed the name to the Individuals with Disabilities Education Act (IDEA). The word “handicapped” was replaced with “disabled,” which allowed for expansion of services to students with disabilities. Amendments at that time expanded transition services to begin at age 16 for students with disabilities. Other amendments in 1990 included the addition of assistive technology, and rehabilitation counseling services to students with disabilities.

With regard to parent and student participation, schools are required to work with parents and adolescent students in designing and carrying out special education programs.

*Individuals with Disabilities Education Act 1997 (PL 105-17)*

The reauthorization of IDEA in 1997 created numerous changes to over sixty percent of the original amendments that improved the educational opportunities for children with disabilities. Transition planning was expanded to begin at age 14. The role of parents was strengthened even more in the educational and decision making process. The amendments provided opportunities for partnerships between parents and school professionals (20 U.S.C. Sect. 300.650(1)(2)). The school or public agency was required to consider parents’ concerns and the information parents provide in making any decision (20 U.S.C. Sect. 300.343(c)(iii)). Parents also had a right to provide information, express concerns, participate in discussions, and make decisions about the education of their child (20 U.S.C. Sect. 300.650(1)(11)(B)). Meaningful student access to the general curriculum was further developed as well. The amendment’s guarantee that students with disabilities have a free appropriate public education that emphasizes special education and related

services designed to meet their unique needs and prepare them for employment and independent living (20 USC Sec. 1412(a)(1)(A) and 34 CFR Sec. 300.1(a)).

*Individuals with Disabilities Education Improvement Act of 2004 (PL 108-446)*

Like previous amendments that kept the overall structure of preceding laws, a considerable portion of IDEA was retained in PL 108-446. However, significant changes were made in some areas. Procedural safeguards, the definition of a “highly qualified” teacher, state performance goals, performance monitoring, maximum state grant calculations and funding for children with high-need disabilities were all affected.

President Bush made the following comments on December 3, 2004 upon signing the Individuals with Disabilities Education Improvement Act of 2004 that further stressed the importance of parental involvement in the education of children with disabilities:

In the bill I sign today, we’re raising expectations for the students. We’re giving schools and parents the tools they need to meet them...Some students with disabilities will need intensive, individualized help. So this law, for the first time, will support tutoring programs to help children in schools that need improvement. When schools are so busy trying to deal with unnecessary and costly lawsuits, they have less time to spend with students. So we're creating opportunities for parents and teachers to resolve problems early. We're making the system less litigious, so it can focus on the children and their parents.

Bush went on to discuss the role of schools:

The people who care most about the students are of course the teachers, and especially the parents, who know their needs and know their names. So we're giving more flexibility and control over the students' education to parents and



teachers and principals. We'll make sure that parents and schools can change a student's educational program to better meet their needs, without having to attend unnecessary meetings or complete unnecessary paperwork. We trust the local folks to meet high standards for all our kids, and this bill gives them the freedom and flexibility to meet our goals (Office of the Press Secretary, 2004).

With regard to parental involvement, the above comments are directly reflected in the findings and purposes of the legislation noted below:

(B) Strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home (IDEA, 20 USC Sect. 602 (5) (b)).

And further:

...to ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinated research and personnel preparation; coordinated technical assistance, dissemination, and support; and technology development and media services (IDEIA 20USC Sect. 602 (d) (3))

As a result of this legislation, the Office of Special Education Programs (OSEP) requires states to report levels of parental involvement, and they then monitor and analyze the percentage of parental involvement.

### *No Child Left Behind*

The No Child Left Behind Act (NCLB, 2001) reauthorized the Elementary and Secondary Education Act of 1965 (ESEA) and was designed to improve the performance of American schools through six key principles: accountability, school safety, parental

choice, teacher quality, scientifically based methods of teaching, and local flexibility.

IDEA (2004) was brought into alignment with NCLB.

One provision of NCLB is stronger accountability. Academic proficiency by all students is something that states are working to improve. Progress must be reported to parents and communities annually.

Another provision of NCLB is more freedom for states and communities. Districts can use federal education funds to meet their own specific needs. Whether it is to provide professional development, additional teacher training, or hire new teachers, up to fifty percent of federal grant monies can be transferred to several education improvement programs.

The use of proven education methods is still another way NCLB hopes to improve the educational performance of American schools. Educational programs must be scientifically based; meaning that the programs and practices have been established as effective teaching programs and practices through scientific research.

NCLB also offers more parental choice. Parents may transfer their children to better performing public schools if their “home school” is considered lower performing for two consecutive years. If transporting the child to a better performing school is an issue, the district must provide transportation. Additional educational support is available to those low-income children who are enrolled in a lower performing school for three years or more. Additional educational support may include after-school services, tutoring and summer school.

Federal laws created the framework and provided the parameters for programs that revolve around the education of children with disabilities. The next section will

discuss different models of a family-centered philosophy that describe programs which enable professionals and parents to work alongside each other in a more unified manner.

*Family Faculty Models*

The Department for Family Support Services of the Kennedy Krieger Institute in Baltimore, Maryland created a family-centered consultation model by enabling the staff and other parents to work together alongside families of children with disabilities (Leviton, Mueller, & Kauffman, 1992). Families are accepted as the “real” experts on their children and as service delivery decision makers. Professionals are recognized as consultants and it is their responsibility to provide information that supports the decisions parents feel are right for them and their families.

Trinity College in Burlington, Vermont also incorporated family involvement throughout the required coursework in their early childhood and elementary teacher education program. The commitment to family involvement originally began from a focus on special education. “Pre-service teachers attend guest lectures led by parents who discuss issues related to parenting, finding appropriate child care, raising a child with special needs, and making the difficult transitions involved in sending a child to public school” (Shartrand, Weiss, Krider, & Lopez, 1997, np). Teacher preparation students are required to interview parents and other family members about issues related to early childhood. They also participate in a community service project where they provide child or respite care and gain a deeper understanding of what it is like to work with the families (Shartrand, Weiss, Kreider, & Lopez, 1997).

The Rural Special Education Project at Northern Arizona University prepares pre-service teachers to work with Navajo students with special needs. Up to ten special

education teachers participating in the project learn to work with Navajo families and other members of the community, while being culturally immersed by living on the Navajo reservation. The teacher preparation students are paired with a Navajo teacher aide who will assist the teacher preparation students to adapt to the community and learn about the Navajo culture. The teacher aides were previously students in the program (Shartrand, Weiss, Kreider, & Lopez, 1997).

The Parent Power Project at California State University matches pre-service teachers primarily with families of children with learning difficulties. Participants are matched with families for ten weeks. They participate in and complete projects and activities with the families. Activities may include conducting family interviews, conducting a school record review with the family, and modeling successful teaching strategies for family members. Weekly progress reports and a final summary are written by the participants as well. Participants will assist parents with creating a resource notebook as well as lead a parent discussion group and a children's self-esteem group on a weekly basis (Shartrand, Weiss, Kreider, & Lopez, 1997).

McBride, Sharp, Higgins-Hains, and Whitehead (1995) described a program at the University of Wisconsin which offered a faculty-parent co-taught class in a pre-service setting. They identified three objectives of co-instruction: “to model family-provider collaboration, to provide an affective understanding of family-centered practice, and to infuse a family-centered perspective throughout the course of the curriculum” (p. 345). They went on to say that co-instruction can occur on a continuum. “At one end of the continuum, parents may participate in well-defined but limited activities, whereas at the other end of the continuum, a parent comes to every class in the course with a more

pervasive and comprehensive responsibility” (p. 346). McBride et al. noted it is up to the faculty and parents to decide to what degree the parent will participate in the course.

McBride, et al. stated, “co-instruction provides an opportunity for students to see how the family-provider relationship develops and how important effective communication is to this relationship” (1995, p. 345). They went on to report, “if we have heard the pain or frustration that a parent feel as he or she describes being left out of a crucial decision related to his or her child’s care, we question present practices and are stimulated to discuss options to provide families with choices and power to make decisions” (1995, p. 345).

Families that participated in the co-instruction setting were said to be enthusiastic about sharing their daily family experiences. McBride et al. reported that benefits were widespread for families, students, and faculty, as a result of the experience. They stated that parents commented that good often arises from a difficult situation, and sharing their story enabled the parents to realize just how strong they actually are while providing benefit to others. Faculty reported that after co-instructing with a parent, they felt they were better teachers. Faculty also noted that a parents’ presence gave a sense of validity to course content. Clarification and feedback could be provided by a parent that would otherwise be unavailable.

Universities in New Mexico are working with Parents Reaching Out to improve the ability of teachers to collaborate with families of students with disabilities. The following sections will provide an overview of their efforts.

### *Parents Reaching Out*

Federal legislation recognizes that parents may need support in order to participate as partners in their children's educational decisions. In 1983, each state was required to establish a Parent Training and Information Center (PTI) to support parents. Parents Reaching Out (PRO) is the PTI for New Mexico. It is a state-wide non-profit organization that has operated in New Mexico since 1981. PRO's mission "is to enhance positive outcomes for families and children in New Mexico through informed decision making, advocacy, education, and resources" (PRO website, 2009). PRO accomplishes this mission by: developing family leadership, connecting families to each other, building collaborative partnerships, and providing families' knowledge and tools to enhance their power.

PRO is an organization that provides information, support, and education to unite and empower families throughout the state. Through a system of programs, workshops, consultation services, and newsletters PRO is able to provide parents, families, educators, other service providers, and professionals' opportunities to learn, problem solve, and network on a variety of levels. An assortment of informational and educational materials is created by PRO for dissemination throughout the state.

### *Families as Faculty*

Families as Faculty (FAF) is a program initiative developed by PRO in collaboration with The University of New Mexico. It receives funding from the New Mexico Public Education Department, New Mexico Department of Health, Family Infant and Toddler program (FIT) and the University of New Mexico Medical School-Continuum of Care. The FAF program "promotes family leadership skills and

professional learning opportunities for future teachers and doctors that prepare them to work in partnerships with families to improve services, systems and outcomes” (PRO website, 2009). FAF began with medical students in 1995, and in 1996 the program was expanded to include undergraduate and graduate teacher preparation programs in special education, elementary education, and secondary education (Keefe, Rossi, de Valenzuela, & Howarth, 2000).

The foundation of the FAF program is that it provides undergraduate and graduate-level teacher preparation students the unique opportunity to meet with families of children with special needs. Faculty from UNM and PRO collaboratively plan each FAF experience. Parents from PRO co-present class sessions to students enrolled in special education courses. Teacher preparation students are paired with the family of a child with a disability. All family participants are referred to as Family Faculty reflecting the parity with university faculty. Teacher preparation students meet with the family, usually at the family’s home; stories are shared by the members of the family of what their lives are like as they raise a child with special needs. The students get a glimpse of what a family experiences on a daily basis. It opens the door for communication and collaboration and emphasizes to the teacher preparation students that family-professional collaboration and communication are vital pieces to the puzzle in the education of a child with special needs. The students write a reflective paper on the experience they had with the family. They are asked to relate their experience to future and/or current teaching practices. At the end of the experience, the students and families gather at the PRO offices to discuss their experiences. They discuss how the experience might impact their teaching practices in the future.

Faculty from UNM and PRO staff have worked together to evaluate outcomes for teacher preparation students on an ongoing basis (Schmitz, 2004). The results of the Schmitz study indicated that participating in the FAF program was beneficial to the teacher preparation students that participated. Their participation in FAF influenced their beliefs which then ultimately influenced their practices in a positive manner.

There is limited research on family-university partnerships. There is also very little research on utilizing parents as partners in teacher preparation programs. Universities need to address the issue of parent involvement through various approaches. Colleges of Education need to prepare teachers who have the skills to collaborate with parents in school settings.

The outcomes of this project are of great interest to the FAF program, UNM, PRO, and the field of special education. There is a need to further explore the benefits families receive from this type of collaboration. This research could potentially impact the development of more teacher preparation programs that include a family involvement component. Allowing the families of children with disabilities to share their stories is crucial to the education of teacher preparation students. Parent and family involvement is vital if there is to be successful home/school communication, changes in teacher perception of students with disabilities, and change in teacher practice. It is critical that collaboration with families should be emphasized in all teacher preparation programs.

#### *Purpose of the Study*

The purpose of this study was to explore the experiences of families who participated as faculty in FAF. The research questions guiding the study were:

1. Why do families choose to participate in this program?



2. What are the benefits and challenges they experience as participants in the program?
3. What about their experience influences their decision to continue or terminate their participation in the program?

*Summary*

Chapter one examined the background and rationale for the current study. It is apparent that parental involvement plays a critical role in a child's educational experience. Students, families, and schools benefit when parents are involved in a child's education. The importance of parental involvement in education is increasingly stressed in the laws that are being developed and in the programs that are being created to provide students, with and without disabilities, an effective education.

## CHAPTER 2

### Literature Review

Interest in parental involvement in special education has grown since the passage of federal legislation that mandated parental involvement. As this legislation has changed over time, the requirement of parental involvement has intensified. Parent and families are provided an opportunity and are expected to participate in the education of their children with disabilities to a greater extent than ever before. The 2004 IDEA amendments mandate partnerships between parents and school professionals. The school or public agency must take into account parents' concerns and the information parents provided in making any decision. Parents also have the right to present information, state concerns, contribute in discussions, and make decisions about the education of their child.

Summers, Turnbull, Poston, Hoffman, and Nelson (2005) noted that the term "partnership" incorporates shared terminology including, collaboration, multidisciplinary teams, family or parent involvement. This study employs their definition of partnerships as "mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterized by a sense of competence, commitment, equality, positive communication, respect and trust" (p. 66). The purpose of the literature review was to find all articles that included research into the outcomes of partnership programs between institutions of higher education and families.

*Selection Process*

EBSCO Host was used to conduct a search of the literature in the areas of teacher preparation, parental involvement, and parent perceptions. The following key descriptors were used for the search: “teacher preparation,” “special education,” “parent perceptions,” “parent participation,” “parent voice,” “collaboration,” “families as faculty,” “parents as professionals” and “parents as educators.” The criteria used for this review included studies pertaining specifically to parental involvement in special education, family involvement in special education, parent perceptions in special education, and teacher preparation. A hand search was also completed by looking for articles listed in the reference sections of the articles found in the EBSCO Host search that pertained to the same criteria.

*Parent/Family- Professional Partnerships in Special Education*

A number of articles report the value of parent-professional relationships in general. Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) conducted a study utilizing focus groups and individual interviews of fourteen education professionals and eighteen families of students with disabilities who also had limited English proficiency. After data collection and analysis, six broad themes emerged, communication, commitment, equality, skills, trust, and respect.

Parent participants in the study stressed that positive partnerships cannot occur without communication that is open and frequent. The professional participants agreed with the parents about open and frequent communication but also noted that it should be free of jargon. Both groups spoke of “the importance of listening carefully and respectfully” (p. 175).

With regard to commitment, parent participants noted that the professionals should view their jobs as “more than just a job” and “They want the professionals to exhibit that commitment, and dedication in their partnerships” (p. 175). Professional participants agreed they need to show their commitment by viewing their job as a “calling” and going the distance for the families without regard to their job description.

Comments from parent participants in the equality theme described the importance of having parents feel validated and empowered when they share their point of view with professionals. The professional participants noted that there needed to be that common ground, however, they also noted that failure by one team member to collaborate could be detrimental to a partnership.

Parent participants in the study admired professionals whom they perceived could “make things happen”, in terms of concrete help for their child or their families (Blue-Banning et al., 2004, p. 178). Those professionals that held high expectations for the parents’ children were admired as well. The professional participants’ comments were geared more toward interagency partnerships rather than partnerships with parents, however, “the skills they wanted their colleagues to have were consistent with the qualities parents wanted for all professionals” (p. 178).

With regard to trust, parent participants used it to mean three things, reliability, safety, and discretion. Professionals who were reliable were trustworthy. If a child was in a safe environment free from harm, the professionals were viewed as trustworthy. And, if personal information was shared with professionals and the professional kept it confidential, then they were trustworthy. Dependable was a term that came up in the

professional participant interviews. If a service provider was dependable they were viewed as more trustworthy.

The importance of mutual respect was noted by both groups in the Blue-Banning et al. study. Parent participants felt common courtesy is often lacking in family-professional partnerships leading the authors to conclude, “The results of this study underscore the point that common sense and ordinary human decency are at the heart of positive partnerships between families and professionals serving children with disabilities” (2004, p. 181).

Soodak and Erwin (1995) conducted a study involving twenty parents utilizing open-ended telephone interviews. The focus of the study was on parent-professional collaboration. The participants were chosen because of their high interest in having their children with disabilities educated in inclusive classrooms. The data were analyzed and the following three themes emerged: what parents’ want for their children, parents’ perceptions of special education philosophy and practices, and parents’ perceptions of their relationship with school personnel. Soodak and Erwin found that the parents’ wanted the same thing for their children with disabilities as they would of typical children, for example, “They wanted their children to have a sense of belonging and self worth and be exposed to the same educational experiences as nondisabled siblings and peers” (1995, p. 265). They also found that the parents believed that their own educational and social goals for their children are not supported by a school’s philosophy or practice. Parents were concerned about the idea of segregated education because, “Segregated education denotes exclusion and degradation; which is the antithesis of what they most want for their children-a sense of belonging” (p. 267).

In addition, Soodak and Erwin (1995) found a need for more “meaningful collaboration” when parents wished to have their children enrolled in inclusive educational environments. They stated, “If a parent disagreed with what was recommended, they were reminded that the school, not the parent, were the expert on educational decisions” (p. 273). The school personnel would often use school jargon that the parents didn’t understand; they would also try to ridicule, manipulate, and ignore the parents’ if they had comments or concerns to share. However, they found that this didn’t prevent parents from going after the services they wanted for their children.

Nelson, Summers, and Turnbull (2004) conducted a study on family professional relationships with the purpose of understanding the participants’ views of parent-professional relationships. Data were collected through 34 focus groups which included 107 participants. Nelson et al. found that three themes emerged, availability and accessibility, breadth of responsibility, and dual relationships.

Nelson et al. concluded that the theme of availability and accessibility was related to parent-professional boundaries set within the relationship. They also noted that those boundaries were not visibly clear. Parents and professionals agreed that professionals should allow flexibility when services are being provided.

Breadth of responsibility is the theme that described professionals who provide services outside what was required. Examples of professionals who went above and beyond the call of duty and those that lacked a willingness to provide services were described. It was noted that, “Professional’s who go above and beyond are perceived as having a genuine interest in the child and family as persons, hence the impression that

such professionals view their relationships as ‘more than just a paycheck’ (Nelson et al., 2004, p.161).

The final theme described by Nelson et al. of dual-relationships was the least clearly defined. They were discussing family-professional relationships that went beyond professional into friendship. The researchers noted that these types of relationships could be open to the misinterpretation and conflict. Many participants believed there is risk and benefit with the development of those relationships.

Stoner, Bock, Thompson, Angell, Heyl, and Crowley, (2005) conducted a study to explore the perspective parents of children with Autism Spectrum Disorder (ASD) with regard to those parents’ interactions with education professionals. Participants included eight sets of parents. Semi-structured interviews were utilized to collect data. Interviews were analyzed using cross-case analysis. Each parent set was interviewed three times.

Stoner et al. found that parent interactions with education professionals were influenced by their struggle to obtain a diagnosis from professionals. The self-education that followed receiving a diagnosis allowed the parents to “perceive they were on equal footing with the education professionals in terms of their knowledge base” (pg. 43).

The parent participants reported that the first IEP meeting left them feeling confused which then resulted in parent distrust of the special education system. These feelings of distrust led the parents to be even more prepared for future IEP meetings and demand frequent, open communication with education professionals. It was noted that “administrators who were accessible, were supportive, and addressed parental concern were perceived more positively by parents” (pg. 46). Parent participants also reported that

teachers needed to have a “heart to teach,” meaning that as the relationship between teachers and parents developed and lengthened, a teachers’ positive nature allowed more trust. Stoner et al. stated that the process of interaction between parents and education professionals is multifaceted. They asserted that education professionals must understand the parent and child perspective. It is a vital piece to successful communication and collaboration.

Hess, Molina, and Kozleski (2006) studied parent perceptions regarding special education and inclusive practices. Focus groups and open-ended individual interviews were utilized to gather data. Twenty-seven parents participated in the study. The data were collected and analyzed using a constant comparative method. Three themes emerged that were related to parents, teachers, and schools.

In the first theme regarding parents, Hess et al. found that parent participants shared stories of how they advocated for their children with disabilities, but also stories of how they felt they had been “othered”, meaning they felt “something had been done to their family with little input from them” (2006, p. 152). Advocacy emerged as parent participants helping their own child, but helping others too, which allowed a sense of empowerment. However, with the sense of empowerment, they also had anxiety for the future. They worried about their children becoming more independent and changing placements.

The second theme regarding teachers enabled Hess et al. to find that “parents perceived teachers as critical to their child’s success” (2006, p. 153). However, parents were more concerned with a teacher’s perceived ability to be caring and open to communication. Parent participants spoke of frustration with the lack of communication



and partnership between home and school. Participants felt that this lack of communication led to feelings that the teacher did not understand the needs of the child or family.

The final theme relating to schools led the researchers to the conclusion that the parent participants not only place great importance on the services their children received, but they also “wanted to find a place where their child could belong” (p. 154) and further, “Families want a responsive school marked by a welcoming atmosphere and open communication” (p. 156).

Hess et al. (2006) argued that the first step to creating an equal partnership between families and education professionals is meaningful communication that is centered on family needs. They go on to note that the educators’ lack of understanding of family culture may lead to problems with creating and maintaining collaborative relationships between families and education professionals.

#### *Grandparents as Partners*

The body of research found on grandparents in education focused on how to be a support in the grandchild’s life through being a provider of childcare, provider of financial means, and/or emotional support. (Mitchell, 2008; Al-Azami, 2006; Gardner, Scherman, Mobley, Brown, et al., 1994) It also focused on how schools can support grandparents who are raising grandchildren with and without disabilities by linking them with family services (Mitchell, 2008). However, no research was found on utilizing grandparents who are primary custodial care-givers of children with disabilities as more than a school or classroom volunteer.

*Parent/Family-Professional Partnerships and the Child's Perceived Benefit*

There is a large body of research that indicates that all children benefit from family involvement in education (National PTA, 1997; Henderson, Johnson, Mapp, & Davies, 2007). Many authors' agree that student success and academic achievement, as well as a positive attitude and improved behavior can all be linked to parental involvement (National PTA, 1997; Henderson, Johnson, Mapp, & Davies, 2007). The perception of children toward schools, teachers, and family attitude toward education and how they feel about school and family involvement is a growing field (Eiserer, 1954; Vaughn & Bos, 1987; Deslandes & Cloutier, 2002). Research found on the perception of students with disabilities about family involvement was limited to transition planning (Morningstar, Turnbull, Turnbull, 1995).

*Family-Centered Approach in Clinical and Medical Practice*

In response to the needs of patients and families, family-centered care has evolved as a philosophy of care. The family-centered approach is successfully implemented when health care providers and families work collaboratively to create respectful relationships. Leviton, Mueller, and Kauffman (1992) noted family-centered practice allows the families to identify needs and goals. Additional information and/or concerns may be communicated by the professionals, however it is up to the family to accept or refuse the information. Professionals and family members work collaboratively to identify all possible resources and interventions needed so that the needs and goals of the families are met.

*Professional Partnerships at the State Level*

This section includes information on one study that was found, where parents were utilized as educator in an early intervention program. Georgia has implemented a state-wide early intervention family involvement model that utilizes parents of young children with disabilities as parent educators. Babies Can't Wait (BCW) mission is to actively promote family participation by disseminating current information to families of children with disabilities. Parent educators are hired to develop and distribute educational materials, provide information, develop and implement early intervention programs and activities for families, as well as other outreach duties. Gallagher, Rhodes, and Darling, (2004) conducted a study of the BCW program. The focus of the study was on parent educators and their changing roles and perceptions over time. Six focus group sessions were held over a period of five years. The data were analyzed and three themes emerged, roles, challenges, and success.

The parent educators initially described their roles and responsibilities in more generic terms, such as being responsible for gathering, sharing, and disseminating information, linking families to resources, and representing the parent perspective at local and state committee meetings. Over time, they became more specific in expressing the nature, value and importance of their role. As time went on, they desired more training, and they saw themselves as a bridge between the early intervention program and the families. They felt they assisted the professionals with understanding the unique needs of the families. They also felt because they were in the public eye more, they were viewed as professionals.

Challenges included confidentiality issues and professional "gate-keeping" as they impeded the efforts of the parent educators to be in touch with families on a regular

basis. Another challenge was assisting the local district with becoming more family friendly. Policies and procedures did not allow an environment that was conducive to family needs. And, like with all professionals, balancing home and family life also became an issue. There were not enough hours in the day to manage all the phone calls, meetings, and parental responsibilities.

Successes included assisting parents with needs; assisting with the development of public relations in a positive manner; educating professionals, and as a result, gaining the respect of professionals; and personal level success – contributing financially to the family and personal growth as a professional.

#### *Family-Professional Partnerships in Teacher Preparation*

Pruitt, Wandry, and Hollums (1998) studied what special educators could do to be more sensitive to the needs of families from the family perspective. Students in their parent-professional relationship course were required to interview the parent of a child with a disability. Seventy-eight parents were interviewed. The researchers found that parents want to be listened to. Parent participants want educators to know that they know their own children and that any contribution or suggestion a parent makes should be valued and respected.

The researchers also noted that parents feel the quantity and quality of communication between parents and education professionals could be improved. Communication did not appear to occur often enough or to the extent that parents believed it should.

Parent participants also believed that educators do not seem to understand that every family has its own unique set of characteristics and they need to be more sensitive

to that. They felt that education professionals should take the time to get to know the families on a more personal level. Some of the parent participants stated that the education professionals needed to increase their knowledge about various disabilities.

Forlin and Hopewell (2006) conducted a research project that examined the outcomes of parent participation in one university course. During this special education course, the mother of a child with severe disabilities shared her experiences with a group of 4<sup>th</sup> year primary and secondary education students. The mother shared her story, during a thirty-minute session at a university in Western Australia. The purpose was to find out what perceptions the teacher trainees held after hearing the mother's story. Data were collected from 46 of the students written reflections.

Analysis of the data led to the emergence of three themes: empathy, understanding, and personal growth. Within the empathy theme, the students were touched by the mother's story in a "deeply personal and emotional way." Many of them referenced their own experiences with family or friends in their writing. Their reflections indicated that they felt compassion and kindness toward the mother. They viewed her as a strong and courageous person who persevered.

The students gained 'understanding' of the fact that a parent really does know their child the best. Several noted that a teacher will not have the degree of understanding of a child's needs. It was also noted that without firsthand experience, no one can fully comprehend what the family or child needs.

'Personal Growth' was exhibited when students noted that they were realizing that children were actual individuals, not just numbers in a class, who come to school with complicated family backgrounds. They seemed to also realize that educational

opportunity is not equal for all students; some parents had to fight a little harder for their children. Also evident was an interest in how they, as future teachers, could better collaborate with parents. It was noted that opportunities to connect with other parents in similar situations would add greater insight. Including those parents who may have had potentially marginalized experiences could aid pre/in-service teachers in gaining a better understanding of the breadth of skills needed to work with all parents.

A similar study was conducted directly with the FAF program at the University of New Mexico (Schmitz, 2004). Sixteen in-service teachers who were participating in a graduate level special education course participated in the FAF program as a course requirement. The purpose was to find out if the FAF experience had an impact on the beliefs and long-term practices of the participants, the in-service teacher. Data were collected through the student's reflection papers and an evaluation survey, as well as through interviews with eleven participants. Data were analyzed utilizing a constant comparative method that revealed five major themes: teacher preparation courses, practitioners' beliefs, adversity-advocacy, home-school relations, and practice.

The first theme indicated that the participants benefitted, and were impacted by participating in the FAF experience. They indicated that it was a positive experience that did influence their beliefs about children with disabilities and their parents and families. Participants made positive comments about the experience and how it enabled them to gain a better understanding of what the families went through. Participants also spoke of the need for this type of experience to be required for undergraduate and graduate level students. Participants also perceived that family faculty benefitted by sharing their story.

The second theme, practitioner's beliefs, explored the participants' personal beliefs about individuals with disabilities and their families. Although many of the participants had worked with children with disabilities, however, they had not thought about the reality of having a child with a disability twenty-four hours a day. The participants took notice of that fact that "all families wanted their child to be happy, to be able to do what all other children do, and to be treated the same as others" (Schmitz, 2004, p.57). Participant's beliefs regarding empathy, admiration, and respect were all impacted by participation in FAF.

A third theme, adversity-advocacy, emerged as a theme based on the hardships and struggles the families had faced. Participants understood that the families became advocates for their children because of the hardships and struggles. One participant noted, "The parents have had to stand up for their children's rights time and time again, and they really knew their rights as parents and the rights of their children" (Schmitz, 2004, p. 70).

The fourth theme, home-school relations, exemplified the need for collaboration and communication. The participants noted that their communication and collaboration with the parents was also influenced by participation in the program. They realized that effective communication and collaboration was essential to build and maintain home-school partnerships. Participants in the Schmitz study seemed to understand family faculty were individuals they could learn from. The parents were able to provide the kind of information on the child that no one else could.

Theme five, practice, referred to knowledge gained and applied, which ultimately led to changes in classroom practice. The participants felt more at ease if they wanted to

ask the parents for ideas on helping their children. They felt they could and should incorporate parents' observations and input into the IEP.

The Schmitz (2004) study provided a long-term look at how the FAF program impacted practitioners. The participants had been teaching for a year when they were interviewed again. It was found that the same factors discussed above still impacted their practice up to a year after the FAF experience was completed.

### *The Importance of Narratives*

The stories of our lives are shared in bits and pieces as we journey through each day. They are a means to let people know who we are and what we are about. The sharing of stories enables us to get to know other people and to share our experiences, and their experiences, good or bad. Stories, or narratives, are a way to share the lived experience in that, "Narratives invite us to stretch our imagination to grasp events befalling another individual. To exercise our imagination is to affirm our capacity to move beyond the boundaries of own bodies and experiences to appreciate others' storied representations of reality" (Harter, 2009, p. 147).

The use of narratives with individuals with disabilities and/or chronic illness and their families is included in a large body of research. Since the 1960's there has been an increase in the use of narratives as a tool in the healing process. Fields including medicine, psychology, and counseling are all using narratives as a therapeutic approach to healing. Generalizing the problem through story encourages an individual's healing. This enables an individual to not feel so alone. Sharing their stories provides individuals with a sense of control; they gain a better awareness of themselves and their relationships (Brody, 2003).



Researchers in the field of education utilize narratives in studying the experiences of administrators, teachers, parents, and students (e.g. Martell & Antrop-Gonzalez, 2008; Campano, 2007). The narrative approach has also been utilized to study the perceptions of students with disabilities (Moore and Keefe, 2004; Allodi, 2002).

### *Summary*

Research showed that family- professional partnerships in special education is critical for the successful educational experiences of children with disabilities. Frequent communication and collaboration, as well as the continued development of trust and respect within the relationships were indicated by both parents and professionals as vital to successful partnerships.

The family-centered approach in clinical and medical practice has evolved as a philosophy of care. A successful family-centered approach is evident when health care providers and families work collaboratively to build respectful and effective relationships.

Professional partnerships at the state level are being formed. Georgia's ability to implement a statewide program provides a learning opportunity for other states on how to implement similar partnership programs across the state.

Family-professional partnerships in teacher preparation provide innovative ways to increase the skills and abilities of teacher preparation students. Students need to receive an education that provides them with skill that enables them to develop relationships that foster frequent communication and collaboration with families.

The review of the literature suggests creative and innovative ways to prepare special and general education teachers for life in the classroom has begun to take place

through the use of the family-centered approach. The research indicates applying this approach to the university setting has allowed students, parents, and faculty to gain essential knowledge and skills about family-professional partnerships (McBride, et al., 1995; Schmitz, 2004; Forlin & Hopewell, 2006).

The educational participants in both the Schmitz (2004) and Forlin and Hopewell (2006) studies appeared to truly value their experiences with families and thought that the experience had been transformational. They reported that they gained knowledge and understanding about the families and they understood the importance of their interaction with the parents and other family members. Neither study mentioned what the mother/parents/families gained as a result of sharing their stories.

This literature review demonstrates that there is a lack of research into the experiences of family members who collaborate with faculty at institutions of higher education. The current study will help to fill this gap by reporting the results of a study documenting the experiences of family members who participate in Families as Faculty in New Mexico. This research has great relevance for both parent organizations and teacher preparation programs that want to implement similar models as well as policy makers who fund such initiatives.

### *CHAPTER 3*

#### Methodology

##### *Theoretical Framework*

This study employed a Phenomenological Study approach which attempts to “understand how individuals construct, and are constructed, by their social reality” (Gall, Gall, & Borg, 2003, p. 481).

##### *Phenomenological Study*

Gall, Gall, and Borg (2003) defined phenomenology as “the study of the world as it appears to individuals when they place themselves in a state of consciousness that reflects an effort to be free of everyday biases and beliefs” (p. 481). Creswell (2007) explained phenomenology as the study of the significance of lived experiences for several individuals. For Stringer (2004) phenomenology is a philosophical approach that investigates the subjective aspect of personal experience. He explained that this type of research strives to expose and understand the significance behind individual life experience. Mertens and McLaughlin (1995) described phenomenology as the ability to consider and illustrate an event from the participant’s point of view. Phenomenology, while defined differently by researchers, is ultimately the study of an individual’s lived experiences. Bruyn (1966) stated “phenomenology serves as the rationale behind efforts to understand individuals by entering into their field of perception in order to see life as these individuals see it” (p. 90). Gall, Gall, and Borg (2003) stated phenomenological studies can be used to explore a variety of educational phenomena.

A major advantage of utilizing a Phenomenological approach in this study was that information was collected through in-depth interviews; this allowed the participant to speak freely.

#### *Positionality/Validity*

The underlying assumptions that a researcher holds play a critical role in the ultimate findings of his/her research. As a parent, and teacher, I strongly believe that parent involvement is a critical aspect of the overall successful education experience for any child. As a former participant in the Families as Faculty project, I have seen firsthand how the project has changed thought processes and lives by enabling pre- and in-service teachers to experience a day-in-the-life of a family of a child with a disability. For those teachers who have never had the opportunity to work with a child with a disability, the experience can be truly transformational. The parents and families of FAF have the ability to provide a wealth of information that cannot be gained by only having a child in the classroom. FAF provides the opportunity for university students to *see, experience* and *feel* the stories of these families on a deeper level. These parents and families have stories to tell. Without hearing these stories, teachers and teachers in training are overlooking an important piece of their education. Therefore, I entered into this research project with beliefs and assumptions that parents and families of children with disabilities play a crucial role in the education of pre- and in-service teachers. I also held the belief that these parents have a story to tell, and that their story is critical.

#### *Setting*

As previously mentioned, the foundation of the FAF program is that it provides undergraduate and graduate-level teacher preparation students the unique opportunity to

meet with families of children with special needs. Families are recruited by PRO and attend a course, Host Family 101, which is designed to teach the family faculty about the FAF program, and help them identify stories to share. It is a training that occurs so that the families can plan for a successful student visit. An additional workshop, Host Family 201, is available to those families that have been participating in the FAF program. It is designed for the families to share their experiences, the successes and challenges they have had with students, and to discuss ways to improve their visits with the students. Once a family has participated in Host Family 101, they, along with Faculty from UNM collaboratively plan each FAF experience. Parents from PRO co-present class sessions to students enrolled in special education courses.

Teacher preparation students are then paired with the family of a child with a disability. Teacher preparation students meet with the family, usually at the family's home; stories are shared by the members of the family of what their lives are like as they raise a child with special needs so that the students get a glimpse of what a family experiences on a daily basis. It opens the door for communication and collaboration and emphasizes to the teacher preparation students that family-professional collaboration and communication are vital pieces to the puzzle in the education of a child with special needs. Each step of the FAF experience is deliberately and consciously planned so that every student and family faculty member has a great experience.

#### *IRB*

This research project was approved through UNM IRB in April 2008. The IRB explained the Parents Reaching Out and Families as Faculty programs. It also explained how participants from FAF would be involved in the project. The data collection procedures

were described, which included telephone interviews, as were procedures to protect the identities of the participants. Consent to participate was obtained from all participants.

### *Participants*

Recruitment of participants occurred through an announcement in the Families as Faculty Newsletter that goes out to all families that participate in FAF throughout New Mexico, past and present. The newsletter is sent out by PRO. Family members who were interested in participating notified PRO that they were willing to participate. PRO provided this investigator with the participants, contact information. Initially, this investigator was provided with a list of ten names and their contact information. Two possible participants could not be contacted through the information provided. Eight possible participants were contacted about participation. Ultimately six potential participants agreed to participate.

Participants who agreed to participate received a telephone call explaining the consent form and research process. The consent to participate letter was sent via regular mail delivery to the participants. They signed and returned the form to this investigator. Once I received the consent to participate, I contacted the participants to schedule a telephone interview.

The participants in this study included six parents of children with disabilities who have participated in the Families as Faculty Program at PRO as Family Faculty (see Table 1). All participants were female, four were mothers, and two were grandmothers. The sample included four participants who identified themselves as Caucasian, and two who were Hispanic. Three of the participants lived in urban locations and three lived in

rural locations. The number of times family faculty had hosted students ranged from once to ten times.

Table 1. Participants

Participant	Ethnicity	Relationship	Number of children with a disability	Age of children with disability	Live in a rural or urban location	Number of times a host family
Bonnie	Caucasian	Mother	1	12	Urban	6
Clare	Hispanic	Mother	6	11, 10, 8, 7, 3, 7 mos.	Urban	10
Eve	Caucasian	Grandmother	3	8, 6, 5	Rural	1
Iris	Hispanic	Grandmother	1	9	Rural	7
Joan	Caucasian	Mother	2	23, 18	Urban	8
Rachel	Caucasian	Mother	2	Unk.	Rural	1

### *Confidentiality*

To ensure confidentiality pseudonyms were used throughout. Data will be kept for three years and then destroyed.

### *Procedures*

#### *Method*

Semi-structured interviews were utilized to collect data during a telephone interview with each participant (Spradley, 1979). I telephoned the participants to set up time for interviews. The interviews were conducted via telephone in May of 2008. Each

interview lasted 10-40 minutes. The interviews were recorded. The interviews were transcribed in August and September 2008. Follow-up phone calls to each participant occurred in September 2008 for clarification purposes. Semi-structured interviews were utilized to collect data.

The semi-structured interview questions were:

- 1) Tell me how you became a host family for FAF.
- 2) Describe what happens during a typical visit by students.
- 3) Are you going to be a host family again? Why/why not? Would you do anything differently next time?
- 4) What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?
- 5) In what way(s) do you hope this experience might have an impact on the future teacher's classroom practice.
- 6) Do you think your relationship with your own child's teacher is better as a result of your participation in FAF. Can you give an example?
- 7) How has PRO prepared you and supported you for your role as a host family? Can you give an example?
- 8) How have you and/or your family benefitted from participation in the FAF program?

Consistent with Spradley (1979) semi-structured interview questions were utilized. Interviews were tape recorded and then transcribed. Each participant was assigned a specific color of print. Color coding of transcript print was done so that responses could be identified with specific participants during analysis. Each transcript



was formatted into two columns per page. The data were read several times to look for repeated words, ideas, and common phrases. The interviews were cut apart into statements representing individual thoughts. These units of thought were then recorded on index cards.

### *Analysis*

Analyzing the transcribed interviews starts with coding the data. Lincoln and Guba (1985) discussed a constant comparative method where data is read several times to look for repeated words and common phrases. They go on to mention that categories give names to semantic relationships. The data analysis method for this study matched the procedures from the constant comparative method of Lincoln and Guba (1985). These repeated common words and phrases were defined as the formation of a major idea through overlapping and interrelation of codes, or themes (Creswell 2002). The prevalence of the idea in data is noticed by the researcher who labels them to characterize the nature of the idea (LeCompte and Schensul 1999).

As noted above, interviews were transcribed, the print was color-coded, and broken down into units of thoughts on index cards. The index cards were sorted into preliminary themes.

### *Trustworthiness*

Utilizing multiple approaches to the phenomenon allowed me to enhance the trustworthiness of the findings of this study. By utilizing multiple sources and negotiating themes and codes with critical friends, trustworthiness was increased. A critical friend provided “fresh eyes” in assisting with thematic analysis and coding. This investigator sorted the statements into themes and color-coded each theme. Then, a critical friend

categorized the statements into themes and the color-coding was compared with mine. The coders discussed the units and themes, looking for agreement and checking for similarities and discrepancies. When discrepancies occurred, the coders discussed these until consensus was reached. A sample of 100 cards was then taken and another independent critical friend sorted them again to see if they were placed them in the same color-coded categories. The findings were discussed and compared until consensus was reached. Anderson, Herr, and Nihlen (1994), referred to this as, “dialogic validity” (p. 32). The comparison and ensuing discussion of the findings led to an advanced degree of accuracy.

#### *Member Checking*

Member checking procedures employed by Lincoln and Guba (1985) took place. Member checking provided participants the opportunity to agree that what was said during the individual interview was a fair representation of what they said, and that it was interpreted correctly.

The member check... is the most crucial technique for establishing credibility. If the investigator is to be able to purport that his or her reconstructions are recognizable to audience members as adequate representations of their own (and multiple) realities, it is essential that they be given the opportunity to react to them. (1985, p. 314).

Initially, it was this investigator's intent to have a focus group with available participants for a member check. However, due to some participants living in rural parts of the state, and the other participants in the urban area being unavailable, member check was conducted through electronic mail. Each participant received the results of the study

via electronic mail or regular mail delivery and was asked to provide feedback consistent with Lincoln and Guba (1985). The feedback provided by the participants will be discussed in Chapter 4.

## CHAPTER 4

### Results

#### *Thematic Analysis of the Data*

This chapter summarizes the findings of data collected from April 2008 thru April 2009 from six Family as Faculty host parents. The data consisted of six transcribed interviews. The transcripts were read several times to look for repeated phrases or comments. The transcript print was color-coded for easy identification of individual participants. Each interview was dissected into units that represent one thought. Each unit was pasted onto index cards. The index cards were then sorted into major themes. The major themes that emerged were individually color-coded. After the preliminary analysis, two other coders re-sorted the units of thought into themes. They discussed the themes and looked for similarities and differences. Discrepancies were discussed and agreement was reached. Themes were combined or re-named and the units were again re-sorted into the major themes. Discrepancies were again discussed until agreement was reached. All three coders came to agreement on the final themes.

The first set of themes consisted of the following:

1. Family-School Challenges – parents can help teachers, teachers need to understand
2. PRO Process – training, talked to someone else who had been involved, received a flyer
3. Home Visit – story changes every time,
4. Perspective – change perspective, give a different view, see

5. Raise Expectations for kids – expectations
6. Impact on practice – be more creative
7. Family as a Source of Information – parents are the expert, teachers are not the expert, respect, listening
8. Benefit – benefit, it makes a difference
  - a. Teacher – every student is different
  - b. Family – confidence, empowerment

As discussion ensued between coders, the themes evolved and were combined or re-named. “Family school challenges” was added as a sub-category under the “Family as a source of information” theme, “PRO process” and “Home visit” were placed under a new theme “Process”.

The second set of themes that emerged included the following:

1. Process
  - a. PRO Process - training, talked to someone else who had been involved, received a flyer
  - b. Home Visit process - story changes every time
2. Perspective - change perspective, give a different view, see
3. Raise Expectations for kids – expectations
4. Family as a Source of Information - parents are the expert, teachers are not the expert, respect, listening,
  - a. Family school challenges - parents can help teachers, teachers need to understand, communication
5. Impact on Practice – every student is different

6. Benefit – benefit, it makes a difference
  - a. Teacher - every student is different
  - b. Family – confidence, empowerment

Further discussion and a re-sorting of units of thought led to the final set of themes. Themes were once again combined and/or re-named. Under the theme “Process”, “PRO process” was re-named “Initial involvement” and “Home visit” was re-named “Home-visit experience.” “Teacher Benefit” was combined with “Impact on Practice” which became “Impact on Teacher” with “Expectations,” “Practice,” and “Change in Perspective” becoming sub-categories. “Benefit” stayed as a major theme, but “Parents” and “child with a disability” became sub-categories.

The third and final set of themes that emerged included:

1. Process
  - a. Initial involvement - saw a flyer, talked to someone who was involved or had done it, training
  - b. Home visit experience - it changes every time,
2. Family as a Source of Information - teachers aren't the expert on the child, parents are the expert, understanding, listen, respect, parents can help teachers
3. Impact on Teacher
  - a. Expectations - teacher understanding that every child is different
  - b. Change in perspective - more to the student than what they see, think differently
  - c. Practice - become more creative in their teaching, remember the experience (home-visit)

4. Benefit
  - a. Parents – benefit, teacher understanding, makes a difference, being positive, learn from others, empowered, confidence
  - b. Child with a disability - confidence

These four major themes emerged from the data analysis. Three of the four themes have sub-themes, or sub-categories. Each theme and sub-theme will be described and defined through the use of the participant's actual words. The family's view of the importance of Families as Faculty on a teacher's educational experience is presented through these themes.

#### *Theme #1 Process*

The first theme that emerged, Process, It was determined that data were part of the overall process, but fell into two distinct categories within the process theme.

##### *Initial Involvement – "I could do that"*

This sub theme shows how participants first became involved in FAF. Results indicated that two of the participants, Rachel and Eve, became involved in FAF as a result of receiving a flyer about the program. Rachel stated, "...yes, I am sure it was just a flyer I got through PRO and I called them and said, you know, I just want to be involved." Eve said, "I became a host family through Early Head Start. I had grandchildren in there that were going and they had a flyer that came through and they asked for families to go." One participant, Joan, became involved as a result of needing assistance from PRO, and knowing someone who was already a host family. She said, "It wasn't until we got some help from PRO and we asked about it, and through another friend who had done it and could see the benefits, and she suggested that we do it...that's

how we started.” Two other participants, Clare and Bonnie met or spoke with the program coordinator, either at a training or convention. Bonnie stated, “I attended a workshop at PRO...and I remember that being discussed, hosting was discussed and they said if you are interested in hosting, then you could attend the Hosting 101 workshop.” The final participant, Iris, just recalls volunteering to participate, “It’s been so long ago, I think somebody asked me would I, and I think I said yes, I could do that.”

*Home Visit Experience - “I find it’s never the same”*

The procedure for setting up a home visit is essentially the same each time. The students attend a two hour orientation class facilitated by Family as Faculty staff. Students are provided with family contact information and the best time to call. Students then contact the family to set up the two-hour home visit which takes place in a location of the family’s choosing, usually the family home. The students are expected to be prepared to ask questions. The home visits are meant to be relaxed and informal and not an interview situation. It is up to the family who will be present for the visit.

Data indicated families have different approaches to the home visit. Two of the host parents described how they would meet with the students one-on-one initially before bringing in other members of the family. They share a bit of their story before introducing the child. Iris revealed, “I get to do my introduction of Jack even though they haven’t seen him yet. Then, I’ll have a caregiver bring him out without his helmet, and they can interact with him a little bit...” Bonnie stated, “I generally try to set it up so the students come to my house about an hour and a half before my son’s bus arrives, that way I have them come in and chat with them for a few minutes...”



Other host families included other members of the family from the beginning of the visit. Rachel explained, “We started up, and what I did is this, they met the boys, and we went into the boy’s, what we call their therapy room.” Eve said, “Well, the teachers come, and we all sit down and basically we just visit. I introduce them to the children. Sometimes they ask the children questions, sometimes they don’t. We just make it a big visiting party.” Joan noted, “And I think our kids, it’s been fun to watch them go in and talk as they’ve gotten older, they’ve been able to participate a little more. Before, Roger would just disappear, they got to meet him briefly, but now they got to see that aspect of how hard it is being around people, but now, Roger will come in and talk. Jacob, when he was younger he would always want one of them to go play a game with him.”

During the home visit the host parents share their story. Rachel pointed out, “The two students and myself just sat there with the door closed so we wouldn’t be interrupted and I just told really what we’ve gone through and what happened, the most trying times and the things that have work really well.” Eve mentioned, “We tell them what our views and expectations are of the teachers that deal with our children, and what kind of results we get.” Bonnie said, “I explain that his development was normal and he seemed very bright. I don’t actually tell them what his disabilities are until I am that point in my story that I knew myself, which was after third grade.” The participants indicated that uncertainty played a role during the initial visits. Joan recalled, “At first we were very nervous when they were coming, and we weren’t quite sure what to say, and we just kind of talked and talked.” But as time goes on, and they gain more experience at being a host family, several participants stated how the home visit changes over time. Clare stated, “But when I had to sit down with a captive audience who didn’t know me at all, and

didn't know anything about our family, but they knew why they were here, but they didn't know anything about us. I think it has helped me refine what I talk about and how I talk about our family." Iris noted, "I find it's never the same, truly the same. Our story is always the same, but the questions they ask are different. Some of the points that I bring out may be different; I can't say I like to do it different every time, it just seems that way." Joan explained, "I think the first couple, we talked so much about autism, which at that time, one of our boys was on the spectrum. But as we went on, we started realizing these things apply to other people. So we kind of bring that more in because other parents and the training, so they realize it's not just about autism, it's about many children." Bonnie said, "Each time I host, I have a document that I have put together on my computer, and each time I host, I look at it to see what needs to be updated because maybe he's had another test done, or maybe he's finished another grade, or maybe he's had struggles or accomplishments in different areas."

*Theme #2 Family as a Source of Information – "Hearing it from someone who is an expert on their child"*

Family as a Source of Information theme was a result of the participants feeling that they had something to offer to pre-service and in-service teachers. They each felt that they could help the teachers if the teachers would listen, respect, and understand what they, as parents had to say. They felt they could be a source of information for the teachers and help them in dealing with their children, or children the teachers might have in the future. Each one made a comment regarding the fact that they know their children better than anyone else. Rachel stated, "They (the teacher) aren't the expert on the child even though they are the expert in the classroom." Clare remarked, "It opens my mind a

little bit to help them understand what our kids are like outside of the school setting, which I think can really help these teachers realize the parents are the experts on their kids, not sometimes or usually, but always are.” She went on to state, “When you are thinking about a child that you may come into a situation with, who is cognitively just not there, and really listening and hearing what I have to say about Caty, and the things she has done. Hearing it from not just an “oh mom’s talking,” but hearing it from someone who is an expert on their child.”

Having a healthy respect for both parent and teachers was mentioned by two participants. Bonnie stated, “I think it is very important that the teachers respect the parents and that the parents respect the teachers, and that they support each other and that they have good teamwork and good understanding when there are special needs. Rachel noted, “In particular, those with other issues than just besides learning disorder, that they really do know their children best and should be respected for what they have to say.”

The ability of the teacher to really listen to the parent was important to the participants. Esther remarked, “If the teacher deals with and listens to what the parents have to say, because the parents deal with their children all the time, and they may have insight into how the children are acting and how to deal with them in a setting, any setting.” Clare said, “The way to have a very beneficial educational experience is sometimes to really listen to the parents and to the techniques and ways that they work with their kids, and how they can use those types of experiences in the classroom to really create a dynamic education for the kids.”

Compassion and understanding from the teacher was another area that participants talked about. Rachel said, “And to see when a family doesn’t follow through with what

they've said, that they can understand the family has their reasons for doing that due to the abilities they see for their child, or if the parents push for something, the teachers need to look at these parents, and know that they know their kids better than the teachers ever will. One participant, Eve, had a child who had had a stroke join their family, she noted, "We have a whole new set of disabilities to help them understand." She went on to say, "The families are a great source if they will just go to them. The families can help them understand a lot of times how to deal with the children." When speaking of her son, Bonnie noted that he often had difficulty waking up and getting to school on time, that he was one or two minutes late quite often. She said, "I wanted, if they had a kid in the future who was on the verge of being late every day, I want them to understand it was very frustrating for us, for my husband and I."

### *Theme #3 Impact on Teacher*

This theme encompasses three sub-themes that emerged from the collected data. Raising expectations, classroom practice, and change in perspective all surfaced as important issues under the Impact on Teacher theme.

#### *Expectations – "You don't need to expect less of them"*

The importance of having expectations for children with disabilities is of utmost significance in a child's educational experience. The participants in this study further reinforced how vital high expectations are. Joan noted, "I am hopeful that they will see, that every child, especially when they are younger, that they can learn." She went on to say, "That they challenged them, that they didn't give them dummy work, or like in special ed, the kids, they have to perfect something before they go on. We never did that with regular kids." Clare stated, "They (the teachers) will open their eyes to the

possibilities that the kids are part of families who have hopes for them no matter the disability.” Eve remarked, “All teachers need to understand that just because a child has a problem, it doesn’t mean that you need to expect less of them than you would expect of normal children.” She stated further, “We have high standards for our children and we strive for them to meet those high standards. And if they need extra help, that’s fine, we don’t mind providing it. We want teachers to understand that you should expect as much out of a disabled child as you do a child that isn’t disabled.”

*Change in Perspective – “It just takes seeing the other side of the coin”*

A vital piece to the FAF program is that it provides students with a change in perspective. It offers them a glimpse of what it might be like to raise a child with a disability. They are offered a rare opportunity to hear about the good times and the challenging times, in order to gain a deeper understanding of what the families go through on a daily basis. To the participants, this change in perspective for future teachers is very important. Iris stated, “My grandson has a seizure disorder, so he is supposed to wear a helmet all the time. One of the things I do is I have the students come and see him without the helmet and observe him and see how he is. And then, I put the helmet on and I point out to them, would you have the same impression of him with the helmet as without? Most of the time, that is huge for them and they say “no”. Usually when you see him, you see him with the helmet and you make assumptions. And I tell them no, you can’t make an assumptions, because this is still a kid. The helmet is just a prosthetic device. There is still a kid underneath there who has the same things all the other kids have, plus some extra baggage that they have to deal with.” She went on to say, “I have had several student teachers who have come who have said that it really just takes seeing

the other side of the coin to see what it is like to be the family of the child with special needs, to see what all they have to go through, to see all the expertise that goes into their care of the child in order to see a different perspective.” Clare remarked, “I think that teachers who are teachers already, and university students who are becoming special education teachers, it’s invaluable to have them look at children with special needs in all the different lights than they are used to. They get to see these children at home as part of vibrant and busy families.” She further stated, “Their disabilities are not the forefront of their home life, their quality of life becomes the forefront. They (the teachers) get to see where they live, the dynamics of the family and I think sometimes it changes the ideas that these kids live in some kind of bubble, some kind of alternate universe that the rest of us.” Rachel commented, “I hope it gives them a different view, a different perspective, so that when they are approaching the IEP and all of that, so that they are thinking of it as a child and not just a piece of paper to be completed and a process that has to be gotten past. I think it is important for teachers to realize that there is something other than what they see in the classroom.” Iris shared a similar statement, “I think the experience of being with a family that has a kids with actual disabilities before they are thrust out there in the real world, I think helps them see in a more practical manner, seeing the logistics of getting through the day. And I think it helps them see in a more practical way, this is a family, this is the way they live.”

*Classroom Practice – “Look outside the box”*

It is the hope of the FAF parents and FAF program that students who participate in the program will use the experience as a cornerstone in developing and implementing their classroom practice; that they will remember what they saw and heard, and be more

creative in their approaches. The participants in this study reinforced this hope. Joan remarked, "I think through some of our experiences, because each child is very unique, hopefully they'll pick up some of these things. We're hoping if they are teaching and they have a student, maybe like one of ours, one of the same experiences that they'll remember, "wait a minute, I've had that experience" and maybe some of it will come back to them that they can actually use and benefit some other kids." Joan observed, "I hope that every student that goes through their class will never have to go through the experiences that my kids had, the negative experiences. That they will bring back and they'll approach it in a different way. And that the kids will not be hit, or yelled at or abused in any way like my kids were at times, because the teacher didn't understand." Bonnie noted, "I hope they are more patient and more understanding as well as maybe recognize some things going on in kids, that maybe they haven't received their IEP yet, but they don't know what's going on, or maybe there hasn't been an IEP, maybe there hasn't been a diagnosis, but they've recognized something going on in the kid, so maybe something I've shared with them about my son will help them to be creative to reach a child in the future." Clare commented, "To look outside the box and be creative in their ideas to teach special kids. That there is always a way to teach and sometimes the smallest progress is giant steps for that child."

The importance of keeping up with the latest classroom practices was also mentioned by participants. Iris noted, "Sometimes when you are purely clinical or purely educational, you have a tendency to forget things." Joan mentioned that her husband, who is a teacher, was reminded to keep up with the latest practices. "And because sometimes you know if you are teaching, you go and do things, he talks about, "Oh, I should go and

do this for one of my students” or it reminds him to try to keep on top of things. We all need something to keep us fresh. And so, I think as a teacher, doing this has actually helped him.”

Two of the participants ran into students at a later date that had participated in the FAF program and been to these individuals’ homes. Joan observed, “We’ve ended up...running into them later, and have been all excited, because one in particular we saw years later, and she recognized us first and remembered every single one of our children and she just came out and said, “I am going into teaching children with autism because of your family.” And to us, that was huge for us to realize she has gone into something because she had been to our home.” Rachel shared a similar experience, “Then a couple of weeks later, I was in the store and I see one of them, and she was like, “hey, Rachel, how are you, and how are the boys?” It was nice to have that connection and to know that they actually cared enough to remember my name and know it made an impression on them.”

#### *Theme #4 Benefit*

Two sub-themes emerged in the results. The results indicate that the parents benefitted in several ways, but that their children with disabilities also benefit from participating in the program as well.

##### *Parent Benefit – “I feel a little more empowered”*

The participants expressed that participating in the program has given them a sense of confidence that they previously didn’t have. Joan observed, “It’s given us more confidence to go in and talk to teachers.” She went on to mention, “When things aren’t right, we know we have to change it, and there are some times when things aren’t going



to work out and we've had to change teachers or we've had to change an EA. And I think we've got more confidence to be able to do that. Iris mentioned, "...I didn't have the self-confidence before...it's like, well, I've learned to listen to my own feelings, listen to when I feel uncomfortable then there is a problem. I learned to go with my gut."

Results indicate that participants gained a feeling of empowerment by participating in the program. Eve noted, "It makes me speak out a little more and to know that maybe I can change their opinion on how to deal with my children." Clare stated, "And so I think it's made me feel empowered on being an expert on my kids." Bonnie observed, "I feel a little more empowered in the educational system, because the students I am speaking with will hopefully all become teachers or the majority will become teachers, so I feel I have a little bit of impact in their future, and therefore the future students."

Participating in the FAF program has enabled participants to have a more positive outlook. Clare mentioned, "I think it has really helped me to refine my story and try to be positive even when I'm giving them the stuff that's not so good about what happened educationally." Joan remarked that by being a host family they have become more positive, "I think we've become a lot more positive through doing all of this. And I think that rubs off into family life, into when we work with our teachers that we always start out any of our meetings with the positive things about our children. We talk so much about being positive, and about growth, and that negative stuff doesn't really help a lot." Not only do the host families feel more positive, but they get positive feedback from the students, and that to them is a benefit. Iris noted, "I think we get benefit in that the

feedback is always positive. Not only when they are here, but then they get a chance to make comments.”

A better understanding of teaching and teachers was noted in the results. Clare feels she has gained a better understanding of what teachers are learning. She noted, “Well, I think for me, it makes me understand what I think the teachers are being taught.” Bonnie shared a similar comment, “...it has helped me understand some of the basic legalities, some of the requirements of teachers...” Joan, whose husband is a teacher shared, “I also think because my husband is a teacher, it reminds him of what’s important.”

Participants benefitted from being able to make a difference. Rachel commented, “For me it’s just a feeling of being able to make a difference hopefully for us down the line if we were to end up with one of these teachers, but if not, at least for somebody. I mean, eventually if any of my kids ever has one of the teachers as a teacher, then we will have definitely benefitted in that way.” She also noted, “It was just awesome to see that they really took to heart what I said, and that it really did make an impression on them.” Joan noted, “We saw how wonderful teachers are willing to accept these students, will to kind of believe in them, that they can learn, and make a difference.” She also said, “If we can hopefully help a teacher, and help some of these other students that are coming through, to us, that makes it feel more worthwhile. We feel like some of the hard times we went through, that there is actually a benefit from them, that we can use those experiences to shape the way these student teachers are thinking and try to increase their understanding so that they will end up being better teachers.” Iris remarked, “It helps me see that it does make a difference to them; it does help them see the difference between

teaching the child and having the child twenty-four-seven, and how daunting a task it is just to have a child like that and then how daunting it might be to teach a child like that.”

Learning from others was another benefit associated with participation in the program. Iris reflected, “But having people come here and being able to talk to them and then not having the same kind of conversation, even if you were talking about the same thing with someone else, show me there is a problem. It really helped to recognize there is something going on here that is not positive. And so it helped me to do things a little bit differently with that teacher.” When speaking of the training parents receive regarding the FAF program, Joan noted, “I think with the training and meeting other parents who have done it, because you hear from their stories, things that they have said or done, and you think, “Wow I could do that.” So I think being together with the host families, I think it’s been really important.”

Results indicated that being able to share their story is important to the participants. Rachel noted, “I wanted to give them ideas of what they could do right, what has worked well and some of the things that have impressed me the most regarding teachers and the ones that acted like they cared and understood the situation, it wasn’t about what we can get on my part, it was about what we can give.” Eve noted, “I believe the greatest benefit is letting teachers understand the family dynamics of dealing with their disabilities.” Bonnie commented, “I think for me, I have enjoyed being able to share the information with the students.” Iris noted, “I have felt privileged to have the students come over. And I have really felt blessed in the encouragement they have given me. They have told me they feel privileged to come and experience what happens here every day.”

Another added benefit was that the parents receive a small stipend for participating in FAF. The stipend is evidence that not only shows respect for the parents, but that their time is valuable. Bonnie noted, "...I am a stay at home mom, so that's very helpful every now and then to have extra money".

*Child Benefit – "Our children have gotten more confidence"*

Another area where the results indicated a benefit was with the children in the families. The children, who range from elementary to college age, and from mildly disabled to severely disabled, seemed to have benefitted in that their parents report they have increased confidence and a sense of self worth that they didn't previously have. Eve remarked, "It gives them a better self esteem of themselves if they can accomplish more." Bonnie reflected, "...it gives my son a chance to see that teachers are people too. You know, they all start out as students, they are not just adults who are able to issue homework and tests, you know, they are people too." Joan commented, "...our children have gotten more confidence through talking to other people." When speaking about her son Roger, she noted, "and we realized that it is just part of his disability. And they need to see that part too, that a lot of these kids are uncomfortable just being there...Roger may come out and leave, and actually he has gotten more confidence. He will come out and talk more." She went on to say, "And the kids, because they have a disability, they feel like they are able to help; that they can actually benefit other people. We talked about it to our kids, they can help others by helping student teachers be more aware and understanding that they can help other teachers. I think that means an awful lot to my boys."

*Member Check Results*

The results of this study indicate that parents and families of children with disabilities that participate in the FAF program have a wealth of knowledge to share. It is important to them that they make a difference for their own children and for children in future classrooms. They want to help teachers better understand children with disabilities, and they want to be listened to and respected for the information they have to share. They also want to have an impact on classroom practice by changing teacher perceptions about students with disabilities. The results also indicate that there are benefits to participating in FAF. Parents and children benefitted by obtaining increased confidence, a sense of empowerment, being more positive, being able to make a difference, learning from others, and being able to share their story.

Four participants provided feedback via electronic mail. Clare stated, "I do agree with the quotes that you attribute to me. It was very interesting to read through your paper. For 6 different women with 6 different lives, we each seem to be affected by this program pretty much the same". Rachel remarked, "I've actually experienced another FAF visit since talking to you and it was completely different than any other meetings. This time I had no one else at home to watch the boys so we stayed in the living room with the students and enjoyed the time together. They enjoyed interacting with my youngest son. After sharing with them the differences between the boys and their personalities that made school totally different for each of them, my oldest not going to school and my youngest loving all the interactions, etc. One of the students was about to cry and stated that she was so thankful that I had shared that as she had come into this experience completely against inclusion, due to an experience with her niece who has

Downs. She finally understood that for some students inclusion was the right choice. I shared with her that until I had my youngest son and saw how great school was for him that I too disagreed with inclusion. It was a great experience.” When asked if she would change the way she conducts her home visit based on this last experience, she responded, “It will probably depend on the day and the kids moods but I would probably have the boys around more just because the students can see the boys as boys not just students or disabled children. I think it's good the students to realize that we are a family and have family stuff going on and the boys are BOYS above all else!” Joan commented, “I think you have an accurate account of all we talked about. I cannot think of any other comments”. Bonnie stated, “Your report looks very interesting”.

## CHAPTER 5

### Discussion and Recommendations

The purpose of this study was to investigate the experiences of families who participate as faculty in FAF. The three main questions to be investigated were:

1. Why do families choose to participate in this program?
2. What are the benefits and challenges they experience as participants in the program?
3. What about their experience influences their decision to continue or terminate their participation in the program?

#### *Why do families choose to participate in this program?*

Families became involved in the FAF program primarily because they heard about it from someone else; they received a flyer about it, or were just asked to become involved. Iris noted, "It's been so long ago, I think somebody asked me would I, and I think I said yes, I could do that". Joan became involved as a result of needing assistance from PRO. "It wasn't until we got some help from PRO, and knowing someone who was already a host family."

The results of this study indicated that families choose to participate in the Family as Faculty program so that they can educate current and future teachers. They want to share their stories so that they may provide teachers with a different way of viewing their children. Rachel commented, "We tell them what our views and expectations are of the teachers that deal with our children, and what kind of results we get." The families feel that teachers lack a true understanding of the issues they face. Instead of this limited

understanding, participating families want teachers to experience what it is like for them and their families as they go through each day. Families feel most teachers have only dealt with the children in their own specific classrooms. Therefore, the teachers lack a broader understanding of what it takes to get that child to school, and then what that child does after school and on the weekends. Clare remarked, “It opens my mind a little bit to help them understand what our kids are like outside of the school setting.” Participating families want to share the everyday accomplishments and disappointments, the triumphs and the tragedies so that teachers develop a deeper understanding that these children are from typical families with moms, dads, brothers, sisters, and extended families. The families want teachers to listen, understand, and know that parents have information to share, and that the information they have can help the teachers teach the children. Esther remarked, “If the teacher deals with and listens to what the parents have to say, because the parents deal with their children all the time, and they may have insight into how the children are acting and how to deal with them in any setting.”

*What are the benefits and challenges they experience as participants in the program?*

The results of the study signify that the benefits families receive from participating in the FAF program far outweigh the challenges. In fact, not one participant commented that there were any challenges to participation in the program. As one participant put it, “it is the best thing since sliced bread”.

Many of the reasons that families choose to participate, as discussed above, are also a benefit they receive from participating in FAF. Impacting teacher practice and changing teacher perspective were beneficial to the participants. Clare noted, “To look



outside the box and be creative in their ideas to teach special kids. That there is always a way to teach and sometimes the smallest progress is giant steps for that child.”

Knowing they were making a difference, if not for their own children, but children down the line, was a huge benefit to doing the program. Joan remarked, “I think through some of our experiences, because each child is very unique, hopefully they’ll pick up some of these things. We’re hoping if they are teaching and they have a student, maybe like one of ours, one of the same experiences that they’ll remember, ‘wait a minute, I’ve had that experience’, and maybe some of it will come back to them that they can actually use and benefit some other kids.”

The participants and their families gained confidence and a sense of empowerment by participating in the FAF program. Joan observed, “It’s given us more confidence to go in and talk to teachers.” Iris noted, “I didn’t have the self-confidence before.” Eve commented, “It makes me speak out a little more and to know that maybe I can change their opinion on how to deal with my children.” They commented how they had developed a more positive outlook by participating. Clare remarked, “I think it has really helped me to refine my story and try to be more positive even when I’m giving them the stuff that’s not so good.”

Another benefit was being able to share their story. Each participant noted how much they enjoyed sharing their story with the students. It appeared that it wasn’t necessarily about how they could benefit, it was about what they could give to others.

Still another benefit was that they were able to learn from others. Iris reflected that having the students come gave her the opportunity to talk to someone else about

what was going on in her child's classroom. It gave her a different perspective and helped her to work differently with the teacher.

Another benefit they received by participating in the program was that their children benefitted. The parents reported that the children, by coming out and visiting with the students, had increased self confidence and a sense of self worth. The children will talk more and seem to understand that they are helping too.

*What about their experience influences their decision to continue, or terminate their participation in the program?*

The participants shared that the training and support they receive from the FAF staff and PRO is excellent. They each plan to continue to participate in the program as they feel it is a critical piece of the puzzle in the education of teachers who are going to be working with diverse student populations.

The results of this study were consistent with other articles and reports on family-professional partnerships and, contribute to the limited body of research in this area. Previous findings mentioned parents feeling validated and empowered by communication that centered on family needs (Blue-Banning et al., 2004, & Hess et al., 2006). Other studies revealed parent's suggestions that their involvement should be valued and respected due to their insight into their families unique needs (Gallagher et al., 2004 & Pruitt et al., 1998). Sharing experiences and stories and how important effective communication is to the overall relationship was re-affirming for parent participants. (Mcbride et al., 1995). Additionally, other studies reported that students benefit from participating in programs that utilize parents as co-instructors (McBride 1995; Forlin & Hopewell 2006; & Schmitz 2004).

### Limitations

The limitations of this study that must be considered are that the participant pool was small in number. A larger sample may have yielded a greater variety of response or even a more definitive convergence of information. The fact that three participants were from the same urban area and three were from different rural locations within the state could also be a limiting factor. A larger sample with more participants from each geographical location could have provided information to compare responses.

### *Implications*

The implications of this study are that families benefit from participating in programs such as FAF, and as such, programs such as these should be a required component of teacher preparation, teacher education, and education administration coursework. Not only would pre-service teachers benefit, but seasoned teachers and principals would benefit as well. A true-to-life experience such as FAF prepares students for what they will experience firsthand in classrooms. Such preparation differs from the traditional coursework by enabling the students to have contact with families of children with disabilities prior to their indoctrination into the education system. It would allow the student an opportunity to gain a more realistic picture of the children they teach and their families. The more practical the experience the better suited students, educators and administrators will be when they enter the real world of educating diverse student populations.

### *Future Research*

This current project has filled a gap, but there is more that needs to be done. There are a limited number of programs that are similar to FAF and therefore there is very little

research into the benefits of these programs. Continued research into the area of family involvement in special education and more specifically, into how programs such as FAF benefit families, teachers, and children with disabilities is critical.

Additionally, there needs to be research into outcomes for children with disabilities who participate in FAF. Participants in the current study mentioned how their children benefitted from participating in the home visit, however this researcher was unable to find any research on how children with disabilities benefit from programs such as FAF or how they benefit from parent/family involvement in their education in general. The research that was found came from the perspective of the parent or teacher. The voice of the child with a disability was missing.

Future research may also include how programs such as FAF affect students in classrooms and/or families of teachers who have participated in these programs. Do students or families associated with FAF participants notice a change in teacher beliefs or practice? Do students with disabilities achieve increased self-advocacy if they have a teacher or parent associated with the FAF program?

Other areas of interest may include an explanation of how parent participation in FAF changes over time. For example, research could address whether or not the process of sharing the story changes as the child in the family ages. And, any impact participation in FAF has on the family's perception of their own child's disability?

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Clare

E: Do you live in a rural or urban location?

P: No, I live in a city in Albuquerque

E: How many children do you have?

P: I have nine

E: Nine, ok wow, what are their ages?

P: 20, 17, 16, 11, 10, 8, 7, 3, 7mo

E: What disability label does one or any of them have?

P: My two sons who are ten and eleven were born drug exposed, but now at their age are doing well in every way, educationally, cognitively and emotionally. My daughter who is eight has shaken baby syndrome, or what they call abusive head trauma, she is completely devastated and requires full care and has since she was 1 month old. My daughter who is seven has fetal alcohol syndrome and is developmentally disabled attends school and is doing well educationally in special ed but requires a speaking device because she doesn't speak, she has some oral aversions and some problems with how her mouth and swallowing form to make words its called dysphasia and apraxia. My three year old who we've had since she was three weeks old has a very rare syndrome called oconon (sp?) syndrome, she also has hydrocephalus and a \*\*\*\*\*malformation in her brainstem. She has gone through sixteen neuro-surgeries and is surprisingly cognitively intact, very smart and is doing very well. She has many surgeries ahead of her in her life. The seven month old is our foster daughter and she has a very rare form of dwarfism, its call chondrodysplasia punctata, its very, very rare and now we are just trying to deal with it, with nobody else in the state having it, so we are working with a lot of the doctors at UNM

E: Tell me how you became a host family for FAF.

P: I met Stephanie Johnson at a convention in San Francisco on Family Centered Care.

E: Describe what happens during a typical visit by students?

P: I think at the beginning I was nervous, even though I had told my story before, it had been related to only one of my children, I was very involved nationally with Shaken Baby advocacy, I had told my story about her and a few national conferences. But when I had to sit down with a captive audience who didn't know me at all and didn't know anything about our family and they knew why they were here, but they didn't know anything about us. I think it has helped me refine what I talk about and how I talk about our family. I don't concentrate on one child over the others and I really try to pull in how it affects all of us, to my husband, to my birth children, to all of the adopted kids and to my foster children. And, our outside support, which is my family. And I think it has really helped me to refine my story and try to be positive even when I'm giving them the stuff that's not so good about what's happened educationally. We are always looking for that glimmer of change that sometimes hopefully you can give them, oh just a different way to think about something. Especially when you are thinking about a

child, that you may come into a situation thinking is cognitively just not there, and really listening and hearing what I have to say about C. and the things she has done. Hearing it from not just an “oh moms talking”, but hearing it from someone who is an expert on their child. And so I think it’s made me feel empowered on being an expert on my kids.

E: Are you going to be a host family again? Why/why not? Would you do anything differently next time?

P: Yes, I will continue to be a host family. I believe in the program and what it means to special children and their families.

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: They will open their eyes to the possibilities and that the kids are part of families who have hopes for them no matter the disability. I think that teachers who are teachers already and university students who are becoming special ed teachers, it's invaluable to have them look at children with special needs in all the different lights than they are used to. They get to see these children at home as part of a vibrant and busy families. Their disabilities are not the forefront of their home life; their quality of life becomes the forefront. They get to see where they live, the dynamics of the family and I think sometimes it changes the ideas that these kids live in some kind of bubble, some kind of you know, some kind of alternate universe than the rest of us. And, I think it gives them a chance to see that they have mothers and fathers, and grandparents, and brothers and sisters, and they go places and they do things, and you know they have TV's in their rooms and you know they just get to live like normal kids outside of the school setting.

E: In what way(s) do you hope this experience might have an impact on the future teacher's classroom practice.

P: To look outside the box and be creative in their ideas to teach special kids. That there is always a way to teach and sometimes the smallest progress is giant steps for that child.

E: Do you think your relationship with your own child's teacher is better as a result of your participation in FAF. Can you give an example?

P: To be honest with you I don't know. I think because I am working with teachers who have not gone through the program, I think my attitude toward the whole educational process is a little bit different than theirs. I don't think it has really changed the way we have worked together because I think there are some old processes that are still there based on what their education was and how they approach special ed.

E: How has PRO prepared you and supported you for your role as a host family? Can you give an example?

P: By attending training sessions on how to be a host family. And for letting us know how the students felt about their visits after the wrap up.

E: How have you and/or your family benefitted from participation in the FAF program?

P: Well I think for me, one it makes me understand what I think the teachers are being taught to become teachers. It opens my mind a little bit to help them understand what our kids are like outside of the school setting, which I think can really help these teachers realize the parents are the experts on their kids, not sometimes or usually, but always are. And that the way to have a very beneficial and valuable educational experience is sometimes to really listen to the parents and to the techniques and ways that they work with their kids and how they can use those types of experiences in the classroom to really \*\*\*\* a dynamic education for the kids. Sometimes it's as small as learning to use a head switch, but that's a huge step for some of our kids.

Bonnie

E: Do you live in a rural or urban location?

P: Urban

E: How many children do you have?

P: One

E: And, is it a boy or a girl?

P: A boy

E: And, what is his age?

P: Twelve

E: And, what disability label does he have?

P: Um...ADD, not the hyper-active type, just ADD, and a learning disability in written expression as well as a symbolic dysfunction, which I am told his school district doesn't necessarily recognize those.

E: Tell me how you became a host family for FAF.

P: I attended a workshop at Parents Reach Out and it was probably like an IEP workshop and I remember that being discussed, hosting was discussed and they said if you are interested in hosting then you could attend the hosting 101 workshop and so that's how I was introduced to it and I signed up for it.

E: Describe what happens during a typical visit by students.

P: Yes, I generally try to set it up so the students come to my house about an hour and a half before my son's bus arrives that way I have them come in and chat with them for a few minutes to understand about their career goals and what type of students they want to teach, or what age group of students they want to teach, whether it be elementary school or special ed, or whatever and then you know whether they have children or any disabilities of their own, or how disabilities might have impacted them or their families, you know, and so then that takes fifteen minutes or so and then, I usually bring them over to my table and I have pictures of my son from the

time he is an infant until current, and I kind of explain to them my husband and I were married for a number of years and waited several years to have a child and then of course were thrilled when we did have a child. I explain his development was normal and he seemed very bright, I don't actually tell them what his disabilities are, until I am at that point in my story that I knew myself, which was after third grade, so I kind of want them to understand the questions we must have had, and the struggles we must have had and the (inaudible) and the frustrations and what the school district was able to do for us and what they weren't able to do for us. We had to go out of pocket and get testing done and that kind of thing and that's kind of how I share my story. And, as my son is getting older in my story I bring out a more current picture of first grade or second grade or whatever and then I also show them samples of his schoolwork because again written expression is one of his learning disabilities I want them to see what his handwriting is like, umm so I explain that and then my son gets home an hour and a half later and so I introduce him to the students. I just explain to him that they are students who go to college and that they go to the same college his cousin goes to and then just let them chat with him, they usually ask him questions about like "what do you like best about school", or "what don't you like". And you know, he doesn't, you know we just really down play his disability and he doesn't realize it has anything to do with special ed necessarily, and it gives them a chance to chat with him and him with them. And you know I think that might actually be a benefit that I didn't mention earlier is it gives my son a chance to see that teachers are people too. You know, they all start out as students, they are just people too, you know they are not just adults who are able to issue homework and tests, you know they are people too, so... And how it's changed over time, each time I host I have a document that I have put together on my computer and each time I host family I look at it to see what needs to be updated because maybe he's had another test done, or maybe he's finished another grade or maybe he's had struggles or accomplishments in different areas, so usually I just update it based on that and then based on the students background or interest, you know one student that came has dyslexia, so you know when I'm talking about my son's handwriting, he still does some reversals and some of his letters are hard to read, that's nothing compared to what she has dealt with her whole life and her partner was actually taking notes for her and I thought golly that's very interesting and pretty neat that she is in college and she is determined to make it you know even though she's got some pretty severe disadvantages herself. And then another student I spoke with or that had hosted, has a son that I believe is in middle school as well and she had some struggles that were more complicated than my sons and she fought with the school district in her little town and had some problems so you know, I learn from them as well.

E: Are you going to be a host family again? Why/why not? Would you do anything differently next time?

P: Yes, I plan to keep it up. It's pretty convenient for me because the students come into my home and I am glad to be able to share the experiences we've had with my son, and his school, and his teachers. And I hope that some of the things that happen to us will help them help students in the future. My son, having Attention Deficit

Disorder and a few learning disabilities, his disabilities don't stand out, they are disabilities the teachers may not even be aware of except that he has an IEP, so usually like a month into school they give a list of everybody that has IEPs. Even though it was the teachers in elementary school who noticed there were somethings that were unusual and they were the ones actually that encouraged us to visit what was going on and eventually had the diagnosis done. Anyway, so I think there's lots of kids who have some type of attentional issues or disabilities that are in each class and I am hoping that different things that I share with them, that maybe they'll come up with another kid in the future that my explanation will remind them of Lucas' situation and our situation, and maybe they'll be a little more patient with the child or maybe they'll be a little more creative in what to do about the situation or maybe it will encourage them to contact the parent. So basically that's why I like to do it and then they come to my home and I get paid to do it to, and I am a stay at home mom so that's very helpful every now and then to have extra money.

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: Well hopefully the impact the teachers have not just on their student, but on their whole family. My son, for several years, for example, he has been very difficult to wake up in the morning and so, before we moved to Albuquerque, we lived in northern California, and they didn't really have bussing unless you lived in another district and so sometimes he was like a minute late, over and over again and so that was very frustrating to me. And I wanted, if they had a kid in the future who was on the verge of being late everyday, I want them to understand it was very frustrating for us, for my husband and I. And that the main thing is the amount of homework that teachers give, that was another issue that was always frustrating because in California they started giving homework in kindergarten, it was very little and I think it just got the kids in the habit of doing homework and got the parents in the habit of working with the kids on homework, but, in first grade it started getting a little more involved, a little more serious, and my son hated homework, and that was another huge issue with us was homework, forcing him to do homework and trying to figure out what time of day, should it be right after school, or should we let him play for awhile and then do it. I tried different things, initially I tried to give him a break, and then it was so hard to get his attention and to get him to sit down and do homework once he had played for a couple of hours. So then I changed it after a few years to where he had to do it right after school, after he changed clothes or whatever, anyway. So homework was a big impact and starting this year finally, he has not been as hard to get up and he is not fighting us so much on homework. Every year I feel there are a few improvements that he makes and those have been beneficial to our family. So not only the impact that the teachers make, but the second thing is the importance of them communicating with the parents especially when there are problems and there are special needs. I think it is very important that the teachers respect the parents and that the parents respect the teachers and that they support each other and that they have good teamwork and good understanding when there are special needs.

E: In what way(s) do you hope this experience might have an impact on the future teacher's classroom practice.

P: I hope they are more patient and more understanding as well as maybe recognize some things going on in some kids, that maybe they haven't received their IEP yet, but they don't know what's going on, or maybe there hasn't been an IEP, maybe there hasn't been a diagnosis, but they've recognized something going on in the kid, so maybe something I've shared with them about my son will help them to be creative to reach a child in the future.

E: Do you think your relationship with your own child's teacher is better as a result of your participation in FAF? Can you give me an example?

P: At this point my son has like seven different teachers because he is in middle school and again just by being involved in PRO has helped me understand some of the basic legalities, some of the requirements of teachers, and I have attended a number of workshops there with the head of special ed from his school district is present, so I had the opportunity to chat with her, so again just FAF being a piece of PRO, I think has been beneficial, umm I can't think of any direct relationship where its necessarily where its helped my relationship with my son's teachers necessarily.

E: How has PRO prepared you and supported you for your role as a host family? Can you give an example?

P: I talked to a couple of people. I talked to Michelle who was the leader of the FAF program, as well as, Erin, who assists her in getting families set up. Anyway, they both felt that the information I would have to share with the occupational therapists would be relevant. And then, after I had the students in my home, the students seemed to think it was relevant as well. So anyway, every now and then I do have questions about students who they are arranging meetings or sessions with. I am always able to call them and discuss my concerns with them.

E: How have you and/or your family benefitted from participation in the FAF program?

P: I think for me, I have enjoyed being able to share the information with the students. I feel a little more empowered in the educational system because the students I am speaking with will hopefully all become teachers or the majority will become teachers so I feel I have a little bit of impact in their futures and therefore the futures of their future students, and the lives of their future students. I typically have the meetings while my husband is at work and my son is at school although I plan them so my son comes home at the tail end of the meeting so he is able to meet the students and they are able to ask him questions. We really downplay his disabilities to him, so I am not even sure if he is aware of what the diagnosis of what he has, but I just explain to him that these are college students who are going to become teachers and they are learning about the way teachers impact students and their families so its really just a little casual thing, a simple thing, I think he kind of enjoys meeting them. And sometimes they'll ask him what his favorite thing is about school or what doesn't he like about



school. I wouldn't say it's had a big impact on him because it really doesn't affect his current teachers or any of his teachers for that matter.

Eve

E: Ok, so my first question for you is, do you live in a rural or urban location?

P: Rural

E: How many children do you have?

P: Three

E: And, what are their ages?

P: Eight, Six and Five

E: And, what disability label does your child or children have?

P: Developmentally delayed, all of them are developmentally delayed. The youngest one has a diagnosis of ????? Dyspraxia.

E: Tell me how you became a host family for FAF.

P: I became a host family through early head start. I had grandchildren in there that were going to early head start and they had a flyer that came through and they asked for families to go. I started to go, but they told me it was for Portales people but then I talked to Susan and she called me and talked to me and told me I could participate.

E: Describe what happens during a typical visit by students.

P: Well, the teachers come, and we all sit down and basically we just visit. I introduce them to the children. Sometimes they ask the children questions, sometimes they don't. We just make it a big visiting party. We try to find out if there is any specific thing they would like to know. We tell them what our views and expectations are of the teachers and such that deal with our children and what kind of results we get.

E: Are you going to be a host family again? Why/why not? Would you do anything different?

P: Yes I believe so. No I don't believe so. My son has gotten with a young lady and they are having a child, but she had a child previously that had a stroke when she was a baby. So we have a whole new set of disabilities to help them (the teachers) to understand. We were out the other day and I was trying to get her to use her hand, her right hand, let's see she had the stroke on her right side. And she doesn't use that hand very much and I was playing with her with a toy, trying to get her to use that hand and a lady asked me if I was trying to switch her from left handed to right handed and I said no, that she had had a stroke and we were trying to get her to use that hand and that side more. So it makes a difference and I think we can add to it besides the other grandchildren I have. Because dealing with each disability is different. When they go into a classroom, the integration is an on-going thing. And so, with her going in, they will have to know how to help her achieve the goals she needs to achieve as well as what they want achieved.

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: If the teacher deals with and listen to what the parents have to say, because the parents deal with their children all the time, and they may have insight into how the children are acting and how to deal with them in a setting, in any setting.

E: In what ways do you hope this experience might have an impact on the future teacher's classroom practice?

P: All the teachers need to understand that just because a child has a problem, it doesn't mean that you need to expect less of them than you would expect of normal children, you know the ones without disabilities. We have high standards for our children and we strive for them to meet those high standards. And, if they need extra help that's fine we don't mind providing it. We want teachers to understand that you should expect as much out of a disabled child as you do a child that isn't disabled. It gives them a better self esteem of themselves if they can accomplish more. You can help them along the way but the expectations need to be there too to help them develop the self esteem and self worth as a child.

E: Do you think your relationships with your grandchildren's teachers are better as a result of your participation?

P: Yes I believe so, because it makes me speak out a little more and to know that maybe I can change their opinion on how to deal with my children.

E: How has PRO prepared you and supported you for your role as a host family? Can you give an example?

P: When I first did it, I talked to Stephanie over the phone, and she gave me a rundown of what the program was, and what it did. And then this last September I went to a program in Portales, a seminar type thing, a class type thing, where they showed us all they were doing, why they were doing it and what they were doing and how it benefitted them, benefitted everybody . The second training helped me understand a whole lot more, what was expected of us, because I didn't get to go to the first meeting they had, I just talked to Stephanie, the second one they had with the new director, I went to it. It helped me to know exactly what questions and everything to answer and what the students would be looking for and such and how to explain it to them a little better without pointing fingers at people and things like that. To be more objective.

E: How have you and/or your family benefitted from participation in the FAF program?

P: I believe the greatest benefit is letting teachers understand the family dynamics of dealing with their disabilities. And the families are a great source if they will just go to them. They can help them understand a lot of times how to deal with the children

Rachel

E: Do you live in a rural or urban location?

P: Rural

E: How many children do you have?

P: Two

E: What disability label do they have?

P: There is not a specific diagnosis for what they have, they have seizures, visual impairments, developmental delay, one son has hearing loss, they don't walk, crawl, sit up on their own, anything like that. Cody has scoliosis, (inaudible), dislocated hips, and Cody is my oldest one.

E: Tell me how you became a host family for FAF.

P: Probably just a flyer I got, yes I am sure it was just a flyer I got through PRO and I called them and said you know I just want to be involved.

E: Describe what happens during a typical visit by students.

P: We started up, and what I did is, they met the boys, and we went into the boy's what we call their therapy room, it's where they get all of their therapies and everything. The two students and myself just sat in there with the door closed so we wouldn't be interrupted and I just told really what we've gone through and what happened, the most trying time and the things that have worked really, really well. Trying to give them a good feel for what doesn't work and what does work. I didn't want it to be a completely negative experience. I didn't want them walking away thinking, can we do anything right. I wanted to give them ideas of what they could do right, what has worked well and some of the things that have impressed me the most regarding teachers and the ones that acted like they cared and understood the situation. And when we were done, they left and then a couple of weeks later I was in the store and I see one of them and she was like "hey Rebekah, how are you?" and she was like "how are the boys?" It was nice to have that connection and to know that they actually cared enough to remember my name and to know it made an impression on them. And then when they had their little notes that came back, that were put in the newsletter, I knew which ones were addressed to me, either because they used a name, or something I could just tell which ones were addressed to me. It was just awesome to see that they really took to heart what I said and that it really did make an impression on them.

E: Are you going to be a host family again? Why/why not?

P: Oh, absolutely. I am not signed up for it this year yet, but the plan is yes.

E: Would you do anything differently next time?

P: No

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: That the parents really do know their children. In particular those with other issues than just besides a learning disorder, that they really do know their children best and should be respected for what they have to say.

E: In what way(s) do you hope this experience might have an impact on the future teacher's classroom practice.

P: I hope that it gives them a different view, a different perspective, so that when they are approaching the IEP and all that, so that they are thinking of it as a child and not just a piece of paper to be completed and a process that has to be gotten past. I think it's important for teachers to realize that there is something other than what they see in the classroom. And to see that when a family doesn't follow through with what they've said, that they can understand the family has their reasons for doing that due to the abilities they see for their child, or if they push for something, they need to look at that these parents know their kids better than we ever will and that they aren't the expert on the child even though they are the expert in the classroom.

E: Do you think your relationship with your own child's teacher is better as a result of your participation in FAF? Can you give an example?

P: I probably wouldn't attribute it to that. I've done a lot of work with the teachers this year with my other son, and ended up with some amazing teachers, so I don't think I would attribute it to that.

E: How has PRO prepared you and supported you for your role as a host family? Can you give an example?

P: The training they do is just fantastic, and examples of how it has been done. Particularly the paper they sent that kind of walked you through everything exactly what was going to happen, and some ideas that you might want to share. All those were really helpful.

E: How have you and/or your family benefitted from participation in the FAF program?

P: I don't know that we really have. It wasn't about what we can get on my part, it was about what we can give. I mean eventually if any of my kids ever have one of the teachers as teachers then we will have definitely have benefitted in that way. But at this point we haven't. For me it's just a feeling of being able to make a difference hopefully for us down the line if we were to end up with one of these teachers, but if not, at least for somebody.

Joan

E: Ok, so my first question for you is, do you live in a rural or urban location?

P: Urban

E: How many children do you have?

P: Five

E: And, are they boys or girls?

P: three boys and two girls

E: And, what are their ages?

P: Twenty-three, twenty-one, nineteen, eighteen, and eleven

E: And, what disability label do they have?

P: My oldest son, Robert has autism, and my son John who is eighteen as pervasive development disorder

E: How did you become a host family for families as faculty?

P: Through another friend who had done it and could see the benefits, and she suggested that we do it. And then we needed some help from PRO and we thought it would be nice to do it and then we started looking into it. But it wasn't until we got some help from PRO and we asked about it and that's how we started. So that's kind of a little bit of PRO and getting some help from them, and also from a friend who actually hosted families.

E: Describe what happens during a typical visit by students.

P: At first we were very nervous when they were coming, and we weren't quite sure what to say, and we kind of just talked and talked and talked. Now I think because of where our focus is, (inaudible) the students, I think it's more streamlined. Everyone we have had has been very positive. I'm trying to think of specific ones, even with our children now, John when he was younger, he would always want one of them to go play a game with him. And I think we've learned (inaudible) that Robert would go somewhere else and wouldn't just stay in the room. And we realized that's just part of his disability. And they need to see that part too, that a lot of these kids are not comfortable around other people. They are uncomfortable just being there. I think this is just part of it, and we are more open to talking to the students and saying you may or may not see Robert. He may come out and leave, and actually he's gotten more confidence. He will come out and talk more. (inaudible) We've ended up some of them, we've run into them later, and have been all excited, because one in particular, we saw years later, and she recognized us first and remembered every single one of our children and she just came out and said "I am going into teaching children with autism because of your family" And to us, that was huge for us to realize she has gone into something because she had been in our home. And so I think that was really big for us. And with music, I think because of our children being involved with music we've realized probably another angle of helping these students. Not being afraid to instead of just focusing on academics that these kids socially need to learn other things. And so that's why we've got our kids, what a blessing it's been for our son, well both sons, because Robert can pick up a tune, because he had a teacher who was going to have him, and the same for Robert, he had a teacher that was going to work with him, not only on the music, but on their social skills, which are so

important. Later on, it's no good if we have all the knowledge but we can't act socially, then we can't get a job. It's given us that confidence; we've been able to relate, our children have gotten more confidence through talking to other people. I think some of it, I wonder with John, because he wants to go into teaching, where being able, talking to other students has probably given him that confidence too, and those ideas.

E: Are you going to be a host family again? And if so, why or why not? And would you do anything differently next time?

P: We were the host family twice this summer for students. And definitely we'll do it as long as we've got a kid in the home and are able to do it. Because if we can hopefully help a teacher, and help some of these other students that are coming through, to us, that makes it feel more worthwhile to us. We feel like some of the hard times we went through, that there is actually a benefit from them, that we can use those experiences to shape the way these student teachers are thinking and try to increase their understanding so that they will end up being better teachers. And I think through some of our experiences, because I think each child is very unique, hopefully they'll pick up some of these things. We're hoping if they are teaching and they have a student, maybe like one of our, one of the same experiences that they'll remember, "wait a minute, I've had that experience" and maybe some of it will come back to them that they can actually use and benefit some other kids.

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: I am hopeful that they will see, that every child, especially when they are younger, that they can learn. And that if they have the right learning environment they can go on to learn. We can't see when they are young how much growth they can obtain by the right people. Because especially, well with both boys, we saw how bad teachers can really injure a kid and do incredible damage. We saw how wonderful teachers are willing to accept these students, willing to kind of believe in them, that they can learn and make a difference. I think John is our one that we see, very powerfully, what benefit a good teacher can be. And now that he's gone to college, that's a definite. So I think it's like you may look at a student when they have, John could talk when he went to elementary school, couldn't do (inaudible), had a load of problems, the way he walked was different, kids laughed at him and called him retard, and yet now he's going off to college, we put in work, we put in therapy, getting the right tools, whether it's therapy at school, having teachers that can maybe see what's underneath that student that's trying to verbalize what they are thinking, that they've got an incredible brain, that they can still learn, and giving them the option, that parents aren't going back and thinking "what if". I think the most important thing is that with behavior, there are reasons for the behavior, I think a lot of these kids end up getting into the wrong behavior program with other children that have maybe similar behaviors but they are not caused by the same problem. They are caused from abuse, rather than autism. And that is so different how you look at that. With behaviors there is a reason and we need to find out why is this behavior so, so the kids are not being punished for something that is beyond their control. They are getting help instead. And that's what is needed.

E: In what ways do you hope this experience might have an impact on the future teachers classroom practice?

P: I hope that every student that goes through their class will never have to go through the experiences that my kids had, the negative experiences. That they will bring back and they'll approach it in a different way. And that the kids will not be hit, or yelled at or abused in any way like my kids were at times. Because the teachers didn't understand. Or that they challenged them, that they didn't give them dummy work or like in special ed, the kids, they have to perfect something before they go on. We never did that with regular kids, they have a set thing, they learn, and then they reach a certain point and then they go on to other things. Especially with early math, they do the same things over and over they stay in those basic things, and never really have a chance to really be challenged. I think they are taught very differently and I would like to see them taught, you know give them the help and support that they need and talk in a way that's going to get to them individually. I hope these kids behaviorally are treated differently and never have to go through, I mean that would be my ultimate dream, that they see their potential. And some kids in special ed, they may not go on and get a PhD, but there will be some of those that will and there will be those that can go on to college. You know whatever their potential is in life, that they can go on to get a job, or get a life, you know, that they can fill fulfilled. I think teachers can make a huge impact on that. So hopefully some of that will come out.

E: Do you think your relationship with your own child's teacher is better as a result of your participation in FAF? Can you give me an example?

P: Yes, and I also think because my husband is a teacher, it reminds him of what's important. And because sometimes you know if you are teaching, you go and do things, he talks about "Oh, I should go and do this for one of my students" or it reminds him to try to keep on top of things. We all need something to keep us fresh. And so I think as a teacher, doing this has actually helped him too.

P: I'm not sure I answered that last question, so just repeat it for me.

E: Ok, Do you think your relationship with your own child's teacher is better as a result of your participation in FAF?

P: Yes, because I think one of the things we talk so much about with our family is about being positive, and about growth, and that negative stuff doesn't really help a lot. I think we've become a lot more positive through doing all of this. And I think that rubs off into family life, into when we work with our teachers, that we always start out any of our meetings with the positive things about our children. And I think that you don't end up with those battles quite so much and I think it's helped us. When things aren't right, we know we have to change it, and there are sometimes when things aren't going to work out and we've had to change teachers or we've had to change an EA. And I think we've got more confidence to be able to do that. Our children are important no matter what the disability and even with our other children, it's given us more confidence to go in and talk to teachers. And that we are all equal. And it's the teachers in our children's education; we are all a part of it.

E: How has PRO prepared you and supported you as a host family? And, can you give an example.

P: I think with the training and meeting other parents who have done it. Because you hear from their stories things that they have said or done, and you think, wow I could do that. So I think that being together, the host families, I think it's been really important. And the training, they call us up to make sure that things went ok. And they do try to pair off students knowing the different families and stuff like that. They are careful where the students go and that they do have training for it. And meeting the other parents to pick up ideas (inaudible). I think the first couple, we talked so much about autism, which at that time one of our boys was on the spectrum. But as we went on, we started realizing these things apply to other people. So we kind of bring that more in because of other parents and the training so that they realize its not just about autism its about many children.

E: How have you and your family benefitted from participation in the Families as Faculty program?

P: I think its given us some, hang on, it's not payback, I'm trying to think of what that word is, (inaudible) some of the struggles, some of the nightmare times, that especially Robert went through in high school. It has made it worthwhile because they can use some of those experiences to become better teachers so that other kids wont have to go through some of that. I think it gives us that, you know it wasn't all for nothing. And I think our kids, its been fun to watch them go in and talk and as they've gotten older, they've been able to participate a little more. Before, Robert would just disappear, they got to meet him briefly, but now they got to see that aspect of how hard it is being around people, but now, Robert will come in and talk, and John especially, and they ask when are we going to have another student come by for families as faculty and they've enjoyed those visits. And the kids, because they have a disability, they feel like they are able to help. That they can actually benefit other people. We've talked about it to our kids, they can help others by helping student teachers be more aware and understanding that they can help other teachers. I think that means an awful lot to my boys.

Iris

E: Ok, so my first question for you is, do you live in a rural or urban location?

P: Rural

E: How many children do you have?

P: 2 adult sons

E: And, what their ages?

P: 30 and 32

E: And, what disability label does your child or children have?

P: I have a grandson with mental retardation, a seizure disorder, and a wheat allergy

E: How old is he?

P: He is nine, cognitively two and a half.



E: Tell me how you became a host family for FAF.

P: I think I volunteered for it. It's been so long ago, I think somebody asked me would I, and I think I said yes I could do that.

E: Describe what happens during a typical visit by students.

P: Well, it depends on the time of day that is comfortable for them and for me both. Because some of them, their schedules are different, so it's different times depending on the students. They usually present me with two different times that will be comfortable for them and then I pick out of those two that will be comfortable for me. And depending on the time there might be different things happening. If they come during the dinner hour it might be a little more hectic than if they came after he gets home from school, or if we do it on a Saturday or a Sunday. So depending on what their schedule is, I am usually pretty easily adaptive to that, it just depends on the time of day. What I try to do is present Jr. when he is calm and when I've got somebody else here. I can't do it by myself. If I have to talk, somebody has to watch Jr. otherwise he will get into all kinds of trouble. He is a one on one kid. So normally the optimum would be to have someone here. The students come over, I get to do my introduction of Jr. even though they haven't seen him yet, then I'll have the caregiver bring him out without his helmet, and they can interact with him a little bit, and then I'll have the caregiver go get the helmet. Now I have a caregiver that comes here from Heritage, and I also have if its on the weekend or a time that its not the caregivers time because they only are here certain hours, if they come before the caregiver gets here, it's usually my sons who are the caregivers. So I present him without a helmet and after a little while of them interacting with him, I have the caregiver go get the helmet, and when he puts the helmet on, it changes their whole view of him. So I usually present a story our story, have him come out and interact with them a little bit, then have him go get his helmet or have someone put his helmet on him. Its just amazing the difference, because he looks normal, he does not look mentally retarded, he doesn't have anything that someone would be able to look at him and say he has a problem. He is a cute little guy, and so he is presented that way as a cute little guy. He could be one of those kids that is autistic because he doesn't talk much, he could be a gifted kid that doesn't talk much. But then when they see he has to have a helmet on because of the seizure disorder, then that changes their whole view of him in that they see him presented as a normal little kid because he looks like a normal little kid. Because that's what he is, a normal little kid. He might be in his brain a two and a half year old, but he is still a little kid first and foremost. And then when you see the helmet put on him, that changes the perception to yes, he is a little kid, but he has some disabilities. If they see him with the helmet first, that would have been a whole different reaction. If then I took off the helmet that would be different. It's an impact.

E: Are you going to be a host family again? Why/ why not? Would you do anything differently next time?

P: I was just a host family on Wednesday. It seems like every time I do it, it's different. Every time I get the reminders from PRO, I write down things I need to remember to do. As you progress, as you learn, as you grow, there are different things that I stress, different things that I learned are more important. Another thing too is that each one of

the sets of people that come, each one of the students, each one, they are all different, they ask different questions. I find that it is never the same, truly the same, our story is always the same, and the questions they ask are different. Some of the points that I bring out may be different. I can't say I like to do it different every time, it just seems that way. It seems like it is just different every time, depending on where I am in my life.

E: What do you believe is the most important piece of information or aspect of the visit that the future teachers will take away from their visit with you?

P: I have had several student teachers who have come who have said that it really just takes seeing the other side of the coin to see what it is like to be the family of the special needs child to see what all they have to go through to see all the expertise that goes into their care of the child in order to see a different perspective. My grandson has a seizure disorder and what I usually do is I have the students come over and I have him presented without a helmet and they have a whole different reaction after I put the helmet on and they realize he's got a seizure disorder. And it's an epiphany because he looks normal. He could even be one of the kids because they have some kids that are gifted. So they don't know when they come here what is wrong with the child. And so when they see the child and how he interacts and then they see him with the helmet on, it's different. If they would have seen him with the helmet first it would have been different. They get a different perspective that way.

E: In what ways do you hope this experience might have an impact on the future teacher's classroom practice?

P: I think the experience of being with a family that has a kid with actual disabilities before they are thrust out there in the real world I think helps them see in a more practical manner, seeing the logistics of getting through a day. And I think it helps them see in a more practical way, this is a family, this is the way they live. Sometimes, when you are purely clinical or purely educational you have a tendency to forget things. One of the things I do is, my grandson has a seizure disorder, so he is supposed to wear a helmet all the time. One of the things I do, is I have the students come and see him without the helmet and observe him and see how he is. And then, I put the helmet on and I point out to them, would you have the same impression of him with the helmet as without? Most of the time, that is huge for them and they say "no". Usually when you see him, you see him with the helmet and you make assumptions. And I tell them no, you can't make an assumption, because this is still a kid. The helmet is just a prosthetic device. There is still a kid underneath there who has the same things all the other kids have, plus some extra baggage that they have to deal with. So that is one of the things that is constant when I do things. However, there have been incidents when I haven't had the opportunity to or there has been a reason why I could not do that. I have had a couple of times where the meeting had to be at a doctor's office, or McDonalds, or something like that, and I had to have the helmet on. So I wasn't able to do that, but usually that has a huge impact. You know, when you see a kid in a wheelchair you make assumptions, and you can't, you shouldn't, it's still a kid, underneath all that hardware.

E: Do you think your relationship with your grandson's teacher is better as a result of your participation?

P: Yes I do, he has had the same teacher for two or three years and I have been a host family for two or three years. Before I had this teacher, and this one is a good one, I had one that was not so good, and it really helped to have the students come over and be able to talk to them about issues and things like that. Because see what the difference is between communicating with someone who is open and communicating with someone who is closed because the teacher I had prior to this one was not what I would say would be an open, communicative, positive relationship. I did the best I could to make it a working relationship but she was very closed to somethings. But having people come here and being able to talk to them and then not having the same kind of conversation even if you are talking about the same thing with someone else shows me there is a problem. It really helped to recognize there is something going on here that is not positive. And so it helped me do things a little bit differently with that teacher. But this teacher I have now it's really helped in that the communication has been there. So I know, there is a gut feeling, but I've learned to say...I don't know...I didn't have the self-confidence before, I've started to talk myself out of things, well maybe it's just me, but then talking with these other students and teachers and then talking to this other one I was having trouble with and now talking to the one now I am communicating well with, it's like well I've learned to listen to my own feelings, listen to when I feel uncomfortable then there is a problem, when I don't feel uncomfortable then that's good communication. I learned to go with my gut.

E: How has PRO prepared you and supported you for your role as a host family? Can you give an example?

P: Every time a couple of students are going to come, one of the things they started doing here recently, is they paste on one of the cards, what class it is that they are taking and why they are coming to the home. And that helps a lot to know, ok this student has gone through three semesters, they are in 303, so they are fairly far along in this process. So that helps me to gauge how much input I do on this or that or the other thing. If it's an initial class then there are different things I would focus on more so than if someone is fairly far along. I try to tailor the visit according to what the specifications of the class are so it will be useful for them and they will get more out of it.

E: How have you and/ or your family benefitted from participation in the FAF program?

P: I think we get benefits in that the feedback is always positive. Not only when they are here, but then they get a chance to make comments. That is also helpful; it helps me see that it does make a difference to them; it does help the see the difference between teaching the child and having the child twenty-four-seven. And, how daunting a task it is just to have a child like that and then how daunting it might be to teach a child like that

E: Ok, do you have any other information you would like to share or any other comments about FAF or your participation in it?

P: It is the greatest thing since sliced bread. I have felt privileged to have the students come over. And I have really felt blessed in the encouragement they have given me. They have told me that they feel privileged to come and experience what happens here every day. I think it's always been a very positive; I've never had a negative experience with the students. They are all very respectful, and thankful, and prompt. They call when they are supposed to and everything. I have never had a negative experience with this.